Disability after stroke: a systematic review

Incapacidade após acidente vascular cerebral: uma revisão sistemática

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Abstract

Introduction: Stroke is the most common cause of disability in Western countries, yet there is no consensus in the literature on how to measure and describe disability from stroke. Objective: To conduct a systematic literature review on disability in stroke survivors. Method: Observational studies published in the PubMed, LILACS and SciELO online databases were selected, to evaluate disability in adults and in the elderly after stroke in the period 2002–2012. The Downs and Black checklist for non-randomized studies was used to assess the quality of the articles. Results: 212 articles were found from which 16 were selected to compose the study. The mean age of participants was 67 years, and disability affected 24% to 49% of the population evaluated. With regard to measurement instruments, 31% of the studies analyzed presented results of disability by means of the modified Rankin Scale; 19% by means of the World Health Organization's International Classification of Functioning, Disability and Health; 19% by means of Katz' Index of Independence in Activities of Daily Living; 12.5% by means

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of the London Handicap Scale; 12.5% by means of the Barthel Index; and 6.25% by means of the Functional Independence Measure. **Conclusion:** Literature is not uniform as regards means of measuring disability after stroke, but considering the preference of articles in assessing physical performance in activities of daily living, it can be concluded that a quarter to half of the population that survives stroke has some degree of disability.

**Keywords:** Stroke. Disabled persons. Disability evaluation.
online course recommendation of a prior search for systematic reviews on the topic in order to evaluate the need for the study. The search for reviews was performed in the Cochrane library and online using MEDLINE, with the following keywords: "systematic review", "stroke" and "disabled person" (14).

Search strategy

The search strategy for this review included research in three online databases: MEDLINE via PubMed (National Library of Medicine and National Institutes of Health); LILACS (Latin American and Caribbean Health Sciences Literature) and SciELO (Scientific Electronic Library Online). The keywords used were matched in English and Portuguese, and registered in the National Library of Medicine's controlled vocabulary thesaurus (MeSH) and the Health Sciences Descriptors (DeCs) trilingual thesaurus: "stroke" and "disabled persons" in English, and "accidente vascular cerebral" and "pessoa com deficiência" in Portuguese. The terms "disability" and "functional disability" were not used as descriptors because they were not registered in the DeCs. The search period was January 2002 through December 2012, with no restriction on language.

Selection of studies

Titles and abstracts were read for initial selection of the articles identified. The full articles were then read, and those that met the inclusion criteria were included in the data collection phase, performed by means of a standardized form (Annex 1). Identification and selection of the studies was performed by two researchers working independently.

Eligibility criteria

The articles selected were observational and cross-sectional or cohort, with the aim of evaluating the disability or level of assistance required in adults and elderly individuals after suffering stroke. Studies that evaluated other outcomes in addition to disability were included; however, those that associated stroke with other clinical situations, or that compared specific interventions and methods of rehabilitation, were excluded. Articles that were not published in English, Portuguese or Spanish, and those that were not found even after attempting to contact the author were also excluded.

Quality assessment

The studies included were initially divided according to study design, and the longitudinal studies were evaluated for quality by adapting the Downs and Black checklist for non-randomized studies, using only the 13 items relating to assessment of cohort studies. Adaptation of the Downs and Black instrument has already been used in other reviews in order to identify relevant methodological features of observational studies (15, 16, 17).

Results

The initial search yielded 212 documents; of these, 40 were selected. After reading each article in full, 24 were excluded for not meeting the eligibility criteria, leaving a total of 16 articles analyzed and submitted to the data collection phase of this review (Figure 1).

Among the studies analyzed, 56.25% were published since 2008. The articles were listed in descending order by year of publication in Table 1, in which general data such as author/year, objective, study design, sample, participant age, instruments and results were summarized. Eight studies were cross-sectional, two of which presented results from the same Italian population. Eight studies were prospective longitudinal, of which two presented the results from one Australian cohort five and ten years after stroke.

Sample sizes ranged from 13 to 1233 subjects, with the mean being 254 participants of both sexes. The studies included adult populations of various age groups, and the mean participant age was 67 years. The moment of evaluation ranged from three months to ten years after stroke. Diagnostic criteria for definition of cases had some differences between studies: 68.7% conducted clinical examination and the patients were classified according to the International Classification of Diseases (ICD), and 50% had the diagnosis reviewed by image examination. Three studies applied scales for disease classification: Lo et al. (18) used the National
Institute of Health Stroke Scale (NIHSS); Carod-Artal et al. (5) used the Trial of Org 10172 in Acute Stroke Treatment (TOAST); and Patel et al. (19) applied the Oxfordshire Community Stroke Project (OCSP). Three studies did not mention diagnostic criteria used (6, 17, 20).

Four articles (25%) set out to evaluate quality of life (QOL) in addition to disability, and found strong positive association between the physical domain of QOL instruments and disability (5, 7, 17, 19). Of the studies analyzed, 31% (five articles) presented the result of disability by means of the modified Rankin Scale (mRS) (17, 20, 21, 22, 23); 19% (three articles) by means of the International Classification of Functioning, Disease and Health (ICF), one of which used the World Health Organization Disability Assessment Schedule (WHODAS 2.0) (7, 24, 25); 19% (three articles) by means of the Katz Index of Independence in Activities of Daily Living (6, 26, 27); 12.5% (two articles) by means of the London Handicap Scale (18, 28); 12.5% (two articles) by means of the Barthel Index (5, 19); and 6.25% (one article) according to the Functional Independence Measure (FIM) (29).

Considering functional disability as an indicator of disability measured by means of instruments such as the Katz and Barthel scales and the mRS, the result of 12 of the 16 selected articles can be assembled as follows: in the first two years after stroke, disability affected 24% to 49% of the population evaluated; three to five years after stroke, that number was between 26% and 47%; and ten years after, 46% of the population had some level of disability.

The evaluation of quality applied to the cohort studies had a mean methodological score of 10.5, and the studies that obtained the highest score were Hardie et al. (23) and Lin et al. (29). The score of each study can be found in Table 1.

### Table 1- Characteristics of studies selected

<table>
<thead>
<tr>
<th>Reference year/location</th>
<th>Objective</th>
<th>Study design</th>
<th>No.</th>
<th>Mean age (years)</th>
<th>Measurement</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Cerniauskaitė et al. (7)</td>
<td>To assess impact of stroke on quality of life and disability, and the relationship between both.</td>
<td>Cross-sectional</td>
<td>111</td>
<td>57</td>
<td>SF-36, WHODAS 2.0</td>
<td>53% reported that there was no change in health after the stroke; however the SF-36 score was lower when compared with the general population. <strong>Strong correlation</strong> ($p = 0.84$ and 0.75) in the <strong>physical function domains</strong> of the SF-36 with the areas of mobility and <strong>domestic tasks</strong>, respectively, of the WHODAS ($p &lt; 0.01$).</td>
</tr>
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<tr>
<td>Quintas et al. (24)</td>
<td>To demonstrate that stroke alone does not explain the differences and variety of function and disability.</td>
<td>Cross-sectional</td>
<td>111</td>
<td>57</td>
<td>ICF</td>
<td>47% reported moderate to severe gait compromise, and 25% in speaking and understanding. The most reported problems of body function were: function of memory, attention and muscles. In the environment component: family (92%) and healthcare professionals (82%) are the main facilitators.</td>
</tr>
<tr>
<td>Martins et al. (25)</td>
<td>To describe profiles of disability and function by combining use of the ICD and ICF to evaluate survivors of stroke.</td>
<td>Cross-sectional</td>
<td>13</td>
<td>73</td>
<td>ICD ICF</td>
<td>69% were classified as hemiplegic, and 31% hemiparetic. Of events coded by means of the ICF, the most reported body function problems were: movement function (34%), neuromuscular (27%) and damage to structures related to movement. 52% had compromise in activities and participation mainly in daily domestic activities and tasks.</td>
</tr>
<tr>
<td>Hong et al. (22)</td>
<td>To apply the DALY measure to quantify years of life lost due to disability.</td>
<td>Cross-sectional</td>
<td>1233</td>
<td>66</td>
<td>NIHSS mRS DALY</td>
<td>35% were considered dependent for activities of daily living (mRS 3-6). The mean of years lost due to disability was 3.82 (IC 95% 3.68 to 3.96).</td>
</tr>
<tr>
<td>Coss et al. (6)</td>
<td>To evaluate independence index in patients after stroke</td>
<td>Cross-sectional</td>
<td>22</td>
<td>30–90</td>
<td>Katz</td>
<td>45% were aged 70 to 90 years. 41% were dependent for at least one of the six activities evaluated. 4.5% were dependent for all activities.</td>
</tr>
<tr>
<td>Carod-Artal et al. (5)</td>
<td>To identify the determinants of quality of life in survivors of stroke.</td>
<td>Cross-sectional</td>
<td>260</td>
<td>55</td>
<td>Barthel Lawton SIS NIHSS mRS</td>
<td>31.5% had severe disability (Barthel ≤ 60) and 35% moderate disability (Barthel 65-90). 49% were evaluated with mRS ≥ 3. Age (r = -0.20) and presence of other comorbidities (r = 0.35) were correlated to level of dependency. (p &lt; 0.0001). Disability (Barthel) has high correlation with the physical domain of the SIS (r = 0.99).</td>
</tr>
<tr>
<td>Petrea et al. (22)</td>
<td>To explore gender difference in post-stroke disability and incidence in the Framingham Cohort.</td>
<td>Cohort</td>
<td>205</td>
<td>45–94</td>
<td>Katz</td>
<td>Women are 4 times more likely than men to be dependent prior to stroke (OR = 4.3, p &lt; 0.001) and six months after (OR = 3.7). 32% of women presented dependence for transfer, and 37% for walking. For men these percentages were 13% and 18%, respectively (OR = 2.3, OR = 1.91). Quality score: 11.</td>
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(To be continued)
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<tr>
<td>Gall et al. (28) 2008 Australia</td>
<td>To define standard and level, and identify risk factors of disability five years after stroke.</td>
<td>Cohort</td>
<td>352</td>
<td>75</td>
<td>Barthel LHS; IDA</td>
<td>45% of the cohort survived 5 years after stroke. Of those who survived, 70% are among the deciles representing disability (LHS &lt; 90), mainly in the domains of physical independence, leisure and occupation. 47% showed dependence in some BADL (Barthel). Increasing age and recurrence of stroke are factors associated with greater disability. Quality score: 9.</td>
</tr>
<tr>
<td>Lo et al. (18) 2008 China</td>
<td>To investigate changes in levels of disability in survivors of stroke, and identify their determinants.</td>
<td>Cohort</td>
<td>268</td>
<td>77</td>
<td>Barthel Lawton MMSE GDS LHS</td>
<td>Three months after stroke, 24% were dependent in more than one BADL (Barthel &lt; 14) and 30% was in the range 15 to 19. 19% were institutionalized. In the multilevel analysis, depression (GDS), functional disability (Barthel) and advancement of age were strongly associated with disability and severity (LHS) p &lt; 0.001. Quality score: 10.</td>
</tr>
<tr>
<td>Appelros et al. (20) 2006 Sweden</td>
<td>To verify the living scenario and need for assistance for ADL before and one year after stroke.</td>
<td>Cohort</td>
<td>253</td>
<td>75</td>
<td>Barthel FAI mRS GDS MMSE NIHSS</td>
<td>37% of the cohort presented MRS ≥ 3. Before the stroke, 13% lived in institutions; one year after the stroke, 20% lived in institutions, and the factors associated with this change were prior dependency (OR = 17), cognitive impairment (OR = 12) and depression (OR = 4.5) p &lt; 0.001. One year after the event, 36% of stroke survivors needed some help with BADL, and 59% required help with BADL. Quality score: 10.</td>
</tr>
<tr>
<td>Patel et al. (19) 2006 England</td>
<td>To estimate level of disability and quality of life three years after stroke, and examine the relationship between the two domains.</td>
<td>Cohort</td>
<td>490</td>
<td>71</td>
<td>Barthel FAI SF-36</td>
<td>Three years after the stroke, 34% were independent and 26% were moderately to severely disabled (Barthel &lt; 15). 51% were inactive (FAI &lt; 15). Strong correlation (r = 0.79) between FAI and Barthel and strong correlation (r &gt; 0.70) between the physical domain of the HRQOL and disability (Barthel). Quality score: 11.</td>
</tr>
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<tr>
<td>Martins et al. (17) 2006 Portugal</td>
<td>To evaluate the impact of stroke on quality of life and functional capacity nine months after hospital discharge.</td>
<td>Cross-sectional</td>
<td>273</td>
<td>69</td>
<td>Barthel, FAI, mRS, COOP/WONCA</td>
<td>36% of the sample was independent in BADL (Barthel), 47% had disability (mRS ≥ 3), and 29% were self-employed in IADL (FAI). Perception of quality of life (QOL) is strongly associated (0.70, p &lt; 0.01) with functional capacity, the domain physical fitness was the most affected in the assessment of QOL.</td>
</tr>
<tr>
<td>Lin et al. (29) 2005 China</td>
<td>To identify predictors of degree of disability one year after stroke.</td>
<td>Cohort</td>
<td>109</td>
<td>62</td>
<td>FIM</td>
<td>The group classified with severe and very severe disability (59%) presented a mean FIM score of 65 and the group with mild to moderate disability (41%) showed mean FIM score of 87. In the regression model, bilateral involvement (OR = 10.8) and low FIM score (OR = 7.6) were associated with the highest level of disability. Quality score: 12.</td>
</tr>
<tr>
<td>Hardie et al. (23) 2004 Australia</td>
<td>To determine frequency of recurrence of stroke and disability 10 years after first stroke.</td>
<td>Cohort</td>
<td>45</td>
<td>72</td>
<td>mRS</td>
<td>10 years after the first stroke: approximately 15% were institutionalized. 46% were incapacitated. The risk of suffering from another stroke among the subjects of the cohort was 6 times greater than the general population, even after adjusting for sex and age (95% IC -4.5-7.4). Quality score: 12.</td>
</tr>
<tr>
<td>Widar et al. (26) 2002 Sweden</td>
<td>To describe disability and pain in everyday life of survivors who cite pain after stroke.</td>
<td>Cross-sectional</td>
<td>43</td>
<td>33–82</td>
<td>Katz, MPI-S</td>
<td>46% were dependent for one or more BADL (Katz). 52% reported difficulties walking, and 50% depended on mobility equipment. 63% reported moderate pain, 37% reported severe pain.</td>
</tr>
<tr>
<td>Hankey et al. (21) 2002 Australia</td>
<td>To describe disability and dependence five years after stroke in the city of Perth.</td>
<td>Cohort</td>
<td>277</td>
<td>73</td>
<td>Barthel, FAI, mRS, MotrInd</td>
<td>19% had some disability before the stroke. 45% of the cohort had died five years after the first stroke, 17.7% of the survivors were institutionalized, and 36% had some dependency for BADL. The cumulative risk of a new and greater disability was 36%. The prognostic factors of disability were old age (OR = 5.7 in the age range 75-84), recurrence of stroke and apathy in the first evaluation. Quality score: 9.</td>
</tr>
</tbody>
</table>

Note: SF-36 = Short Form Health Survey; WHODAS 2.0 = World Health Organization Disability Assessment Schedule 2.0; ICF = International Classification of Functioning, Disability and Health; ICD = International Classification of Diseases; NIHSS = National Institute of Health Stroke Scale; mRS = modified-Rankin Scale; DALY = disability adjusted life year; SIS = Stroke Impact Scale; LHS = London Handicap Scale; IDA = Irritability, Depression and Anxiety; MMSE = Mini-Mental State Examination; GDS = Geriatric Depression Scale; FAI = Frenchay Activities Index; COOP/WONCA = Primary Care Cooperative Information Project/World Organization of National Colleges Academies; MPI-S = Multidimensional Pain Inventory; MotrInd = Motricity Index.
Discussion

Measurement instruments and results of disability

The studies applied various measurement instruments. Appelros et al. (20) used the Barthel Index, but presented the result of the disability by means of the mRS, concluding that 37% of the cohort was disabled (mRS 3-6). Martins et al. (17) used the same methodology, and concluded that 36% of the sample was independent in Basic Activities of Daily Living (BADL) through Barthel Index, but 47% had disability (mRS ≥ 3).

Hong et al. (22) applied the disability-adjusted life year (DALY) measure to survivors of stroke, and used the results of the mRS for the calculation. As 35% of participants were disabled (mRS 3-6), the mean number of years of life lost due to disability was 3.82 (CI 95% 3.68 to 3.96). Hankey et al. (21) and Hardie et al. (23) also used the modified Rankin Scale (mRS) to present the results of disability.

Of the seven studies that applied the Barthel Index (BI), five used a modified version of the instrument with scoring from 0 to 20 (17, 18, 19, 21, 28). Despite being the most applied instrument among the studies, only two presented the results of disability using the BI: the English cohort of Patel et al. (19) showed 12% with severe disability (BI < 9), 14% moderate (BI 10-14), 34% mild (15-19), whereas 39% were independent (BI = 20). The Brazilian study by Carod-Artal et al. (5) used the original scoring proposal from 0 to 100, and determined that 34% of the subjects were independent, 31% had severe disability (BI ≤ 60), and 35% moderate disability (BI = 65-90).

The other studies used the BI to classify level of dependence, including Lo et al. (18), who showed results of disability with the London Handicap Scale, but classified dependence in two levels: 24% had BI < 14, which is dependency in more than one BADL, and 30% were in the Barthel range 15-19.

The Australian studies by Gall et al. (28) and Hankey et al. (21) evaluated people five years after the first stroke, and also used other instruments to present disability; however, they applied the BI and defined as dependent those subjects who had a score < 20, and found 36% and 47% of their subjects dependent in some BADL, respectively.

Petrea et al. (27), Coss et al. (6) and Widar et al. (26) used the Katz Index in their reviews, and respectively found that 45%, 41% and 46% of their samples was dependent on at least one of the six activities evaluated. Lin et al. (29) used the Functional Independence Measure (FIM), and classified 59% of the sample with severe and very severe disability (mean score of 65), and 41% with moderate and mild disability (mean score of 87). In addition to evaluating the need for assistance with BADL and mobility, the FIM also evaluates communication and cognition.

The International Classification of Functioning, Disability and Health (ICF) was used in three studies (7, 24, 25). Quintas et al. (24) showed that body function problems most frequently reported by subjects that suffer from stroke are: difficulties with memory (more than 50% of the sample), attention (approximately 50%) and muscle function strength (50% of the sample). Furthermore, 47% reported moderate to severe gait impairment. Martins et al. (25) observed that 34% of subjects had difficulty in functions related to movement, and 52% had limitations in activities and participation, especially in domestic activities.

This result corroborates Alves (10), who also showed absence of a well-defined standard to measure disability. The terms “disability” and “level of dependency” were constantly taken alternatively in the articles, instruments such as Barthel and Katz, which were developed to assess level of dependence in ADL, were used to present the results of disability. Guccione (30) and Alves (31) point out that these scales of difficulty and dependence are good instruments for measuring functional disability, which is an aspect of disability. This result shows that there is a preference in the literature for measuring disability according to physical performance in daily activities, a result already observed by Cerniauskaite et al. (7). However, the approach of the ICF warns that disability cannot only be evaluated by dependence in ADL. The WHODAS 2.0, a disability assessment scale created by the WHO, evaluates the individual’s functioning in six areas of activity: understanding and communicating, physical mobility, self-care, living with people, life activities and participation in society. It seems to be an instrument capable of covering all domains of disability, but because of its recent publication, it had little reference in the studies (32).
Disability in time

Functional capacity decreases with time, whereas the risk of developing a chronic condition increases (33). The debilitating process proceeds through the evolution of the chronic condition associated with other factors such as lifestyle, behavior, and biological, social and demographic characteristics (34).

Four cohorts followed the patients during the first year after stroke. Petrea et al. (27) found that three months after the event, the level of incapacity was greater than when compared after six months. Lo et al. (18) had a similar result, and concluded that its participants were less disabled after one year than in the third month, suggesting that functionality can improve between the third and twelfth month after stroke. This finding is consistent with previous articles that report a recovery between the third and sixth month after stroke (35, 36).

Most of the cross-sectional studies did not define the exact moment after stroke, and assessed subjects at various times (5, 6, 7, 24), while 19%, four cohorts, investigated long-term disability. Hankey et al. (21) stated that disability and institutionalization are the most common long-term results, affecting one-third and one-seventh of the survivors respectively. These authors also consider that the most important modifiable prognostic factors for these results are the low levels of physical activity and recurrence of stroke. Patel et al. (19) found that five years after stroke, 36% of the survivors of their cohort were dependent in some way. Gall et al. (28) found a similar result, where 47% of the survivors were dependent for some ADL after five years.

Evaluation of methodological quality and limitations of the study

The methodological variation between the studies, such as period evaluated, measurement instruments used and the form of data presentation made it difficult to gather the results of the 16 articles. Although the eight longitudinal studies evaluated had good methodological quality within the criteria of Downs and Black, the studies with cross-sectional design were not evaluated due to lack of scale or criterion for this purpose, which can be considered a limitation.
of this study. In addition, four articles were excluded from the study, two because they were not found, and two due to language.

Conclusion

This systematic review revealed heterogeneity in the literature when the subject is disability among stroke survivors. Most studies evaluated aspects of disability, failing to include all domains involved in this phenomenon. Furthermore, there is still no consensus as to the instrument to be used.

Wagering on functional disability as a reliable indicator of disability, it is possible to conclude that 24% to 49% of the population that survives stroke has some level of disability, which can vary according to age, stroke recurrence, time of evaluation and instrument applied. Most of the studies present disability by means of instruments that measure physical performance in activities of daily living, affirming functional disability as the most used indicator to define disability in people after suffering stroke. The Barthel Index was the instrument most used in the articles; however, the modified Rankin Scale was preferred to present results of disability.

References


Disability after stroke


Annex 1

Data collection form

Information of studies included

Title:
Publication date:
References:

Methods

Research Question:
Objective:
Study type:
Instrument used to determine outcomes:
Study location:
Sample representation:
Calculation of statistical power:

Participants

Age:
Sex:
Inclusion criteria:
Exclusion criteria:
Diagnostic criteria:
Number of participants:

Outcomes

Results