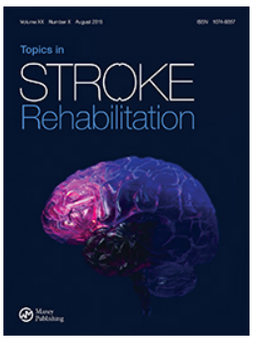

Topics in Stroke Rehabilitation

ISSN: 1074-9357 (Print) 1945-5119 (Online) Journal homepage: https://www.tandfonline.com/loi/ytsr20

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To cite this article: Galeoto Giovanni, Iori Francesca, De Santis Rita, Santilli Valter, Mollica Roberta, Maria Auxiliadora Marquez, Julita Sansoni & Anna Berardi (2019): The outcome measures for loss of functionality in the activities of daily living of adults after stroke: a systematic review, Topics in Stroke Rehabilitation

To link to this article: https://doi.org/10.1080/10749357.2019.1574060

Published online: 18 Feb 2019.

TOPICS IN STROKE REHABILITATION
https://doi.org/10.1080/10749357.2019.1574060

The outcome measures for loss of functionality in the activities of daily living of adults after stroke: a systematic review

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ABSTRACT

Objective: To provide clinicians and researchers information regarding (1) the existing outcome measures to assess the loss of functionality in the activities of daily living (ADLs) of patients with stroke and (2) the presence of these assessment tools in the Italian context.

Study Design and Setting: For this Systematic Review Medline, CINAHL, and PsycINFO were searched for articles published up to 4 July 2017. Two authors independently identified eligible studies on the basis of predefined inclusion criteria and extracted data. Study quality and risk of bias were assessed using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.

Results: Of 370 publications identified and screened, 46 studies fell within the inclusion criteria and were critically reviewed. The most commonly used tools were: the Frenchay Activities Index and the *Functional Independence Measure*.

Conclusion: This review has emphasized the need for agreement among researchers as to which tool must be studied in depth or adapted to other national contexts in order to develop universal norms and standards.

ARTICLE HISTORY
Received 26 August 2018
Accepted 19 January 2019

KEYWORDS
ADL; questionnaire; reliability; review; psychometric properties; stroke rehabilitation; tools; validation

Introduction

During the acute phase after stroke, treatment focuses on specialized medical intervention and continuous rehabilitation for a long period of time.[1] Patients may experience reduced motor and cognitive function, difficulties in performing daily activities, and a reduced health-related quality of life.[2,3] Health professionals and rehabilitation professionals often use a person's ability or inability to perform activities of daily living as a measurement of their functional status, this focus on rehabilitation after a stroke, especially in occupational therapy, aims to identify the best treatment methods and routines to help patients return to their previous lives and daily activities. The use of the term "activities of daily living" (ADLs) is familiar to many, however, universal agreement of the concept and definition of ADL has been problematic, with subdivision of ADL into basic or personal ADLS (BADL,PADL) and instrumental or extended ADLs (IADL, EADL). Activities of Daily Living (ADLs) are defined by the Medical Dictionary as "the things we normally do… such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure".[4] Consistent with the Medical Dictionary's definition we have considered for ADLs including basic, personal, instrumental, and extended activities of daily living.

Thus, to identify the best treatment methods and routines to help patients return to their previous lives and daily activities the first step is to identify the correct assessment tool to robustly assess the efficacy of interventions both at the level of the individual stroke survivor and in the context of clinical trials.

The classic clinical trial is designed to test the efficacy of a particular intervention as compared to another intervention or a control group. Facilitating comparison between groups requires a standard measure of outcome that is relevant and suited to the clinical question, valid for the population studied, and meaningful to the research team.[5] Therefore it was decided to do this systematic review because clinicians and researchers need to know the most reliable, valid, and universally accepted measures currently available for addressing this clinical construct in stroke survivors and to allow comparisons between different rehabilitation programs.

Systematic reviews and meta-analyses have become increasingly important in health care. Clinicians read them to keep up to date with their field[6,7] and they are often used as a starting point for developing clinical practice guidelines.[8–14] Of course, within a single review, it would be impossible to analyze all the scales that may be needed on a stroke survivor's journey, a number of reference works exist in literature for stroke-specific and generic scales,[15–17] but none of these analyzes the loss of functionality on ADLs. In the literature, a wide range of tools have been used to evaluate the loss of ADL functionality on various ADL domains in patients with stroke, and no broadly accepted consensus as to which are preferred has been reached.

This study aimed to provide clinicians and researchers information regarding the existing outcome measures to assess the loss of functionality in the activities of daily living (ADLs) of patients with stroke and the presence of these

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assessment tools in the Italian context (culture, rehabilitation practices and language) based on reviewing, analyzing, comparing, and critically appraising the available outcome measures and their distribution in the international literature.

Methods

Protocol and registration

After registering the protocol on the Prospero website, the international prospective register of systematic reviews, available at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017076815, this review was carried out in accordance with the 27-item PRISMA Statement for Reporting Systematic Reviews[9,10] on the basis of MECIR.[6–8]

Eligibility criteria for considering studies for this review: types of studies and types of participants

A systematic review of the English-language literature was undertaken by looking for studies that evaluated the psychometric properties of outcome measures that explored the loss of functionality in the ADLs of adults with a history of stroke. Consistent with the Medical Dictionary's definition we have considered for ADLs "the things we normally do… such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure",[4] including basic, personal, instrumental, and extended activities of daily living. All studies that evaluated the psychometric properties of a clinician's report, a patient's self-report, and/or physical performance outcome measures that measured functionality in the ADLs of patients in at least one domain of the tool were included. Studies were limited to people with stroke, regardless of clinical course or length of time since diagnosis. Studies with mixed diagnosis samples were included if a subgroup of participants could be identified and for which separate data were available. Studies were included if participants were 18 years or over or if separate data were available for those over 18 years old. No restrictions were applied to the publication period or to the country in which the study was conducted but the searches were limited to studies published in English.

Inclusion criteria

(1) Validation studies and cross-cultural adaptation studies;
(2) Studies about the loss of functionality in active ADLs and IADLs performance;
(3) Studies about tests, questionnaires, and self-reported and performance-based outcome measures;
(4) Studies with a population of patients with stroke;
(5) Population ≥ 18 years old; and
(6) Studies published in English.

Exclusion criteria

(1) Trials or studies that evaluated the effectiveness of interventions where a questionnaire is used as an endpoint (without studying the measurement properties);
(2) Studies including measures that measure cognitive, motor and other constructs;
(3) Studies with mixed diagnosis samples if a subgroup of stroke participants could not be identified with separate data; or
(4) Studies with mixed age samples if a subgroup of adult participants could not be identified with separate data.

Search methods for identification of the studies

Studies were identified for inclusion through individualized systematic searches of three electronic databases. All potential studies were identified by two reviewers.

Electronic searches

The review's primary reviewer developed the search strategy, following consultation with an expert and using guidance from relevant past reviews. The initial search strategy was constructed for MEDLINE (via PubMed) on 4 July 2017. A combination of terms and keywords was used: ((("stroke") AND "activities of daily living") AND "validation") AND ((("scale") OR "questionnaire") OR "test") and adapted to other databases. The following electronic databases were searched:

(1) Medline (via PubMed);
(2) CINAHL (via EBSCO); and
(3) PsycINFO (via EBSCO).

Study selection

Titles, keywords, and abstracts identified through the databases were screened independently by two occupational therapists. After the first screening, the primary reviewr selected the relevant studies and assessed them against the inclusion criteria. Then, a second reviewer cross-checked the studies. After the second screening, studies were systematically excluded that did not fit the inclusion criteria and others were identified that appeared pertinent. A final list of studies that were eligible for inclusion was compiled, and any disagreements were resolved by the third reviewr or by consensus. The studies that met the criteria were then subject to a full text review to select studies to decide whether or not to include them in the review.

Data collection, data items, and assessment of risk of bias

The approach to data extraction was chosen on the basis of the Cochrane Methods.[18] Two reviewers independently extracted patient demographics and descriptive information and each study was keyworded for generic issues such as language, country, focus, population, and so on.[19] These characteristics were judged on the basis of the information provided in the reports on the studies. For the data collection, we followed the recommendations from the COSMIN initiative,[20–23] which takes into account the special aspects of validating patient-reported outcome measures (PROMs). Outcome measures reported within each publication were recorded and categorized for comparison. We decided to report the following psychometric characteristics: Cronbach's alpha for internal consistency, intraclass correlation coefficient

for stability, and Pearson's correlation for validity. The studies' content and methodology were analyzed qualitatively. Aspects of validity were defined and a checklist was used to determine which aspects had been evaluated. Study quality and risk of bias were assessed using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAT).[24] The QAT scale is composed of 14 items; 2 of these (items 6 and 7) are used exclusively for observational cohort studies, which were not included in this review. Therefore, each study in the review was evaluated with the remaining 12 items.

Results

Study selection: description of the studies and results of the search

The search strategy identified 370 results. After removing duplicates, 329 articles were screened by reading titles and abstracts, resulting in 106 papers that were screened further by reading the full text. Figure 1 provides a flowchart demonstrating the search and screening process.

Excluded studies

In total, 283 studies were excluded on the basis of the exclusion criteria. During the title and abstract screening, 223 studies were excluded because they had not studied specific outcome measures that assessed the loss of functionality in the ADLs of patients with stroke (i.e quality of life outcome measures). Of the studies that received a full text review, 67 articles were excluded; of these, 34 were studies that evaluated the effectiveness of interventions where a questionnaire was used as an endpoint, 25 were not active ADL's performance specific, 7 had mixed diagnosis samples without separate data for a stroke subgroup, and 1 was not published in English.

Included studies

Out of the 39[25–63] articles that fell within the inclusion criteria and were critically reviewed, 2[33,43] validated two measurement tools at the same time. A total of 41 tools were identified and 6 of these were validated by multiple studies. We found 33 different outcome measures that assessed the loss of functionality in the ADLs of patients with stroke. A summary of the studies' descriptive information is presented in Table 1.

Study characteristics: types of design and types of participants

All the studies were cross-sectional.[25–63] The sample size in the studies varied from 17[34] to 603.[30] The majority of the participants were in their mid to late 60s, with mean ages ranging from 53 ± 13 years[56] to 77.8 ± 7.5 years.[35] The most represented languages were Chinese[27,28,36,40–43,53,62] and

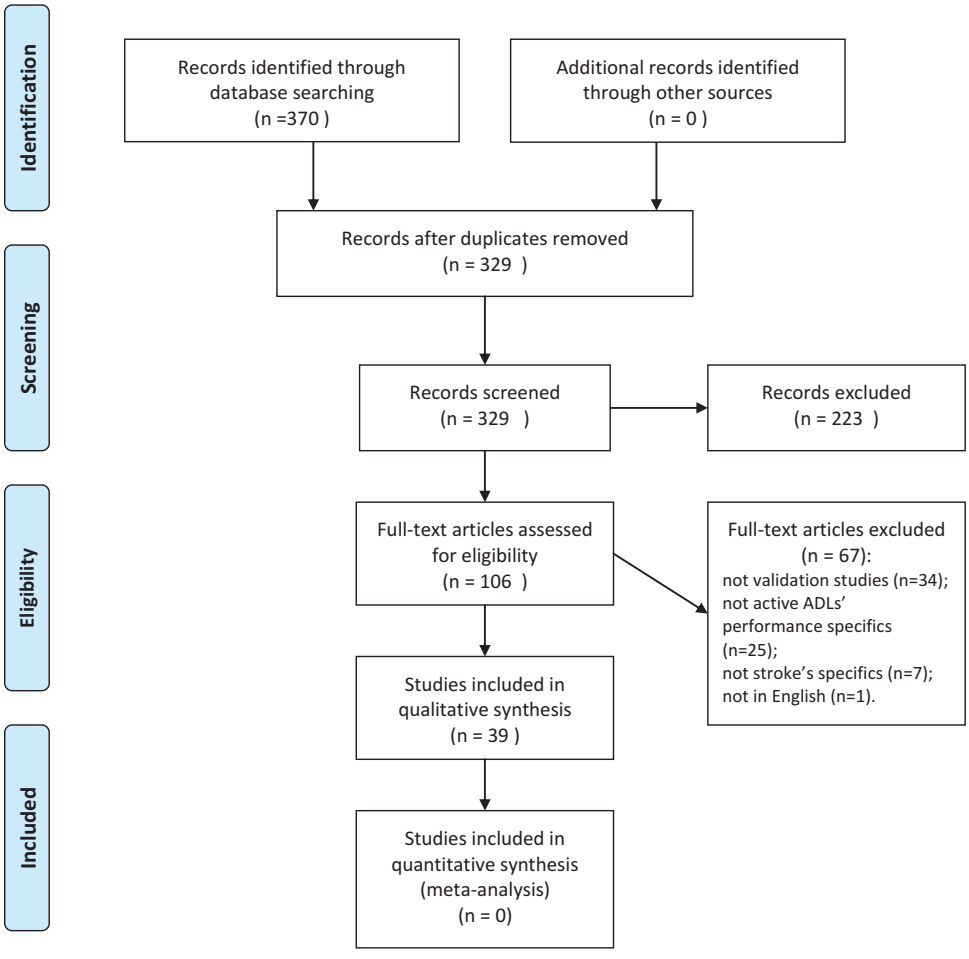

Figure 1. Flowchart of search and screening process.

Table 1. Descriptive information of included studies.

Scale	Authors	Language	Items	Sample size	mean±SD age	Administration
Abilhand questionnaire	Wang et al. 2011	Chinese	23	51	55.26 ± 10.31	Test
Ability Scale	Lee et al. 2014	Chinese	8	306	61 ± 13.8	Test
Activity Card Sort	Chan et al. 2006	Chinese	65	60	74	Self-reported
	Katz et al. 2003;	Israeli	88	56	57.7 ± 11.6	Self-reported
ACTIVLIM-Stroke	Batcho et al. 2012	French (Belgium and Benin)	20	204	57.1 ± 13.4	Questionnaire
Canadian Occupational Performance Measure in stroke patients	Cup et al. 2003	Dutch	5	26	68 ± 15	Questionnaire
Combined Measure of Basic and Extended Daily Life Functioning After Stroke	Chen et al. 2013	Chinese	39	188	55,96 ± 11,7	Questionnaire
Comprehensive Activities of Daily Living	Hsueh et al. 2012	Chinese	23	168	65.4 ± 10.3	Questionnaire
Daily Living Self-Efficacy Scale	Li et al. 2016	Chinese	12	172	63.39 ± 11.06	Questionnaire
	Maujean et al. 2013;	Australian English	12	424	65.25 ± 12.65	Questionnaire
Extended Activities of Daily Living	Gompertz et al. 1994	English	22	159	N.R.*	Self-reported
	Lincoln et al. 1992;	English	22	352	67	Self-reported
Extended Barthel Index with Acute Ischemic Stroke Patients	Jansa et al. 2004	Slovenian	16	33	62	Test
Frenchay Activities Index	Lin et al. 2012;	Chinese	15	127	55.27 ± 11.73	Questionnaire
	Post et al. 2003;	Dutch	15	35	71,1 ± 14,8	Questionnaire
	Piercy et al. 2000;	English	15	45	55.6 ± 10.9	Questionnaire
	Monteiro et al. 2017	Brazilian	15	161	57.3 ± 17.0	Questionnaire
Functional Independence Measure	Naghdi et al. 2015	Persian	18	40	60 ± 14.9	Test
	Brosseau et al. 1996;	Canadian	18	152	69 ± 14	Test
Functional Indipendence Measure and Functional Assessment Measure	Miki et al. 2015	Japanese	30	42	64.9 ± 14.6	Questionnaire
Human Activity Profile	Teixeira-Salmela et al. 2007	Brazilian	94	24	63.69 ± 11.57	Questionnaire/self-reported/test
Impact on Participation and Autonomy	Fallahpour et al. 2011	Persian	26	102	58,3 ± 11,9	Self-reported
Mayo-Portland Adaptability Inventory 4	Hamed et al. 2012	Arabic	35	17	54.29 ± 3.91	Questionnaire
Modified Barthel Index	Leung et al. 2007	Chinese	10	116	76 ± 7,6	Test
Motor Activity Log	Van der Lee et al. 2004;	Dutch	26	56	61 median	Questionnaire
Motor Activity Log-28	Uswatte et al. 2006	American English	30	222	62,2 ± 13,0	Test/questionnaire
Motor Functional Independence Measure	Lundgren-Nilsson et al. 2006	Scandinavian	13	157	N.R.*	Questionnaire
New Lucerne ICF Based Multidisciplinary Observation Scale	Ottiger et al. 2015	Swiss	45	102	69,3 ± 11,9	Questionnaire
Northwick Park ADL Index	Spencer et al. 1986	Australian English	17	N.R.*	N.R.*	Test
Nottingham Leisure Questionnaire	Drummond et al. 2000	English	30	603	N.R.*	Questionnaire
Occupational Gaps Questionnaire	Fallahpour et al. 2011	Persian	31	102	58,4 ± 11,9	Questionnaire
Perceived Life Satisfaction	Fallahpour et al. 2011	Persian	11	102	58,4 ± 11,9	Questionnaire
Reintegration to Normal Living Index	Tooth et al. 2003;	Australian English	11	57	70 ± 12	Questionnaire
	Pang et al. 2011	Chinese	11	75	64.4 ± 12.3	Questionnaire
Rivermead Activity of Daily Living Scale	Lincoln et al. 1990	English	31	105	65	Questionnaire
Self-perceived Difficulty Scale	Lee et al. 2014	Chinese	10	306	61 ± 13.8	Questionnaire
Short Version of the Motor FIM	Yamada et al. 2006	Japanese	7	356	70:07:00	Questionnaire
Stroke Activity Scale	Horgan et al. 2006	Irish	5	41	77.8 ± 7.5	Test
Sunnaas Index of Activities of Daily Living	Korpelainen et al. 1997	Finnish	12	55	59,07 ± 11	Test
Vision-Dependent Activities of Daily Living Instrument	Mennem et al. 2012	American English	38	30	63.8 ± 8.1	Self-reported
World Health Organisation Disability Assessment Schlote et al. 2009 Schedule II	Schlote et al. 2009	German	36	77	53 ± 13	Questionnaire

*N.R. Not Reported.

English,[31,34,45,46,55] with 10 and 5 validated tools, respectively. The measurement properties for each version of each tool are summarized in Table 2.

The most commonly used tools were: The Frenchay Activities Index (FAI), validated in Chinese,[43] Brazilian,[50] English,[54] and Dutch[55]; the Activity Card Sort (ACS), validated in Chinese[27] and Israeli[38]; the Daily Living Self-Efficacy Scale (DLSES), validated in Chinese[42] and Australian English[47]; the Reintegration to Normal Living Index (RNLI), validated in Chinese[53] and Australian English[59]; the Functional Independence Measure (FIM), validated in French-Canadian[26] and Persian.[51] Additionally, two further studies included the FIM instrument, one[49] in Japanese validating its use in combination with the Functional Assessment Measure (FAM) scale, the other study[46] validating only the motor subscale in the Scandinavian language. The Extended Activities of Daily Living (EADL) is a tool whose measurement properties have been studied by two English authors in two different research studies.[33,45] The Lincoln et al.[45] study only evaluated content validity through the reproducibility and scalability coefficients. Gompertz et al.[33] investigated construct validity by comparing it with other comparable outcome measures, expressing that relationship through the Spearman Rho's value.

Risk of bias within studies

The risk of bias in the 39[25–63] included studies was mixed. The quality scores from the responsiveness subset questions of the QAT[24] checklist are reported in Table 3. In general, the studies were found to have fairly good quality. Items 1(Was the research question or objective in this paper clearly

Table 2. Measurement properties of included studies.

Authors	Scale	ICC	R-PEARSON	α-CRONBACH
Wang et al. 2011	Abilhand questionnaire	0.87	0.66	0.88
Lee et al. 2014	Ability Scale	N.R.*	N.R.*	N.R.*
Chan et al. 2006	Activity Card Sort	0.98	0.86	0.89
Katz et al. 2003;		N.R.*	N.R.*	0.72
Batcho et al. 2012	ACTIVLIM-Stroke	0.92	0.83	0.95
Cup et al. 2003	Canadian Occupational Performance Measure in stroke patients	N.R.*	N.R.*	N.R.*
Chen et al. 2013	Combined Measure of Basic and Extended Daily Life Functioning After Stroke	0,91	N.R.*	0.94
Hsueh et al. 2012	Comprehensive Activities of Daily Living	0.96	0.75	0.94
Li et al. 2016	Daily Living Self-Efficacy Scale	N.R.*	0.87	0.96
Maujean et al. 2013;		0.98	0.59	0.95
Gompertz et al. 1994	Extended Activities of Daily Living	N.R.*	N.R.*	N.R.*
Lincoln et al. 1992;		N.R.*	N.R.*	N.R.*
Jansa et al. 2004	Extended Barthel Index with Acute Ischemic Stroke Patients	N.R.*	N.R.*	0.94
Lin et al. 2012;	Frenchay Activities Index	N.R.*	0.99	0.88
Post et al. 2003;		N.R.*	N.R.*	N.R.*
Piercy et al. 2000;		0.90	N.R.*	N.R.*
Monteiro et al. 2017		0.82	N.R.*	0.99
Naghdi et al. 2015	Functional Independence Measure	0.98	0.95	0.96
Brosseau et al. 1996;		N.R.*	N.R.*	0.96
Miki et al. 2015	Functional Indipendence Measure and Functional Assessment Measure	N.R.*	0.73	0.95
Teixeira-Salmela et al. 2007	Human Activity Profile	0.89	0.99	N.R.*
Fallahpour et al. 2011	Impact on Participation and Autonomy	N.R.*	0.75	N.R.*
Hamed et al. 2012	Mayo-Portland Adaptability Inventory 4	N.V	0.73	N.R.*
Leung et al. 2007	Modified Barthel Index	N.R.*	0,91	0,93
Van der Lee et al. 2004;	Motor Activity Log	N.R.*	N.R.*	0.88
Uswatte et al. 2006	Motor Activity Log-28	0,82	0.72	0.94
Lundgren-Nilsson et al. 2006	Motor Functional Independence Measure	N.R.*	N.R.*	N.R.*
Ottiger et al. 2015	New Lucerne ICF Based Multidisciplinary Observation Scale	0.9	0.9	0.98
Spencer et al. 1986	Northwick Park ADL Index	N.R.*	N.R.*	N.R.*
Drummond et al. 2000	Nottingham Leisure Questionnaire	N.R.*	N.R.*	N.R.*
Fallahpour et al. 2011	Occupational Gaps Questionnaire	N.R.*	0.46	N.R.*
Fallahpour et al. 2011	Perceived Life Satisfaction	N.R.*	0.46	N.R.*
Tooth et al. 2003;	Reintegration to Normal Living Index	0.36	0.65	0.80
Pang et al. 2011		0.87	0.43	0.92
Lincoln et al. 1990	Rivermead Activity of Daily Living Scale	N.R.*	N.R.*	N.R.*
Lee et al. 2014	Self-perceived Difficulty Scale	N.R.*	N.R.*	N.R.*
Yamada et al. 2006	Short Version of the Motor FIM	0.99	N.R.*	N.R.*
Horgan et al. 2006	Stroke Activity Scale	N.R.*	0.91	N.R.*
Korpelainen et al. 1997	Sunnaas Index of Activities of Daily Living	N.R.*	0,88	0.95
Mennem et al. 2012	Vision-Dependent Activities of Daily Living Instrument	N.R.*	0.99	0,99
Schlote et al. 2009	World Health Organisation Disability Assessment Schedule II	0.67	N.R.*	0.97

*N.R. Not Reported.

stated?), 9(Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?), and 11(Were the outcome measures -dependent variables- clearly defined, valid, reliable, and implemented consistently across all study participants?) had the highest number of positive responses. The less represented items were 2 (Was the study population clearly specified and defined?), 5(Was a sample size justification, power description, or variance and effect estimates provided?), and 13(Was loss to follow-up after baseline 20% or less?).

Results of individual studies

Study population

About half of the studies, 20, described the group of people from which the study participants were selected or recruited, using demographics, locations, and time periods. In the other studies, the authors did not report information about when and from where the population was recruited. In addition, only 10[26,30–32,42,45,50,56,58,61] of the analyzed studies contained the percentage of eligible people who participated in the study. If fewer than 50% of the people who were eligible participated in the study, then there is a concern that the study population does not adequately represent the target population.

Groups recruited from the same population; uniform eligibility criteria; sample size justification

In 32 studies, the inclusion and exclusion criteria were developed prior to the recruitment of the study population and the same criteria were used for all of the subjects involved. Two studies[38,63] did not provide sufficient information to determine the inclusion and exclusion criteria development methods. In only 2 studies[58,62] did the authors present their reasons for recruiting the number of people included and discuss the statistical power of the study. In the other studies, 37, it was not being possible to determine if the study had enough participants.

Different levels of the exposure of interest; exposure measures and assessment; repeated exposure assessment; blinding of outcome assessors

In 8 studies[26,27,33,36,38,58,62,63] we found a stratification for pathology levels. In almost all the studies, the authors used accurate and reliable measurement tools for the detection of

Table 3. Quality scores of the included studies.

STUDIES	ITEM 1	ITEM 2	ITEM 3	ITEM 4	ITEM 5	ITEM 6	ITEM 7	ITEM 8	ITEM 9	ITEM 10	ITEM 11	ITEM 12	ITEM 13	ITEM 14	TOT YES
Batcho 2012	Y	Y	N.R.*	Y	N.R.*	N	N	N.A.**	Y	N.R.*	Y	N	N.A.**	Y	6
Brosseau 1996	Y	Y	Y	Y	N.R.*	N	N	Y	Y	N.R.*	Y	N	N.A.**	Y	8
Chan 2006	Y	N	N.R.*	Y	N.R.*	N	N	Y	Y	Y	Y	N	Y	Y	8
Chen 2013	Y	Y	N.R.*	Y	N.R.*	N	N	N	Y	N	Y	Y	N.A.**	N.R.*	6
Cup 2003	Y	Y	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N	N.A.**	Y	7
Drummond 2000	Y	N	Y	N.R.*	N.R.*	N	N	N	N	Y	N	N.A.**	N	Y	4
Fallahpour 2011	Y	Y	Y	Y	N.R.*	N	N	N.R.*	Y	N	Y	N	N.A.**	N.R.*	6
Fallahpour 2011–2	Y	Y	Y	Y	N.R.*	N	N	N.R.*	Y	N	Y	N.R.*	N.A.**	Y	7
Gompertz 1994	Y	Y	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	N	Y	7
Hamed 2012	Y	Y	N.R.*	Y	N.R.*	N	N	Y	Y	N	Y	N.R.*	N.A.**	N.R.*	6
Horgan 2006	Y	N	N.R.*	Y	N.R.*	N	N	N	Y	N	Y	N	N.A.**	N.R.*	4
Hsueh 2012	Y	N	N.R.*	Y	N.R.*	N	N	Y	Y	Y	Y	N	N.R.*	N.R.*	6
Jansa 2004	Y	N	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	N.R.*	N.R.*	5
Katz 2003	Y	Y	N.R.*	N	N.R.*	N	N	Y	Y	Y	Y	N.R.*	Y	N.R.*	7
Korpelainen 1997	Y	Y	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	N	N.R.*	6
Lee2014	Y	N	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N	N.R.*	N.R.*	5
Leung 2007	Y	N	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N	N.A.**	Y	6
Li 2016	Y	Y	Y	Y	N.R.*	N	N	N	Y	N	Y	N	Y	Y	8
Lin 2012	Y	N	N	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	N.R.*	Y	6
Lincoln 1990	Y	N	N.R.*	Y	N.R.*	N	N	N	Y	N	Y	N.R.*	N.R.*	N.R.*	4
Lincoln 1992	Y	Y	Y	N.R.*	N.R.*	N	N	N.R.*	Y	N	Y	N.R.*	N	N.R.*	5
Lundgren-Nilsson 2006	Y	N	N.R.*	N.R.*	N.R.*	N	N	N.R.*	Y	N	Y	N.R.*	N.A.**	N.R.*	3
Maujean 2013	Y	Y	N	Y	N.R.*	N	N	N.R.*	Y	N	Y	N.R.*	N.A.**	N.R.*	5
Mennem 2012	Y	N	N.R.*	Y	N.R.*	N	N	N.R.*	Y	N	Y	N.R.*	N.A.**	N.R.*	4
Miki 2015	Y	Y	N.R.*	Y	N.R.*	N	N	N	Y	Y	Y	N	N.A.**	N.R.*	6
Monteiro 2017	Y	Y	Y	Y	N.R.*	N	N	N.R.*	Y	Y	Y	N.R.*	N.R.*	Y	8
Naghdi 2015	Y	N	N.R.*	Y	N.R.*	N	N	N.R.*	Y	Y	Y	N	N.R.*	Y	6
Ottiger 2015	Y	Y	N.R.*	N.R.*	N.R.*	N	N	N.R.*	Y	Y	Y	N.R.*	N.R.*	N.R.*	5
Pang 2011	Y	N	N.R.*	Y	N.R.*	N	N	N.A.**	Y	Y	Y	N.R.*	Y	N.R.*	6
Piercy 2000	Y	Y	N	Y	N.R.*	N	N	N.R.*	Y	N	Y	Y	N.A.**	N.R.*	6
Post 2003	Y	N	N.R.*	Y	N.R.*	N	N	N.R.*	Y	Y	Y	N.R.*	N.R.*	N.R.*	5
Schlote 2009	Y	N	Y	Y	N.R.*	N	N	N.R.*	Y	Y	Y	N.R.*	N	N.R.*	6
Spencer 1986	Y	N	N.R.*	N.R.*	N.R.*	N	N	N.R.*	Y	N.R.*	Y	N.R.*	N.R.*	N.R.*	3
Teixeira-Salmela 2007	Y	N	N.R.*	Y	Y	N	N	Y	Y	Y	Y	N.R.*	N	Y	8
Tooth 2003	Y	Y	Y	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	N.R.*	N.R.*	7
Uswatte 2006	Y	N	N.R.*	Y	N.R.*	N	N	N.R.*	Y	Y	Y	Y	N.R.*	N.R.*	6
Van der Lee 2004	Y	N	Y	Y	N.R.*	N	N	N	Y	Y	Y	N.R.*	Y	N.R.*	7
Wang 2011	Y	Y	N.R.*	Y	Y	N	N	Y	Y	Y	Y	N.R.*	Y	N.R.*	9
Yamada 2006	Y	Y	N	N	N.R.*	N	N	Y	Y	Y	Y	N.R.*	N.R.*	N.R.*	6
Total YES	39	20	10	32	2	0	0	8	38	24	38	3	6	13	

*N.R. Not Reported.
**N.A. Not Applicable.

the variables of interest as gold standards and they were defined in detail. Only one article[29] did not clarify the comparative measurements. Just over half, 24, of the studies provided the exposure for each person measured more than once during the course of the study period. In 3 studies,[25,26,57] this information was not reported. Only 3 studies[28,54,60] provided sufficient information to determine they were blinded.

Follow-up rate; statistical analyses

Thirteen studies[25–27,29,30,32,33,41–43,50,51,58] reported data on follow-up. Usually, an acceptable overall follow-up rate is considered to be 80% or more of participants whose exposures were measured at baseline. In 6 studies,[27,38,40,42,54] this percentage was lower than 20%. Only in 13[25–27,29,30,32,33,41–43,50,51,58] studies were key potential confounding variables measured and adjusted for, such as by statistical adjustment for baseline differences; in other studies this process was not reported.

Outcome measures

The two most commonly used stroke scales resulted from this review are the Frenchay Activities Index (FAI)[42,50,54,55] and the FIM[26,51] with two modified versions.[46,49] The FAI is a formal interview for patients who have suffered a stroke or their caregivers to compare functional abilities preceding and following a stroke. It has been used to assess ADLs three and six months before a stroke and consists of 15 items that measure complex activities in the categories of domestic activity, work/leisure, and outdoor activity.[50] The FAI score is based on the frequency with which activities are performed, ranging from 0 (inactive) to 45 (very active): 0–15 = inactive, 16–30 = moderately active, and 31–45 = very active. The cutoff of ≥ 18 has been used as a predictor of mild disability after stroke.[50] According to its developer, the FAI can be used to record premorbid levels of functioning, thus facilitating the negotiation of realistic rehabilitation goals, and to measure changes in the levels of functioning due to stroke.[55] It usually takes only a few minutes to complete and is very easy to administer.[43] The FAI has shown significant correlations with the Barthel Index, the Sickness Impact Profile, and the Stroke Impact Scale-ADL/IADL, as well as with the modified Nottingham Extended ADL.[50]

The FIM[26,51] is widely used throughout the world; it provides a uniform system of measurement for disability based

on the International Classification of Functioning, Disability and Health.[64] It measures the level of a patient's disability and indicates how much assistance is required for the individual to carry out ADLs through 18 items composed of 13 motor tasks and 5 cognitive tasks.[26] The Scandinavian study[46] explored in this review validated only the motor subscale of the FIM. The Japanese study[49] validated the FIM in association with the FAM. The FAM is a 30-item global measure of disability that was constructed by adding the 12 unique items [that emphasize the cognitive, communicative, and psychosocial aspects of the disability) to the original 18 items of the FIM; it was developed as a measure for evaluating disability in patients with traumatic brain injury (TBI). Items of the FIM +FAM have been grouped into two subscales based on principal component analysis: a motor subscale comprised of 16 items and a cognitive subscale comprised of 14 items.[49] Both the FIM and the FAM use a 7-point scoring system based on whether or not the assistance of another person is required for an individual to perform ADLs effectively. A rating of 1 indicates total dependence and 7 complete independence, with intermediate levels rated as: 6 modified independence, 5 supervision or set up, 4 minimal contact assistance or the subject expends > 75% of the effort, 3 moderate assistance or the subject expends 50 to 74% of the effort, and 2 maximal assistance or the subject expends 25 to 49% of the effort.[51] It is recommended that the FIM be administered by well-trained raters.[49]

Discussion

This study was conducted by a research group composed by medical doctors and rehabilitation professionals from the "Sapienza" University of Rome and from "Rehabilitation & Outcome Measure Assessment" (R.O.M.A.) association. R.O.M.A. association in the last few years has dealt with several systematic reviews and the validation of many outcome measures in Italy.[65–74]

Summary of the quality of the evidence

The assessment of ADLs in adults who have had a stroke is a crucial moment for the entire field of rehabilitation. Outcome measures are frequently used to determine if patients have made meaningful changes in their recovery process and may influence the intensity and duration of care. Researchers use outcome measures during the investigation of the efficacy and effectiveness of a given treatment intervention. Therefore, the aim of this study was to provide clinicians and researchers with evidence-based recommendations regarding what outcome measures should be used to assess the loss of functionality in the ADLs of patients following a stroke. This was achieved by reviewing the most frequently used outcome measures and determining whether there is evidence to support their use. The data available in the major databases up to July 2017 permit the identification of different measurement tools internationally. The research was conducted using keywords and no time limits were set so as not to exclude any study that could have made important contributions to the review. The studies that emerged were published between November 1986[57] and March. 2017[50] In total, 33 studies tracked the use of an assessment tool.[25–63] In these studies, a strong heterogeneity of validated tools among the various national contexts can be seen. This heterogeneity can be assumed to have a positive meaning if one thinks about the multiple needs of the clinical context, but certainly leads to the need to make the tools more suitable for various cultural contexts. These findings suggest that clinicians have conflicting or incomplete information available to use when making decisions in patient care; furthermore, the lack of consistency and the deficiency of standardization in outcome assessment has hindered comparative research and meta-analysis. Further investigation of outcome measures would benefit patients, researchers, and clinicians. A universal, validated outcome measure is needed to allow comparisons across practice; therefore, we recommend that future researchers use a common set of outcome assessments.

The variety of methods used throughout the literature to measure responsiveness illustrates the present problem of defining and standardizing a method or standard descriptor that can be used to accurately report responsiveness among various outcome measures. The COSMIN checklist was published in 2010 to assess the methodological quality of studies on measurement properties.[20–23] Through an international consensus process, the COSMIN framework was developed, providing specific recommendations on terminology, taxonomy, and methodology in studies dealing with PROMs and their measurement properties. We performed this systematic review in line with the recommendations of the COSMIN initiative but we found great difficulty in tracking all the desired values; for some studies, this trend was hypothetically attributed to the year of publication. The assessment of the studies through the QAT provided a more specific overview of the quality of the studies tracked by the review. Only 16[25,28,31,32,34,36,42,43,47–53,62] of the 39 studies were published after the publication of the COSMIN checklist and these guidelines were not followed in the majority of the included studies; however, according to the QAT, the studies published after 2010 do seem to have higher quality.

This review has demonstrated that no perfect stroke-ADL scale exists, therefore many assessment tools, spanning various ADL domains, are available to clinicians and researchers working with stroke survivors. We have described the flavor of the marked heterogeneity in the use of assessment tools and we have deliberately avoided suggestions that one scale is better than another. We have focused, as exemplars, on the two most commonly used stroke scales: the Frenchay Activities Index (FAI)[42,50,54,55] and the FIM[26,51] with two modified versions.[46,49] These scales have been validated, are familiar to many, and have proven utility with each suited to differing assessment scenarios. Thus, in the absence of a "perfect" assessment, we recommend continuing the use, validation, and adaptation of these assessment scales for adults with stroke in different countries to develop a common language throughout the world for discussing ADLs and functionality.

In response to the secondary objective of this review, it was not possible to find tools to assess the loss of functionality in

ADLs specific to adults with stroke that were validated in the Italian context.

Limitations of the study

There are several limitations of this review that need to be considered. Despite having systematically searched three electronic databases, it is possible that not all relevant studies were identified. Studies may have been published in journals that were not covered by the databases. In addition, this review only included published studies; therefore, studies that have been submitted and not accepted for publication or were accepted for publication only recently would be excluded. Only English-language articles were included, making it possible that this systematic review is not a complete representation of the evidence available worldwide. Finally, studies may not have been identified with the search strategy used, in fact some instruments, such as SIS 3.0 and others, are not considered in the study. Due to the nature of problems with ADLs, which affect many areas of life, it is possible that some relevant articles did not use the words applied in the search strategy; for example, if an article was about the validation of an outcome measure for assessing disability, it would not have been included.

Finally, one of the bias associated with the FAI and FIM is their publication date and the fact that they have existed for much longer, especially given they were the only ones available at their respective times. As a result, they have grown to prominence and have been revised more over time to present with better psychometric properties.This systematic review revealed large inconsistencies among the current available ADL outcome measures. The limitations of this study can be attributed to the difficulty of bringing the reporting of studies according to the general principles; this makes it difficult to compare study results and to create norms and standards for the loss of functionality in the ADLs of stroke patients. We believe that further exploration, analysis, and adaptation of existing instruments is needed rather than the development of new outcome measures.

Conclusions

To our knowledge, this is the first systematic review that describes the outcome measures of the loss of functionality in the ADLs of adults with stroke with the parameters of validity, reliability, responsiveness, and languages in the literature. It is important for the development of clinical practice and research that practical and appropriate measures are universally accepted; this would allow comparisons and meta-analysis of high quality randomized controlled trials of people with this ever-increasing injury. At present, there is no one broadly accepted ADL assessment tool for adults with stroke that would allow for the comparison of study results. It is hoped that this review has emphasized the need for agreement among researchers as to which tool must be studied in depth or adapted to other national contexts as well as which one measurement instrument should be standardized in its use in order to develop universal norms and standards for the performance of adults with stroke. Thanks to this review, we have highlighted the lack of a valid and reliable assessment tool for the ADL functionality of adults with stroke in Italy. Future studies could enrich and integrate the Italian rehabilitation context of adults with stroke by culturally adapting one of the tools that emerged from this review to create standardized and shared evaluation paths.

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