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A protocol for a systematic review on motivation assessments in ABI patients: a survey of available tools

Béatrice Rodarie (✉ beatrice.rodarie@hotmail.fr)

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES

Shams Ribault

Physical Medicine and Rehabilitation Department, Henry Gabrielle Hospital, Hospices Civils de Lyon, Pathophysiology and Genetics of Neuron and Muscle, CNRS UMR 5261, INSERM U1315, Université Lyon1, Faculté de Médecine Lyon Est

Sébastien Mateo

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES, France, Physical Medicine and Rehabilitation Department, Henry Gabrielle Hospital, Hospices Civils de Lyon

Eric Chabanat

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES

Laurence Havé

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES

Jacques Luauté

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES, France, Physical Medicine and Rehabilitation Department, Henry Gabrielle Hospital, Hospices Civils de Lyon

Sophie Jacquin-Courtois

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES, France, Physical Medicine and Rehabilitation Department, Henry Gabrielle Hospital, Hospices Civils de Lyon

Karen T. Reilly (✉ karen.reilly@inserm.fr)

Université Claude Bernard Lyon 1, CNRS, INSERM, Centre de Recherche en Neurosciences de Lyon CRNL U1028 UMR5292, TRAJECTOIRES

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Abstract

Acquired Brain Injury (ABI) is a term that covers several aetiologies, including stroke and traumatic brain injury. Patients with ABI can experience a range of symptoms, both physical and cognitive, that can limit their quality of life and participation. Specialised rehabilitation centres can help patients improve their capacities and develop compensatory strategies that enable them to more fully participate in social and family roles and to have a higher quality of life. The rehabilitation process is, however, long and challenging, and success requires active participation of the patient and collaboration between the patient and the rehabilitation team. One essential element of this active participation is the patient's motivation to improve and to engage in rehabilitation. Even though it is essential in the rehabilitation process, motivation is often measured subjectively. The aim of this review is to survey the tools that have been used to measure motivation in the context of rehabilitation.

Following the PRISMA guidelines, we will conduct a systematic review including four databases: PubMed, Embase, Web of Science, Google Scholar. Selected studies will include all types of studies related to motivation and rehabilitation (e.g., randomized, non-randomized controlled trials, case reports ...). Studies involving children and elderly people will be excluded as well as articles regarding traumatic brain injury in the context of sport concussion without subsequent rehabilitation. The data will be classified according to patient population, rehabilitation context, and tools used to assess motivation. We will summarise these data and make recommendations for clinicians and researchers regarding which tools to use in which contexts. We will also identify potential future needs in terms of tool development and/or cross-cultural validation of existing tools.

Introduction

Introduction :

Acquired brain injury (ABI) is an umbrella term that describes all brain injuries that occur after birth. As such, it includes numerous aetiologies, the two main ones being stroke and traumatic brain injury (TBI). The last few decades have seen a reduction in mortality as well as major improvements in functional outcome after stroke and TBI. This is due to several factors, including the introduction of acute reperfusion therapies as well as the development of intensive care units specialised for stroke and TBI, and the development of stroke units that offer early, high intensity rehabilitation (Goyal et al., 2016; Langhorne et al., 2020; Powers et al., 2019). Despite improvements in functional outcomes, many patients experience long-term sequelae that can include sensorimotor deficits, spasticity, aphasia, cognitive impairment, depression, or fatigue. Decreasing mortality rates and age of first stroke mean that improving functional outcomes via rehabilitation treatment represents a major public health issue. Specialised rehabilitation treatment can reduce the impact of sequelae help patients recover previously-held social and family roles, and is often an essential element in return-to-work success.

In France, stroke patients receive between 3 and 6 months of specialised rehabilitation treatment (Haute Autorité de Santé, 2019), and while the duration for TBI patients is less precise it is recommended that they have access to multidisciplinary rehabilitation provided by a Physical Medicine and Rehabilitation department (Bayen et al., 2012). A unique feature of rehabilitation treatment, that sets it apart from many other medical treatments, is the active participation of the patient in their own treatment. Furthermore, a patient's motivation to recover and engage in their treatment is considered by many professionals to be a vital aspect of treatment success (Duncan et al., 2005; Goršič et al., 2017; Rapolienė et al., 2018). This can only be achieved if the patient is actively engaged in the rehabilitation process, so it is also important to focus treatment around each patient's individual needs and goals.

Patients with ABI often have motivational deficits which affect their ability to adhere to their treatment (Al-Adawi et al., 1998). This is important to take into consideration as the rehabilitation process can be long and very challenging. The rehabilitation team encourages patients to engage in intensive, repetitive, sometimes painful, exercises as it is known that the amount, type and intensity of practice is critical for maximizing functional recovery (Rizzo et al., 2005). This highlights the crucial role of motivation in engagement and participation in rehabilitation (Kusec et al., 2018; Oddy et al., 2008).

Despite its importance in the rehabilitation process, objective tools to measure motivation are rarely used, and motivation for rehabilitation is mostly determined informally or implicitly based on clinical judgement (Maclean et al., 2002). For example, clinicians often refer to patients as having low motivation and use this to explain lower-than-expected levels of functional recovery, but the criteria used to identify high and low levels of motivation are rarely clearly defined (Maclean et al., 2002). Furthermore, there is no commonly-accepted definition for motivation in rehabilitation, even though it is generally accepted to be the willingness to participate in rehabilitation treatment (Colombo et al., 2007; Maclean et al., 2000). A precise definition can be found in the psychological literature, which defines motivation as "the need, drive, or desire to act to achieve a specific end" (Miller, 1959 cited by Chervinsky et al., 1998).

Regardless of the challenges involved in defining, measuring, assessing, and potentially altering something that is inherently subjective, the scientific community has taken up the challenge of attempting to assess motivation. The literature has been continually expanding since the 1980s and now includes theoretically-oriented papers (e.g. Maclean & Pound, 2000; Ryan & Deci, 2000), studies focused on developing standardised tools to measure motivation, as well as quantitative studies using measures of motivation to look at acceptance of, adherence to, and engagement in rehabilitation therapies (e.g. Colombo et al., 2007; Colomer et al., 2016; Gorsic et al., 2020; Goršič et al., 2017). Surprisingly, very few studies have investigated the link between level of motivation before treatment and treatment success (see Boosman et al., 2017 for an example).

A review on a similar topic was recently published (Verrienti et al., 2023) but their authors limited the research to stroke patients, only included clinical trials or randomised clinical trials, only examined studies published between 2012 and 2022, and limited their search to two databases (Google Scholar and PubMed). Thus the objective of the current review is to perform a larger survey of the literature

including both stroke and TBI patients, and to identify tools that have been used to assess patient motivation in all types of studies involving these patient populations, and to analyse the results taking into account the various contexts in which the tools are used. Our long-term goal is to identify an easy-to-use, clinically-informative tool that can be used in clinical practice with a population of French-speaking ABI patients.

Objective:

The research question for this review is: which evaluations (e.g : instruments, assessments, scales, questionnaires ...) have been used to assess patient motivation in adults with an ABI in a rehabilitation context.

We will identify tools, determine how often they are used and in which contexts (e.g. motivation for a given activity, motivation for change, ...)

If our search equation identifies papers that describe the development of patient-reported outcome measures (PROMs) we will assess the psychometric properties of these measures.

Reagents

Equipment

Procedure

Method:

The protocol of this study was registered in the International Prospective Register of Systematic Reviews (PROSPERO) (registration number : CRD42023408730) on March 27 2023.

Our research protocol will be reported following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol 2015 Statements. (Moher et al., 2009)

We will use a PRISMA flow diagram to report the different phases of the screening process. The number of excluded articles and the reasons for their exclusion will be recorded at each stage.

For any identifies PROMs, we will evaluate their psychometric properties and grade their quality evidence using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach and following the standardized COSMIN guidelines for systematic reviews of patient-reported outcome measures (Prinsen et al., 2018).

2.1 Inclusion criteria

2.1.1 Type of studies and participants

This review will consider all studies in a rehabilitation context that assess motivation in adults (between 18 and 80 years old) who have an ABI. Any study reporting to measure motivation as a primary or secondary outcome or as a descriptive measure in a case report. Studies measuring motivation using a sub-scale of a tool measuring another construct (i.e fatigue or quality of life) will be included. Studies published in English, French, or Italian will be screened for inclusion. There will be no restrictions on publication date. Initial screening will include studies published up to May 31 2023 and the search equation will be re-run before submitting the paper to identify any relevant papers published after this date.

2.1.2 Types of outcome measures

The primary outcome will be a summary of all the measurement existing to assess ABI patient motivation in a rehabilitation context.

Another outcome of this study, for identified PROMs, will be the assessment of their psychometric properties following the COMSIN guidelines.

2.2. Exclusion criteria

Studies that measure motivation in children or elderly people (< 18 years old or >80 years old) or in TBI patients in the context of a sport concussion without subsequent rehabilitation will be excluded from the review.

2.3 Data collection and analysis

2.3.1 Electronic searches

We will search several databases : PubMed, Google Scholar, Embase and Web of Science.

2.3.2 Identification

The research equation will combine several words related to : motivation, brain injury and assessments. Table 1 contains the search equations.

Table 1: Search strategy equations

PubMed

```
((("motivation brain injury"[tiab:~20]) OR ("motivation stroke"[tiab:~20])) AND (((((((Surveys and questionnaires[MeSH Terms]) OR (Questionnaire*[Title/Abstract])) OR (Survey*[Title/Abstract])) OR (measure*[Title/Abstract])) OR (evaluat*[Title/Abstract])) OR (assess*[Title/Abstract])) OR (Scale[Title/Abstract]))) NOT (((((((« Hemispatial neglect »[Title/Abstract])) OR (« Visually impaired persons »[Title/Abstract])) OR (blind*[Title/Abstract])) OR (« Visuospatial deficits »[Title/Abstract])) OR (((((Child[MeSH Terms]) OR (Children[Title/Abstract])) OR (Pediatric*[Title/Abstract])) OR (child*
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[Title/Abstract])) OR (paediatric*[Title/Abstract])) OR ((Aphasia[MeSH Terms]) OR (Aphas*[MeSH Terms])) OR (("Virtual Reality"[MeSH Terms]) OR ("virtual reality"[Title/Abstract])) OR (("video games" [MeSH Terms]) OR ("video gam*" [Title/Abstract]))))

Google Scholar

"motivation in rehabilitation" (stroke OR brain injury), AROUND(2), motivation, AROUND(2), (questionnaire* OR survey* OR measure* OR evaluat* OR assess* OR scale) -pediatric* -child* -aphasi* -video -gam* -"virtual reality"

EMBASE

((stroke OR brain) AND injury AND ((measure OR measur*) NEAR/10 (motivation OR motivat*)) OR ((stroke OR brain) AND injury AND (questionnaire* NEAR/10 (motivation OR motivat*))) OR ((stroke OR brain) AND injury AND (scale* NEAR/10 (motivation OR motivat*))) OR ((stroke OR brain) AND injury AND (instrument* NEAR/10 (motivation OR motivat*))) OR ((stroke OR brain) AND injury AND (evaluat* NEAR/10 (motivation OR motivat*))) OR ((stroke OR brain) AND injury AND (assess* NEAR/10 (motivation OR motivat*))) NOT ('hemispatial neglect' OR 'visually impaired persons' OR blind* OR 'visuospatial deficits' OR child* OR pediatric* OR aphasi* OR 'virtual reality' OR 'video games')

Web of science

((AB=(motivation)) AND AB=(stroke OR brain injury)) AND AB=(questionnaire* OR tool* OR instrument* OR assess* OR evaluat* OR assess*) NOT AB=("hemispatial neglect" OR "visually impaired persons" OR blind* OR "visuospatial deficits" OR child* OR pediatric* OR aphasi* OR "virtual reality" OR "video games")

Interrogation of the databases using these equations will result in identification of records. Once the PRISMA procedure completed, additional reference will be searched within the references of the article included in the systematic review.

2.3.3 Study screening

After removal of duplicates in the first stage of screening two authors will independently assess eligibility of the identified records based on their titles and abstracts. The list of accepted /rejected titles and abstracts will then be compared between the authors and discrepancies will be resolved by discussion between the two authors and a third investigator.

2.3.4. Study Eligibility

Two authors will independently examine the full text of each study to ensure that it meets the inclusion criteria. As in stage 1, any discrepancies will be discussed until consensus is reached. If the two authors are unable to reach consensus a third investigator will assess paper eligibility. The whole selection procedure will be reported in a PRISMA flow diagram.

2.3.4. Data extraction and management.

Data will be extracted from the studies that pass the screening process and tabulated using a standardized data extraction form in Excel. The following data will be extracted from each article: study design and methodology; name of the measurement tool and its subscales (when relevant); the authors' reasons for choosing this particular tool; context or domain of the study (i.e. motor, cognitive, physical ...); objectives; outcomes; number of participants ; time post injury; time of the assessment with the tool in the study; validation of this particular tool for the ABI population; psychometric properties of the measurement tool; information about the measurement tool regarding its : development, underlying theory, definition of motivation, languages in which it is available, response mode, completion time.

Two researchers will independently extract the data for all included studies and will discuss the data extracted for each article in order to ensure accuracy and completeness of the data set. In the case of any disagreements a third author will independently complete the data table and then discuss with the team until consensus is reached.

2.7. Subgroup analysis

If the number of included studies is sufficient, we will separate patients into two groups : Stroke and Traumatic Brain Injury. Likewise, if appropriate, results of studies measuring motivation with a sub-scale of a tool measuring another construct (i.e fatigue or quality of life) will be reported separately.

2.10. Ethics

Ethical approval will not be needed because this a systematic review based on published studies.

The data used in this systematic review will not include individual patient data and the review aims to summarise existing assessments concerning ABI motivation in a rehabilitation context in patients with an ABI. If we identify a tool that requires cross-cultural validation in a population of French-speaking patients we will apply for ethical approval for the validation study.

Discussion :

This review aims to further explore the motivation literature, in particular how motivation is assessed. We know that providing patients with state-of-the-art specialised care is insufficient if the patient is not actively engaged in the rehabilitation process. A visible part of this engagement may be the patient's motivation for their rehabilitation. This review will summarise the tools that measure motivation in a rehabilitation context.

One of our long-term goals in undertaking this review is to identify easy-to-use, clinically-informative tools that can be used in clinical practice to assess patient motivation levels and to validate those perform cross-cultural validation of those that appear be most appropriate for use with ABI patients in French rehabilitation hospitals. One possible use of this type of assessment could be to identify a patient's

“motivational profile” and to integrate this information into an individually-tailored rehabilitation programme that also takes into account factors like geographical accessibility of rehabilitation services and high-speed internet for good quality telemedicine consultations. For example, patients with high motivation for rehabilitation might be ideal candidates for home-based rehabilitation, low motivation patients might gain more from hospital-based outpatient rehabilitation, while those with intermediate or unstable motivation levels might benefit from a mix of outpatient and home-based rehabilitation. Rehabilitation is a long, costly process, both for the patient and the health system. Integrating assessments of patient motivation into clinical decision making has the potential to improve functional outcomes and increase patient participation and life satisfaction, to reduce health-care costs, and to lead to better use of health care resources.

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