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REVIEW



Measures used to assess impact of providing care among informal caregivers of persons with stroke, spinal cord injury, or amputation: a systematic review

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ABSTRACT

Purpose: (1) To identify measures used to evaluate the impact of caregiving among caregivers of persons with stroke, spinal cord injury, and amputation; and (2) to systematically evaluate their clinimetric properties reported in validation studies.

Materials and methods: Two separate systematic reviews (Embase, PsycINFO, CINAHL, Pubmed/Medline) were conducted. COSMIN guidelines were used to assess clinimetric properties and methodological quality of studies.

Results: (1) 154 studies published between 2008 and May 2019 were included, in which 48 measures were used, mostly describing negative impact. Thirty measures were used only once and not further described. (2) In general, structural validity, internal consistency, and hypothesis testing were often investigated. Reliability, cross-cultural and criterion validity to a lesser extent, and scale development and content validity were rarely described. Tests of measurement error and responsiveness were exceptional. Most supporting evidence was found for the Zarit Burden Interview Short Form, Caregiver Burden Scale and Positive Aspects of Caregiving Questionnaire.

Conclusions: There is a wide variety of impact of caregiving measures. The present study provided a detailed overview of what is known about clinimetric characteristics of 18 different measures repeatedly used in research. The overview provides clinicians a guidance of appropriate measure selection.

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Caregiving impact; stroke; spinal cord injury; amputation; clinimetric; measures

► IMPLICATIONS FOR REHABILITATION

- Clinicians should be aware that information about measure development and clinimetric properties for most measures used to assess impact of informal caregiving is incomplete.
- Most supporting evidence was found for the Zarit Burden Interview Short Form, Caregiver Burden Scale and Positive Aspects of Caregiving Questionnaire.
- This overview of clinimetric properties provides clinicians guidance for selection of an appropriate measure.

Introduction

Acquired brain injury, spinal cord injury, and amputation are important diagnostic groups in medical rehabilitation. These three diagnostic groups together represent nearly three-quarters of the patients admitted to inpatient medical rehabilitation in the Netherlands [1]. Over 90% of all people with physical disabilities return to independent living in the community, either directly from the hospital or after a period of inpatient rehabilitation. Many of them, however, will need care or support and most of this care is provided by informal caregivers. Informal caregivers are persons, whether relatives or not, who provide unpaid care to a person with disabilities. Informal caregiving is not simply an imposition but arises from emotional bonds with the person with disabilities [2,3]. Care provided by informal caregivers may include practical tasks (e.g., ADL support, visiting a doctor, or arranging

exercises), but also emotional support (e.g., comforting or looking after) [4]. Performing informal care may have negative and positive consequences for the informal caregiver. It is known that many caregivers perceive high levels of caregiver burden on the short term as well as on the long term [5–7], which often has negative consequences for their health and well-being (quality of life, physical, and psychological impact) [8], but also for the patients [9], and society [10]. At the same time, providing care may also have positive consequences, e.g., increased self-esteem and mental health, feelings of rewards or meaningfulness, and feeling of satisfaction [11,12].

In the scientific literature, the measures used to assess the negative and positive impact of providing informal care are diverse. In 2004, Visser-Meily et al. published a review of measures

used to assess burden among informal caregivers of patients with stroke [13]. These authors concluded that the many identified burden scales all lacked sufficient evidence for reliability and responsiveness.

Three more recent reviews published in 2012 [2], 2016 [3] and 2017 [14] provide overviews of tools to measure caregiving-related consequences on health [2,3], quality of life [3] and feelings of burden [14] among caregivers of elderly people [2,3] or of patients with chronic conditions (in this case, Parkinson's Disease, heart failure, Multiple Sclerosis, and Chronic Obstructive Pulmonary Disease) [14]. Although many different scales measuring caregiving impact were described in these reviews, only limited information on the clinimetric properties of these scales was reported. Users need information about the (dis)advantages and clinimetric properties of the measures to be able to make well-informed choices [14]. The use of valid and reliable measures is important to reduce the chance that impact of caregiving will be unnoticed.

In the present study, we aim to provide an overview of recently (last decade) used measures to evaluate negative and positive caregiving impact among caregivers of persons with stroke, spinal cord injury or amputation. We focus on these diagnostic groups because measure use may be sample-dependent and together these groups comprise a large part of the adult rehabilitation population. Furthermore, we want to evaluate clinimetric properties of the found measures in a comprehensive and systematic way. Our research questions are the following:

- Research Question 1 (RQ1): Which measures evaluating the negative and positive impact of caregiving reported by informal caregivers of persons with stroke, spinal cord injury, and amputation have been used in empirical studies published between 2008 and 27 May 2019?
- Research Question 2 (RQ2): For the measures used in more than one study: what are their clinimetric properties, as described in validation studies of these measures published before 3 June 2019?

Materials and methods

We followed the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) methodology for systematic reviews of patient-reported outcome measures [15–17], including the PRISMA statement (Supplementary Table S1) [18]. The protocol of this systematic review has been registered in the International Prospective Register of Systematic Reviews (PROSPERO, ID: CRD42018094796).

RQ1

Search strategy RQ1

The electronic databases Embase, PsycINFO, CINAHL, and Pubmed/Medline were systematically searched for the period between 2008 and 2019 (27 May). The search string consisted of three components – “caregiving,” “caregiver-reported negative and positive impact of caregiving,” and an indication of “diagnosis.” To develop our search strategy, an information specialist was consulted. The search string was adapted for the use of different bibliographic databases. Details of the search string are shown in Supplementary Table S2. Searches were restricted to studies published in the English language. To make sure that no relevant publications were missed, references of relevant publications were checked, as well as publications that used these relevant publications as a reference (“cited-by” function).

Eligibility criteria RQ1

Publications were included when at least one measure was used to assess the negative or positive impact of caregiving among informal caregivers of adult (≥ 18 years) persons with stroke, spinal cord injury or amputation. Informal caregivers had to have a minimum age of 18 years and had to provide informal, not paid, care. Publications were only included when at least 15 caregivers of persons with stroke, spinal cord injury or amputation participated in the study. The study was restricted to empirical studies written in English, published in scientific journals (in print or online) and published between 1 January 2008, and 27 May 2019. Publications were only included if a measure was used that includes a “caregiving component” in its questions, such as the Caregiver Strain Index [19]. If only more general measures of distress or other outcomes of caregivers were used without the “caregiving component”, e.g., the Hospital Anxiety and Depression Scale [20,21], which items do not refer to caregiving, the publication was excluded. Publications were also excluded if only measures were used which do not include a negative or positive evaluation, like measures used to assess objective burden in terms of time spent, frequency and tasks, such as the Caregiver Assistance Scale [22]. Measures which assess several dimensions of impact were included if at least one dimension reflects subjective perception, e.g., the Oberst Caregiving Burden Scale which focus on time spent on caregiving tasks and caregivers perceptions of the difficulty of caregiving tasks [23]. Measures that focused only on evaluation or use of professional care and services, such as the Caregivers' Satisfaction with Stroke Care Questionnaire [24], or on caregivers' knowledge (Caregiving Knowledge Level Scale [25]), were excluded. Furthermore, in RQ1, publications were excluded when a qualitative study, review or validation study was reported, or when no full-text was available in a situation where all needed information was not found in the abstract. Variants of measures, e.g., modified, revised or expanded versions, were counted as separate instruments.

Study selection RQ1

Reference management program Mendeley was used to merge all retrieved publications into one main file and to remove duplicates. The systematic literature review web application Rayyan QCRI [26] was used for categorizing and labeling publications based on title and abstract, and later on, full-text. Titles and abstracts were screened by one reviewer (ES), with a double check by another reviewer (CH) in the initial phase of screening. Disagreements were discussed until consensus was reached and the discussion was used to improve the screening process. In total, 10% of the titles and abstracts were double checked. Given the high level of interrater agreement (94.6% consensus, Kappa = 0.78) [27], we evaluated the 10% double check as sufficient. Relevant publications were read in full-text (ES), again with a 10% double check (CH) in the initial screening phase. The interrater agreement in the full-text screening (96.3% consensus, Kappa = 0.91) was even better [27]. Therefore, again, we decided that a 10% double check was sufficient.

Data extraction RQ1

We made an overview of all identified measures, including names of the authors, year of publication and number of studies in which the measure has been used, including references.

RQ2

Search strategy RQ2

For the second research question, a separate search was conducted. The same databases were searched as we did in RQ1 (Embase, PsycINFO, CINAHL, and Pubmed/Medline). In the search string, two components were combined: the name of the measure and terms indicating clinimetric properties. For the first component, all measures were included which have been used in at least two studies found in RQ1. For the second component, we used the sensitive PubMed, Embase and CINAHL (also adapted for PsycINFO) search filters for finding studies on measurement properties of measurement instruments developed by the COSMIN group [28]. Details of the search string are shown in [Supplementary Table S3](#).

Eligibility criteria RQ2

In RQ2, validation studies were included which reported clinimetric properties of one or more of the included measures. Only full-text articles, published in scientific journals (in print or online) before 3 June 2019, and written in English were considered eligible. We did not limit our search to specific diagnostic groups. Publications were excluded when the measure was used as an outcome instrument (not to validate the measure) or to validate another measure [29]. Publications in which the development of an included measure was described were included afterwards if such a publication was not identified in the search.

Study selection RQ2

The study selection method of RQ2 was identical to the method used in RQ1. The 10% double title/abstract and full-text screening in the initial phase resulted in a good to very good interrater agreement (respectively 99.0% consensus, Kappa = 0.93 and 90.9% consensus, Kappa = 0.62) [27]. Consensus and improvement of the screening process were reached by discussion and, based on the good interrater agreement scores, we evaluated a 10% double check as sufficient.

Data extraction RQ2

We first compiled a table with the main characteristics of the measures: construct, original target population, original mode of administration, number of items, completion time, question example, response categories, subscales, score calculation, score interpretation, original language, available translations, and copyright. From all selected publications, we extracted information about the study population (n , age and gender), study design, administration mode, disease characteristics (disease, duration and severity), background (caregiving setting, country and language), response rate, distribution of scores, information about missing items, and floor/ceiling effects. Extraction was conducted by one author (ES).

Evaluation of measurement properties RQ2

All measurement properties reported in the included publications were evaluated. We used definitions of measurement properties as described in COSMIN guidelines (see [Supplementary Table S4](#)) [15–17]. We used the Risk of Bias checklist for systematic reviews of patient-reported outcome measures (as part of the COSMIN guidelines) to evaluate the methodological quality of single studies [16]. A four-point rating system was used in which each clinimetric standard was rated as “very good” (V), “adequate” (A), “doubtful” (D), or “inadequate” (I). The overall rating of the quality of each measurement property of each study was determined by taking the lowest rating of any standard (i.e., the “worst score

counts” principle). One author (ES) scored the checklist for the found studies. Difficulties in scoring were discussed with all authors. In the next step, we evaluated the results against COSMIN criteria for good measurement properties. Each result is rated as either “sufficient” (+), “insufficient” (–), or “indeterminate” (?).

Data synthesis RQ2

After scoring the separate validation publications reporting clinimetric properties, we summarized, rated and graded the overall results for the different measures. For each measure, we decided whether the results found in different studies were “consistent” (“sufficient” (+) or “insufficient” (–)), “inconsistent” (\pm) or “indeterminate” (?). Finally, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to grade the quality of evidence [30]. Measurement properties were graded as “high” when we were very confident that the true measurement property lies close to that of our findings. Grading’s can be lowered to “moderate,” “low,” or “very low,” based on concerns regarding (1) risk of bias (methodological quality), (2) inconsistency in results between studies, (3) imprecision (refers to the total sample size of studies combined), and (4) indirectness (differences in populations or context). Finally, to come to evidence-based and transparent recommendations, measures were categorized into three categories [15–17]:

- A. Measures with evidence for sufficient content validity and at least low quality for sufficient internal consistency.
- B. Measures categorized not in A or C.
- C. Measures with high-quality evidence for an insufficient measurement property.

A-categorized measures will be recommended for use and results obtained with these measures can be trusted. B-categorized measures have potential, but require further research to assess the quality of the measure. C-categorized measures will not be recommended for use.

Results

Selection of studies RQ1

The search of RQ1 identified a total of 4865 publications. Removal of duplicates, title, and abstract screening and full-texts screening resulted in 192 included publications (see [Figure 1](#)).

In the 192 included publications, 221 times measures were used which evaluated the negative or positive impact of providing care among informal caregivers ([Table 1](#)). Caregiving impact measures were mostly used in research among caregivers of persons with stroke (194 times), followed by spinal cord injury (26 times) and amputation (2 times). All publications describe 154 different studies in which 48 different measures were found, of which 18 were used in at least two different studies.

Selection of studies RQ2

The search of RQ2 identified a total of 3013 publications reporting validation studies. Addition of other references, removal of duplicates, title/abstract, and full-text screening resulted in 96 included publications ([Figure 2](#)). The 96 studies reported 101 measurement validations since three studies reported the validation of two different measures and one study reported the validation of three different measures.

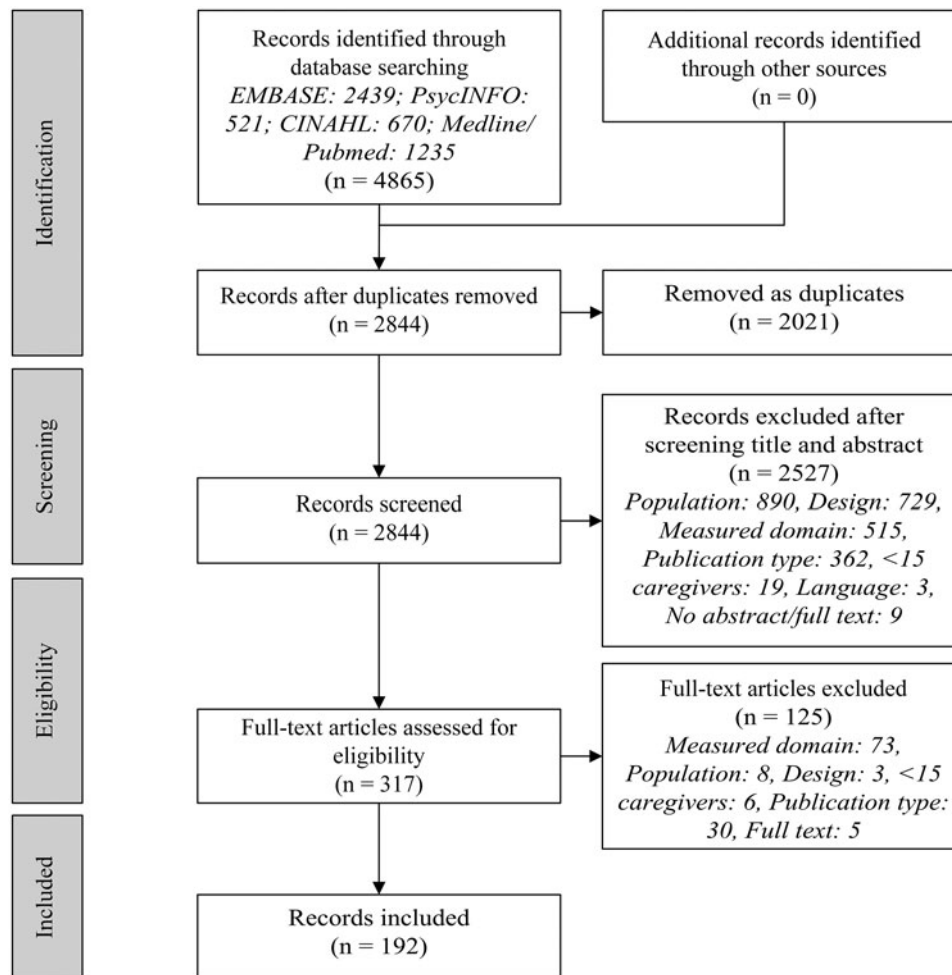


Figure 1. Flowchart search and selection process RQ1.

Scale characteristics, feasibility, and interpretability

Table 2 reports general characteristics of the 18 measures which were used in at least two different studies found in RQ1 (see Supplementary Table S5 for a detailed version of Table 2). Most measures examine negative caregiver impact (e.g., strain or burden) and could be administered as self-report questionnaires. The completion time ranges from a few to 20 min. For most measures, total (sub-scale) scores are calculated by summing item scores, where higher total scores indicate greater impact. The original language of most scales is English.

Study characteristics RQ2

Table 3 provides information about the characteristics of the included clinimetric studies. See Supplementary Table S6 for detailed information per publication [19,77,84,89,126,130,150,174,177,197,210,234,241,256–338]. The Zarit Burden Interview [89] and its short form [126] were most often evaluated in clinimetric studies, followed by the Caregiver Reaction Assessment [210], the Caregiver Strain index [19], and the Caregiver Burden Inventory [150]. No validation studies were found for the Modified Pearlin Burden Scale [170] and the Oberst Caregiving Burden Scale [23]. Sample sizes of the studies ranged from small ($N=14$) to very large ($N=1229$). Age of the caregivers differed greatly, most caregivers who reported caregiver impact were female. Measures of caregiver impact were mostly studied in cross-sectional self-report designs. Diseases of patients differed, but stroke and dementia

were most common. Information about response rate, missing scores, and floor/ceiling effects was often not reported.

Measure development and content validity

Table 4 describes the methodological quality of the development and the content validity of the measures. Publications reporting measure development were not found for three measures (Carer's Assessment of Managing Index [235], Modified Pearlin Burden Scale [170], and Oberst Caregiving Burden Scale [23]). In the found publications, measure development was not described for four measures, content validity not found for eight measures. Based on the "worst score counts" principle of the COSMIN Risk of Bias criteria, all of the measures scored "doubtful" or even "inadequate" on methodological quality of measure development and content validity. The terms "doubtful" and "inadequate" do not mean that the *measure* is doubtful or inadequate, but that in the interpretation of the findings awareness is required regarding the "doubtful" or "inadequate" way in which the specific property has been investigated.

Measurement properties

Tables 5 and 6 report summarized measurement properties results for each measure, including an overall rating and an indication of the quality of evidence based on a GRADE rating (see

Table 1. Measures used to assess negative or positive caregiver impact.

Measure	Author	Year of publication measure	Number of publications in which the measure has been used				Total
			Stroke	Spinal cord injury	Amputation		
<i>Strain/distress</i>							
Caregiver Strain Index	Robinson [19]	1983	44 [5,31,40–49,32,50–59,33,60–69,34,70–73,35–39]	3 [74–76]		47	
Modified Caregiver Strain Index (1)	Thornton & Travis [77]	2003	3 [78–80]			3	
Modified Caregiver Strain Index (2)	Teasdale, Emslie, Quirk, Evans, Fish, & Wilson [81]	2009	1 [81]			1	
Caregiver Strain Index Expanded	Al-Janabi, Frew, Brouwer, Rappange, & Van Exel [82]	2010	1 [83]			1	
Relative Stress Scale	Greene, Smith, Gardiner, & Timbury [84]	1982	1 [85]	1 [86]		2	
Caregiving strain question	Schulz & Beach [87]	1999	1 [88]			1	
<i>Burden</i>							
Zarit Burden Interview	Zarit, Reever, Bach-Peterson [89]	1980	30 [25,79,98–107,90,108–117,91–97]	8 [118–125]		38	
Zarit Burden Interview Short Form	Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell [126]	2001	1 [127]	4 [9,11,128,129]		5	
Caregiver Burden Scale	Elmståhl, Malmberg, & Annerstedt [130]	1996	18 [6,131,140–147,132–139]	2 [148,149]		20	
Caregiver Burden Inventory	Novak, & Guest [150]	1989	10 [151–160]	3 [160–162]		13	
Oberst Caregiving Burden Scale	Carey, Oberst, McCubbin, & Hughes [23]	1991	8 [10,35,163–168]	1 [169]		9	
Modified Pearlin Burden Scale	Pearlin, Mullan, Semple, & Skaff [170]	1990	3 [171–173]			3	
Burden Assessment Scale	Reinhard, Gubman, Horwitz, & Mintz [174]	1994	1 [175]	1 [176]		2	
Burden Assessment Schedule Modified	Das, Hazra, Ray, Ghosal, Banerjee, Roy, Chaudhuri, Raut, & Das [177]	2010	2 [177,178]			2	
Montgomery Caregiver Burden scale	Montgomery, Strull, & Borgatta [179]	1985	1 [180]			1	
Family Burden Scale	Suh, & Oh [181]	1993	1 [182]			1	
Burden Scale for Family Caregivers	Nikolaus, Specht-Leible, Bach, Oster, & Schlierf [183]	1994	1 [184]			1	
Caregiving Burden Scale	Lee, & Wu [185]	1998	1 [186]			1	
Evaluation Questionnaire on Informal Caregiver's Burden	Martins, Ribeiro, & Garret [187]	2003	1 [188]			1	
Family Caregiver Burden Tool	Kim, & Roh [189]	2005	1 [190]			1	
Family Strain Questionnaire – Short Form	Vidotto, Ferrario, Bond, & Zotti [191]	2010		1 [162]		1	
Self-Rated Burden VAS	Vluggen, Van Haastregt, Verbunt, Keijsers, & Schols [192]	2012	1 [192]			1	
Caregiver Burnout Scale	Kim, & Kim [193]	2015	1 [182]			1	
Caregivers quality of life and burden	Menon, Salini, Habeeba, Conjeevaram, & Munisusmitha [194]	2017	1 [194]			1	
<i>Life changes/reactions</i>							
Bakas Caregiving Outcomes Scale	Bakas, & Champion [195]	1999	1 [196]			1	
Revised 15-item Bakas Caregiving Outcomes Scale	Bakas, Champion, Perkins, Farran, & Williams [197]	2006	18 [10,163,202–209,164–166,168,198–201]			18	
Caregiver Reaction Assessment	Given, Given, Strommel, Collins, King, & Franklin [210]	1992	8 [12,11,211–216]			8	
Caregiving Impact Scale	Cameron, Franche, Cheung, & Stewart [22]	2002	4 [217–220]			4 ^a	
<i>Difficulty/needs</i>							
Family Caregiving Factors Inventory	Shyu [221]	2000	1 [111]			1	
Caregiver Needs and Concerns Checklist	Bakas, Austin, Okonkwo, Lewis, & Chadwick [222]	2002	1 [223]			1	
Family Caregiver Conflict Scale	Clark, Shields, Aycocock, & Wolf [224]	2003	1 [115]			1	
Caregiver Needs Questionnaire	Arango-Lasprilla, Plaza, Drew, Romero, Pizarro, Francis, & Kreutzer [118]	2010		1 [118]		1	

(continued)

Table 1. Continued.

Measure	Author	Year of publication measure	Number of publications in which the measure has been used				Total
			Stroke	Spinal cord injury	Amputation		
<i>Competence</i>							
Sense of Competence Questionnaire	Vernooi-Dassen [225]	1993	8 [226–233]			8	
Carer Assessment Scale	Mackenzie, Holroyd, & Lui [234]	1998	2 [54,229]			2	
Carer's Assessment of Managing Index	Nolan, Grant, & Keady [235]	1998		1 [149]		2	
Care Giving Mastery Scale	Lawton, Kleban, Moss, Rovine, & Glicksman Measuring Caregiving Appraisal [236]	1989	1 [237]		1 [176]	1	
Mishel Uncertainty in Illness Scale for Family Members	Mishel, & Epstein [238]	1997	1 [239]			1	
Caregiving Competency Scale	Cheng, Chair, & Chau [240]	2017	1 [71]			1	
<i>Positive aspects/benefits/rewards</i>							
Positive Aspects of Caregiving Questionnaire	Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson [241]	2004	3 [151,152,242]			3	
Positive Aspects of Caregiving Scale	Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson [243]	1997	1 [88]			1	
Rewards of Caregiving Scale	Archbold, Stewart, Miller, Harvath, Greenlick, Van Buren, Kirschling, Valanis, Brody, Schook, et al. [244]	1995		1 [169]		1	
<i>Appraisal/satisfaction</i>							
Appraisal of Caregiving Scale	Oberst [245]	1991	4 [164,202,203,246]			4	
Caregiving satisfaction Scale	Strawbridge [247]	1991	1 [248]			1	
Carer's Assessment of Satisfaction Index	Grant, & Nolan [249]	1993	1 [250]			1	
Caregiver Quality of Life Index	McMillan, & Mahon [251]	1994	1 [73]			1	
Caregiving Appraisal Scale – Revised	Lawton, Moss, Hoffman, & Perkinson [252]	2000	1 [253]			1	
Caregiver Reciprocity Scale II	Carruth, Holland, & Larsen [254]	2000	1 [215]			1	
CarerQol	Brouwer, Van Exel, Van Gorp, & Redekop [255]	2006	1 [192]			1	
Total			194	26	2	221	

^aFour different publications, but one study, therefore, not included in RQ2.

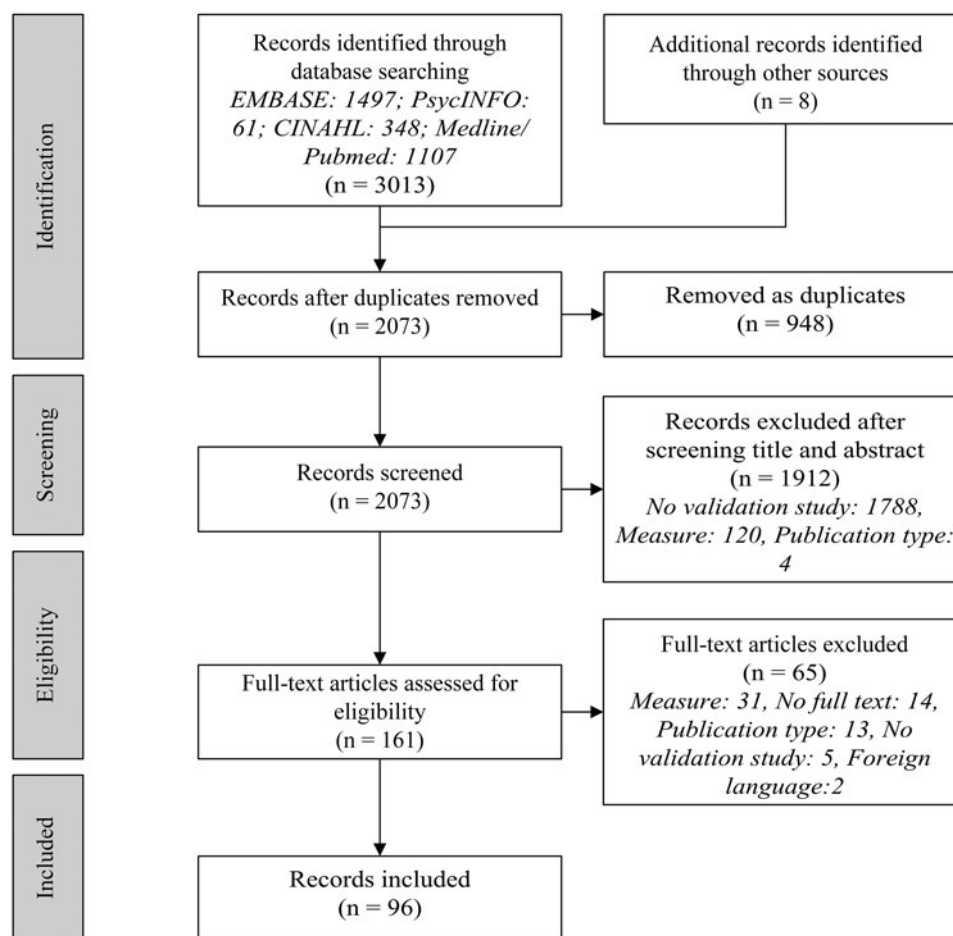


Figure 2. Flowchart search and selection process RQ2.

Supplementary Table S7 for the results of separate publications [19,77,84,89,126,130,150,174,177,197,210,234,241,256–338]).

Structural validity

The degree to which scores of a measure are an adequate reflection of the dimensionality of the construct to be measured, i.e., the structural validity [15–17], was often examined, mostly by factor analysis. However, ratings of structural validity were often lowered due to the absence of indicators of goodness of fit or due to “inconsistent” findings in different studies. The Caregiver Burden Scale [130], Positive Aspects of Caregiving Questionnaire [241] and Zarit Burden Interview Short Form [126] showed “sufficient” structural validity based on high quality. On the other hand, “insufficient” structural validity was found for the Burden Assessment Scale [174], Revised 15-item Bakas Caregiving Outcomes Scale [197] and Zarit Burden Interview [89].

Internal consistency

Relatively much information is available about internal consistency of measures: internal consistency was studied for fourteen of the eighteen measures. Nevertheless, for many measures, the rating of the internal consistency was “indeterminate” due to the absence of evidence for “sufficient” structural validity. The COSMIN guidelines state that for “sufficient” internal consistency, besides Cronbach’s alpha(s) of ≥ 0.70 , at least low-quality evidence for “sufficient” structural validity is needed, or else the rating will be “indeterminate” [15–17]. Positive Aspects of Caregiving

Questionnaire [241] and Relative Stress Scale [84] showed overall “sufficient” results of high-quality evidence.

Cross-cultural validity

Cross-cultural validity was studied for only three measures. The Caregiver Reaction Assessment [210] showed “sufficient” cross-cultural validity with high-quality evidence in terms of language (English, Chinese and Malay), group factors (disease and relationship caregiver) and over time. Results for the Zarit Burden Interview [89] were “indeterminate” due to lack of multiple group factor analysis or differential item functioning analysis. Results suggest cross-cultural validity for the Japanese, Hebrew, and German version of the scale; however, the quality of evidence was moderate. The Zarit Burden Interview Short Form [126] showed “sufficient” cross-cultural validity for a Hebrew translation (quality of evidence was rated as moderate).

Reliability

In general, results regarding test-retest reliability demonstrated that most measures were “sufficiently” reliable. For only two measures, the Caregiver Burden Scale [130] and Zarit Burden Interview [89], the quality of evidence was rated as high.

Measurement error

The systematic and random error of a patient’s score that is not attributed to true changes in the construct to be measured, i.e.,

Table 2. Characteristics of the 18 measures used to assess negative or positive caregiver impact.

Measures (year)	Construct impact of caregiving	Original target population	# items	Question example	Response categories	Subscales (# items)	Score (min-max)
Appraisal of Caregiving Scale (1991) [245]	Benefit, benign, threat, caregiving appraisal	Caregivers of patients receiving radiotherapy for cancer	27	This situation does not affect how I feel about myself	5-point-scale (very true to very untrue)	Threat, general stress, benefit (# items per subscale not found)	Mean score per subscale (1–5)
Burden Assessment Scale (1994) [174]	Burden	Family related to individuals with severe mental disorders	19	Would you tell me to what extent you have had any of the following experiences in the past 6 months? Felt trapped by your caregiving role Has your workload increased after patient's illness	4-point-scale (not at all to a lot)	Objective (10) and subjective burden (9)	Sum per subscale (10–40 and 9–36) and total score (19–76)
Burden Assessment Schedule Modified (2010) [177]	Burden	Caregivers of persons with stroke	20	Has your workload increased after patient's illness	3-point-scale (not at all to very much)	Financial situation, physical and mental stress, family and social relationships (# items per subscale not found)	No scale scores, interpretation items
Caregiver Burden Inventory (1989) [150]	Burden	Caregivers of patients with Alzheimer	24	My care receiver needs my help to perform many daily tasks	5-point-scale (never to nearly always)	Time-dependence burden (5), developmental burden (5), physical burden (4), social burden (5), emotional burden (5)	Sum per sub-dimension (0–20; physical burden weighted by a factor of 1.25), no total score
Caregiver Burden Scale (1996) [130]	Burden	Caregivers of persons with stroke	22	Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?	4-point-scale (not at all to frequently)	General strain (8), isolation (3), disappointment (5), emotional involvement (3), environment (3)	Average of sub-dimensions, no total score
Caregiver Reaction Assessment (1992) [210]	Experiences with providing care	Caregivers of persons with physical impairments and Alzheimer's disease	24	My activities are centered around care for ...	5-point-scale (strongly disagree to strongly agree)	Caregivers' self-esteem (7), lack of family support (5), impact on finances (3), impact on schedule (5), impact on health (4)	Mean subscale scores (1–5), no total score
Caregiver Strain Index (1983) [19]	Strain	Caregivers of patients recently hospitalized for hip surgery or heart problems	13	Feeling completely overwhelmed (e.g., because of worry about ... concerns about how you will manage) I feel completely overwhelmed	Yes/no	N.a.	Sum (0–13)
Modified Caregiver Strain Index (modernization) (2003) [77]	Strain	Long-term family caregivers	13	I feel completely overwhelmed	Yes/on a regular basis/yes, sometimes/or no	N.a.	Sum (0–26)
Carer Assessment Scale (1998) [234]	Level of difficulty in caring	Caregivers of persons with stroke	14	Indicate the extent to which the following areas cause difficulty in caring for a relative with stroke: Inner conflict caused by responsibilities	4-point-scale (no problem to great problem)	N.a.	Sum (0–42)
Carer's Assessment of Managing Index (1998) [235]	Carer ratings of helpfulness of management strategies and their own effectiveness	Carers involved in chronic care	38	Please circle the number that best describes your experience: Talking over your problems with someone you trust	4-point-scale (I do not use this, to very helpful)	N.a.	No scale score, profile
Modified Pearlin Burden Scale (1990) [170]	Burden	Caregivers of community-dwelling individuals with Alzheimer's disease	6	Exact formulation not found	5-point-scale (not at all to a great extent)	N.a.	Sum (6–30)

(continued)

Table 2. Continued.

Measures (year)	Construct impact of caregiving		# items	Question example	Response categories	Subscales (# items)	Score (min-max)
	Difficulty associated with caregiving	Original target population					
Oberst Caregiving Burden Scale (1991) [23]		Caregivers of patients with cancer	15	Exact formulation not found	5-point-scale (not difficult to extremely difficult (first subscale) or none to a great amount (second subscale))	Perceptions of the difficulty (15) and time spent (15) (same items for both subscales)	Sum per subscale (15–75)
Positive Aspects of Caregiving Questionnaire (2004) [241]	Positive aspects of caregiving	Caregivers of patients with Alzheimer's disease	9	Helping your relative ... makes you feel more useful	5-point-scale (disagree a lot to agree a lot)	Self-affirmation (6), outlook on life (3)	Sum per subscale (6–30 and 3–15) and total sum (9–45)
Relative Stress Scale (1982) [84]	Stress	Relatives supporting elderly psychogeriatric patients living in the community	15	Do you ever feel you can no longer cope with the situation?	5-point-scale (never/not at all to always/considerably)	Personal distress (6), life upset (5), negative feelings (4)	Sum per subscale (0–24; 0–20; 0–16) and total sum (0–60)
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	Life changes resulting from providing care	Caregivers of persons with stroke	15	As a result of providing care for the person with stroke: My self-esteem ...	7-point-scale (changed for the worst to changed for the best)	N.a.	Sum (15–105)
Sense of Competence Questionnaire (1993) [225]	Feelings of being capable of caring	Caregivers of patients with dementia	27	I feel that I cannot leave my ... alone, he/she needs me continuously	5-point-scale (agree to disagree)	Satisfaction with the patient as recipient of care (7), satisfaction with own performance as caregiver (12) and consequences of involvement in care for the personal life (8)	Sum per subscale (7–60) and total sum (27–135)
Zarit Burden Interview (revised) (1980) [89]	Burden	Caregivers of elderly persons with senile dementia	22	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	5-point-scale (never to nearly always)	N.a.	Sum (0–88)
Zarit Burden Interview Short Form (2001) [126]	Burden	Caregivers of patients with a memory disorder	12	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	5-point-scale (never to nearly always)	Personal strain (9) and role strain (3)	Sum (0–48), no information found about subscale score calculations

Table 3. Characteristics of the included clinimetric studies.

Measure (year of first publication)	# publications	N range	Range mean age	Gender % female, range	Study design	Mode of administration	Disease characteristics	Country
Appraisal of Caregiving Scale (1991) [245]	2	47–484	53.3–56.5	56.8–77.0	Cross-sectional (1); repeated administration (1)	Self-report (2)	Cancer (2)	United States of America (2)
Burden Assessment Scale (1994) [174]	5	94–300	32.0–58.0	68.1–88.0	Cross-sectional (4); cross-sectional and repeated administration (1)	Self-report (4); interview based and self-report (1)	Mental disorder (3); psychiatric, behavioral or emotional disorder (1); schizophrenia (1)	Canada (1); Germany (1); Sweden (1); United States of America (2)
Burden Assessment Schedule Modified (2010) [177]	1	199	42.5	76.0	Cross-sectional (1)	Self-report (1)	Stroke (1)	India (1)
Caregiver Burden Inventory (1989) [150]	7	113–505	56.2–60.1	52.2–87.1	Cross-sectional (5); repeated administration (2)	Interview based (3); self-report (4)	Dementia (2); elderly (1); first-episode psychosis (1); heart failure (1); pediatric acute-onset neuropsychiatric syndrome (1); various diseases (1)	Brazil (1); Canada (1); Italy (2); Spain (1); United States of America (2)
Caregiver Burden Scale (1996) [130]	3	110–161	37.6–83.3	46.3–89.2	Cross-sectional (1); repeated administration (2)	Self-report (3)	Dementia and stroke (1); hemodialysis (1); spinal cord injury (1)	Iran (1); Sweden (1); Turkey (1)
Caregiver Reaction Assessment (1992) [210]	8	21–1190	55.6–63.4	55.5–81.4	Cross-sectional (6); repeated administration (1); both (1)	Interview based (1); self-report (7)	Cancer (2); dementia (1); elderly (1); malignant disease, dementia and physical impairment (1); physical impairments, Alzheimer's disease and cancer (1); stroke (2)	Germany (1); Japan (1); Singapore (1); Sweden (1); The Netherlands (3); United States of America (1)
Caregiver Strain Index (1983) [19]	8	14–148	42.7–61.0	45.5–83.0	Cross-sectional (5); repeated administration (3)	Interview based (3); self-report (5)	Cancer (2); hip surgery and heart failure (1); multiple sclerosis (1); stroke (3); not reported (1)	Malaysia (1); Spain (1); Taiwan (1); The Netherlands (2); Turkey (1); United States of America (2)
Modified Caregiver Strain Index (2003) [77]	2	158–219	54.7–61.0	71.7	Cross-sectional (1); repeated administration (1)	Interview based (1); self-report (1)	Chronic illness (1); patients who took medications (1)	Hong Kong (1); United States of America (1)
Carer Assessment Scale (1998) [234]	1	14	Not reported	Not reported	Cross-sectional (1)	Self-report (1)	Stroke (1)	Hong Kong (1)
Carer's Assessment of Managing Index (1998) [235]	1	295	18–62% ≥ 65	18.0–79.0	Cross-sectional (1)	Self-report (1)	Elderly (1)	Italy, Poland and United Kingdom (1)
Modified Pearlin Burden Scale (1990) [170]	0	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991) [23]	0	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Positive Aspects of Caregiving Questionnaire (2004) [241]	3	141–1229	58.3–62.9	76.7–81.4	Cross-sectional (3)	Interview based (1); self-report (1); both (1)	Acquired brain injury (1); dementia (1); dementia and cognitive impairment (1)	Hong Kong (1); Spain (1); United States of America (1)
Relative Stress Scale (1982) [84]	2	38–196	63.8; not reported in 1 study	65.0; not reported in 1 study	Cross-sectional (1); repeated administration (1)	Self-report (2)	Dementia (2)	Scotland (1); Norway (1)

(continued)

Table 3. Continued.

Measure (year of first publication)	# publications	N range	Range mean age	Gender % female, range	Study design	Mode of administration	Disease characteristics	Country
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	2	100–147	51.6–52.9	76.0–78.6	Repeated administration (2)	Interview based (1); interview based and self-report (1)	Cancer (1); stroke (1)	Greece (1); United States of America (1)
Sense of Competence Questionnaire (1993) [225]	5	93–198	60.0–66.0	61.7–77.1	Cross-sectional (4); cross-sectional and repeated administration (1)	Interview based (3); self-report (2)	Dementia (2); stroke (3)	Germany (1); The Netherlands (4)
Zarit Burden Interview (1980) [89]	34	28–523	35.3–80.9	51.1–100	Cross-sectional (27); repeated administration (7)	Interview based (10); self-report (20); both (1); unclear (3)	Acquired brain injury (1); amyotrophic lateral sclerosis (1); cancer (1); cancer, cardiovascular disease, neurological condition (1) chronic heart failure (1); dementia (14); Duchenne muscular disease (1); elderly (4); neurological disease, orthopedic disease and traumatology (1); obsessive-compulsive disorder (1); Parkinson's disease (2); schizophrenia (3); stroke (1); stroke, chronic obstructive pulmonary disease and general disabilities (1); not specified (1)	Brazil (3); Canada (1); China (3); France (1); Germany and Switzerland (1); Hong Kong (2); Italy (1); Japan (4); Mexico (1); Scotland (1); Singapore (3); South Korea (1); Spain (2); Sub-Saharan Africa (1); Sweden (1); Taiwan (1); Turkey (1); United Kingdom (1); United States of America (3); United Kingdom and United States of America (1)
Zarit Burden Interview Short Form (2001) [126]	17	45–770	38.1–69.6	53.8–81.0	Cross-sectional (13); repeated administration (3); secondary analysis pooled data (1)	Interview based (7); self-report (8); unclear (2)	Advanced cancer, dementia, and acquired brain injury (1); cancer (1); cognitive deficits and dementia (1); cognitive or physical impairment (1); cognitively impaired elderly (1); dementia (5); dementia, mild cognitive impairment and subjective memory complaint (1); elderly (1); Parkinson's disease (1); physical frail elderly (1); schizophrenia (1); spinal cord injury (1); terminally ill (1)	Brazil (1); Canada (5); Canada and Israel (1); China (2); Iran (1); Israel (3); Singapore (1); Sweden (1); United Kingdom (2)

N.a.: not applicable.

Table 4. Quality of measure development and content validity of the 18 selected measures.

Measure	Design				Concept elicitation	General design requirements	Cognitive interview study			Total development				Content validity		Total content validity
	Clear construct	Clear origin of construct	Clear target population	Clear context of use			Developed in sample representing the target population	General design requirements	Comprehensibility	Comprehensiveness	Total CI study	Relevance	Comprehensiveness	Comprehensibility	Relevance	
Appraisal of Caregiving Scale (1991) [245]	V	V	V	V	D	I	I	I	I	I	I	I	I	-	-	-
Burden Assessment Scale (1994) [174]	-	-	-	-	-	D	D	D	D	D	D	D	D	D	D	D
Burden Assessment Schedule Modified (2010) [177]	I	D	V	V	I	-	-	-	-	-	-	-	-	-	D	D
Caregiver Burden Inventory (1989) [150]	V	V	V	V	-	I	I	I	I	I	I	I	I	D	D	D
Caregiver Burden Scale (1996) [130]	-	-	-	-	-	D	D	D	D	D	D	D	D	D	D	D
Caregiver Reaction Assessment (1992) [210]	V	V	V	V	D	V	D	D	D	D	D	D	D	-	-	D
Caregiver Strain Index (1983) [19]	V	V	V	V	D	V	D	D	D	D	D	D	D	-	-	D
Modified Caregiver Strain Index (2003) [77]	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Carer Assessment Scale (1998) [234]	I	D	V	V	I	V	D	D	D	D	D	D	I	-	-	-
Carer's Assessment of Managing Index (1998) [235]	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Modified Pearlin Burden Scale (1990) [170]	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Oberst Caregiving Burden Scale (1991) [23]	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Positive Aspects of Caregiving Questionnaire (2004) [241]	-	-	-	-	-	D	D	D	D	D	D	D	D	-	-	D
Relative Stress Scale (1982) [84]	I	D	V	V	I	I	-	-	-	I	I	I	I	-	-	-
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	V	V	V	V	I	-	-	-	-	-	-	-	-	-	-	-
Sense of Competence Questionnaire (1993) [225]	V	V	V	V	I	-	-	-	-	-	-	-	-	-	-	D
Zarit Burden Interview (1980) [89]	I	D	V	V	I	D	D	D	D	D	D	D	I	D	D	D
Zarit Burden Interview Short Form (2001) [126]	-	-	-	-	-	D	D	D	D	D	D	D	D	-	-	D

V: very good; A: adequate; D: doubtful; I: inadequate. Total ratings of the quality of each measurement property were determined by taking the lowest rating of any standard ("worst score counts" principle).

Table 5. Summary of measurement properties of the 18 selected measures.

Measurement	Structural validity			Internal consistency			Cross-cultural validity/measurement invariance			Reliability		
	Summary or pooled result, # factors	Rating evidence	Quality evidence	Summary or pooled result	Rating ^a	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Appraisal of Caregiving Scale (1991) [245]	3	?	M	$\alpha = 0.72-0.89$?	H	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Burden Assessment Scale (1994) [174]	2 to 5	?/–	L	$\alpha = 0.64-0.94$?	M	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Burden Assessment Schedule Modified (2010) [177]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	ICC = 0.80–0.84 (inter-rater and intra-rater; for every item)	+	L
Caregiver Burden Inventory (1989) [150]	4 or 5	±	M	$\alpha = 0.72-0.96$	+/?	M	N.a.	N.a.	N.a.	ICC = 0.87–0.94	+	M
Caregiver Burden Scale (1996) [130]	5	+	H	$\alpha = 0.61-0.91$; excepted environment subscale: $\alpha = 0.53-0.63$	±	H	N.a.	N.a.	N.a.	Cohen's Kappa = 0.69–1.00; ICC = 0.75–0.90	+	H
Caregiver Reaction Assessment (1992) [210]	5	?/±	M	$\alpha = 0.62-0.90$	+/?	M	Partial language invariance (Chinese, English, Malay), no important differences between group factors (disease and relationship) and over time	+	H	ICC = 0.58–0.86	±	VL
Caregiver Strain Index (1983) [19]	1, 3 or 4	±	M	$\alpha = 0.66-0.91$	±	L	N.a.	N.a.	N.a.	ICC = 0.56–0.93	±	L
Modified Caregiver Strain Index (2003) [77]	1	?	M	$\alpha = 0.88-0.91$?	H	N.a.	N.a.	N.a.	ICC = 0.88	+	L
Carer Assessment Scale (1998)	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Carer's Assessment of Managing Index (1998) [235]	10	?	M	$\alpha = 0.64-0.80$ (only reported for the seven sub dimensions with the highest α)	?	VL	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Modified Pearlin Burden Scale (1990) [170]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991) [23]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Positive Aspects of Caregiving Questionnaire (2004) [241]	2	+	H	$\alpha = 0.74-0.89$	+	H	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Relative Stress Scale (1982) [84]	3	?	M	$\alpha = 0.70-0.86$	+	H	N.a.	N.a.	N.a.	Correlation coefficient = 0.72–0.88	+	L
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	1	–	H	$\alpha = 0.83-0.90$?	H	N.a.	N.a.	N.a.	ICC = 0.66–0.99	±	M
Sense of Competence Questionnaire (1993) [225]	3	?	H	$\alpha = 0.50-0.89$?/–	M	N.a.	N.a.	N.a.	ICC = 0.84–0.93	+	M
Zarit Burden Interview (1980) [89]	1 to 6	–	L	$\alpha = 0.67-0.95$ ($\omega = 0.89$)	+/?	M	Findings suggest cross-cultural validity	?	M	ICC = 0.88–1.00; correlation coefficient = 0.72–0.76	+	H
Zarit Burden Interview Short Form (2001) [126]	2 or 3 (10 of the 11 studies found 2 factors and were rated + or ?, one study found 3 factors and this study was rated –)	+	H	$\alpha = 0.67-0.95$ ($\omega = 0.84$)	+/?	M	Generally reliable translation from English to Hebrew	+	M	ICC = 0.78	+	L

N.a.: not applicable; –: “insufficient”; +: “sufficient”; ±: “inconsistent”; ? : “indeterminate”; ?/– : “inconsistent” based on “insufficient” scores; +/? : “inconsistent” based on “sufficient” and “indeterminate” scores; ?/± : “inconsistent” scores based on “indeterminate”, “sufficient”, and “insufficient” scores; RMSEA: root mean square error of approximation; CFI: comparative fit index; SRMR: standardized root mean residuals; TLI: Tucker-Lewis index; α : Cronbach's alpha; ω : McDonald's omega; ICC: intra-class correlation coefficient; SDD: smallest detectable difference; SEM: standard error of measurement; AUC: area under the curve; H: high; M: moderate; L: low; VL: very low.
^aInternal consistency is rated “+”, “–”, “?” when there is at least low evidence for “sufficient” structural validity and $\alpha \geq 0.70$ for each unidimensional scale or subscale. Internal consistency is rated “?” if $\alpha \geq 0.70$, but when the criteria for at least low evidence for “sufficient” structural validity have not met. Often rated “indeterminate” due to “insufficient” evidence of structural validity.

Table 6. Summary of findings on measures.

Measurement	Measurement error			Criterion validity			Hypotheses testing			Responsiveness		
	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Appraisal of Caregiving Scale (1991) [245]	N.a.	N.a.	N.a.	Correlation gold standard <0.7	-	H	7+ and 5-	±	M	N.a.	N.a.	N.a.
Burden Assessment Scale (1994) [174]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	3+	+	H	1+	+	M
Burden Assessment Schedule Modified (2010) [177]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Caregiver Burden Inventory (1989) [150]	N.a.	N.a.	N.a.	AUC = 0.67–0.81	+	High	10+ and 5-	±	M	N.a.	N.a.	N.a.
Caregiver Burden Scale (1996) [130]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	6+ and 1-	+	H	N.a.	N.a.	N.a.
Caregiver Reaction Assessment (1992) [210]	SDD 0.8–1.0; SEM 0.3 and 0.5	-	VL	N.a.	N.a.	N.a.	42+ and 7-	+	H	N.a.	N.a.	N.a.
Caregiver Strain Index (1983) [19]	SEM = 1.00; SDD = 2.80	?	VL	AUC = 0.77	+	Moderate	13+ and 5-	±	M	N.a.	N.a.	N.a.
Modified Caregiver Strain Index (2003) [77]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	2+	+	H	N.a.	N.a.	N.a.
Carer Assessment Scale (1998) [234]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Carer's Assessment of Managing Index (1998) [235]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Modified Pearlin Burden Scale (1990) [170]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991) [23]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Positive Aspects of Caregiving Questionnaire (2004) [241]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	18+ and 5-	+	M	N.a.	N.a.	N.a.
Relative Stress Scale (1982) [84]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	3+ and 1-	±	L	N.a.	N.a.	N.a.
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	N.a.	N.a.	N.a.	AUC = 0.94; sensitivity = 91%; specificity = 86%	+	H	6+	+	H	N.a.	N.a.	N.a.
Sense of Competence Questionnaire (1993) [225]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	16+ and 11-	±	M	N.a.	N.a.	N.a.
Zarit Burden Interview (1980) [89]	N.a.	N.a.	N.a.	AUC = 0.69; specificity = 59.0–79.0%; sensitivity = 47.0–77.0%	-/+	M	41+ and 7-	+	H	1+	+	H
Zarit Burden Interview Short Form (2001) [126]	N.a.	N.a.	N.a.	Correlations = 0.70–0.99; specificity = 72.2–94.0%; sensitivity = 49.0–92.0%; AUC = 0.86–0.99	+	H	44+ and 4-	+	H	N.a.	N.a.	N.a.

N.a.: not applicable; -: "insufficient"; +: "sufficient"; ±: "inconsistent"; ?: "indeterminate"; VL: "very low"; Correlation gold standard <0.7; AUC = 0.94; sensitivity = 91%; specificity = 86%; AUC = 0.69; specificity = 59.0–79.0%; sensitivity = 47.0–77.0%; Correlations = 0.70–0.99; specificity = 72.2–94.0%; sensitivity = 49.0–92.0%; AUC = 0.86–0.99
N.a.: not applicable; -: "insufficient"; +: "sufficient"; ±: "inconsistent"; ?: "indeterminate"; VL: "very low"; SEM: standard error of measurement; SDD: smallest detectable difference; AUC: area under the curve; H: high; M: moderate; L: low; VL: very low.

Table 7. Summary of ratings of 8 (maximum) psychometric properties.^b

Measure	+ ^a	±/? ^a	- ^a
Appraisal of Caregiving Scale (1991) [245]	0	3 (moderate–high)	1 (high)
Burden Assessment Scale (1994) [174]	2 (moderate–high)	1 (moderate)	1 (low)
Burden Assessment Schedule Modified (2010) [177]	1 (low)	0	0
Caregiver Burden Inventory (1989) [150]	3 (moderate–high)	2 (moderate)	0
Caregiver Burden Scale (1996) [130]	3 (high)	1 (high)	0
Caregiver Reaction Assessment (1992) [210]	3 (moderate–high)	2 (very low–moderate)	1 (very low)
Caregiver Strain Index (1983) [19]	2 (moderate)	4 (very low–moderate)	0
Modified Caregiver Strain Index (2003) [77]	2 (low–high)	2 (moderate–high)	0
Carer Assessment Scale (1998) [234]	0	0	0
Carer's Assessment of Managing Index (1998) [235]	0	2 (very low–moderate)	0
Modified Pearlin Burden Scale (1990) [170]	0	0	0
Oberst Caregiving Burden Scale (1991) [23]	0	0	0
Positive Aspects of Caregiving Questionnaire (2004) [241]	3 (moderate–high)	0	0
Relative Stress Scale (1982) [84]	2 (low–high)	2 (low–moderate)	0
Revised 15-item Bakas Caregiving Outcomes Scale (2006) [197]	2 (high)	2 (moderate–high)	1 (high)
Sense of Competence Questionnaire (1993) [225]	1 (moderate)	2 (moderate–high)	1 (moderate)
Zarit Burden Interview (1980) [89]	4 (moderate–high)	2 (moderate)	1 (low)
Zarit Burden Interview Short Form (2010) [126]	6 (low–high)	0	0

+ : "sufficient"; ±/? : "inconsistent"; - : "insufficient".

^aBetween brackets the GRADE level of evidence.

^bRated clinimetric properties are: structural validity, internal consistency, cross-cultural validity/measurement invariance, reliability, measurement error, criterion validity, hypotheses testing, responsiveness.

measurement error [15–17], was only evaluated in two scales, both with very low-quality evidence.

Criterion validity

Criterion validity, defined as the degree to which the scores of a measure are an adequate reflection of a "gold standard" [15–17], was only evaluated for six measures. Results were "sufficient" and with high-quality evidence for the Caregiver Burden Inventory [150], Revised 15-item Bakas Caregiving Outcome Scale [197] and Zarit Burden Interview Short Form [126]. The Caregiver Strain Index [77] showed "sufficient" criterion validity of moderate quality. "Indeterminate" results (moderate quality evidence) were found for the Zarit Burden Interview [89]. The Appraisal of Caregiving Scale [245] showed "insufficient" criterion validity.

Hypotheses testing for construct validity (convergent, discriminative, and known-groups validity)

Hypotheses testing was done in thirteen of the eighteen measures. Overall, hypotheses regarding construct validity were mostly supported. Seven measures revealed "sufficient" construct validity based on high-quality evidence (Burden Assessment Scale [174], Caregiver Burden Scale [130], Caregiver Reaction Assessment [210], Modified Caregiver Strain Index [77], Revised 15-item Bakas Caregiving Outcomes Scale [197], Zarit Burden Interview [89], and Zarit Burden Interview Short Form [126]).

Responsiveness

Few studies on responsiveness of the measures were found. Results of two studies indicated responsiveness in sense of hypotheses testing about scores before and after intervention. Results indicate responsiveness for the Burden Assessment Scale (moderate quality of evidence) [174] and the Zarit Burden Interview (high quality of evidence) [89].

Overall results and recommendations for measure use

In line with the COSMIN guidelines, A-categorized ("sufficient" content validity and at least low quality evidence for "sufficient"

internal consistency) measures should be recommended for use. However, none of the measures were categorized as A, since none of the measures showed "sufficient" content validity. The Carer Assessment Scale [234], Modified Pearlin Burden Scale [170] and Oberst Caregiving Burden Scale [23], were applied in empirical studies for respectively 2, 3, and 8 times in the last decade (RQ1), however, no information about measurement properties was found for these scales (RQ2). For the Burden Assessment Schedule Modified [177], only reliability was evaluated ("sufficient" score, low quality of evidence). Based on the lack of clinimetric information, no statements can be made about the quality of these four scales. The Appraisal of Caregiving Scale [245] and Revised 15-item Bakas Caregiving Outcomes Scale [197] had both one "insufficient" rating of high-quality evidence, and therefore were categorized as C and were recommended not to use. All other measures were categorized as B, which means that they may have potential, but more research is required. Table 7 gives an overview of the number of measurement properties evaluated and rated as "sufficient," "inconsistent," or "insufficient" per measure, including statements of the quality of the evidence. "Sufficient" ratings based on relatively high-quality evidence and absence of "insufficient" ratings were found for the Caregiver Burden Scale [130], Positive Aspects of Caregiving Questionnaire [241], and Zarit Burden Interview Short Form [126]. The Caregiver Reaction Assessment [210] and the Zarit Burden Interview [89] had also three "sufficient" ratings of high quality, but also had "inconsistent" and "insufficient" ratings based on very low, low or moderate quality evidence. Alternately "sufficient," "indeterminate," and sometimes even "insufficient" (but based on low to moderate quality evidence) results regarding measurement properties were found for the Burden Assessment Scale [174], Caregiver Burden Inventory, Caregiver Strain Index [19], Modified Caregiver Strain Index [77], Carer's Assessment of Managing Index [235], Relative Stress Scale [84], and Sense of Competence Questionnaire [225].

Discussion

This article extends upon earlier reviews of measures used to assess caregiver impact [2,3,13,14]. We provided an overview of measures used in the last decade to evaluate negative and

positive caregiving impact among informal caregivers of persons with stroke, spinal cord injury or amputation (RQ1). We found 48 different caregiving impact measures, mostly measuring negative impact. Only 18 measures were used in at least two studies. The Caregiver Strain Index [19], Zarit Burden Interview [89], and the Caregiver Burden Scale [130] were used most often. The second aim was to systematically evaluate the clinimetric properties reported in validation studies of the measures which were at least used in two different studies (RQ2). The Caregiver Burden Scale [130], Positive Aspects of Caregiving Questionnaire [241] and Zarit Burden Interview Short Form [126] showed the most supportive evidence. Overall we found that structural validity, internal consistency, and hypotheses testing were often studied, whereas measure development and content validity were often minimally described, and tests of measurement error and responsiveness were exceptional.

Measure development and content validity

In the last decade, significant progress has been made in establishing standards for measure development and testing, which resulted in the development of standards like the COSMIN guidelines [15–17]. We used these guidelines to evaluate psychometric studies mostly executed (long) before the guidelines were established. As a result, most studies did not meet the high standards of the guidelines. In particular, the methodological quality of measure development and content validity were often rated as “doubtful,” maybe mainly due to lacking or incomplete information. COSMIN prescribes to apply a “worst score counts” principle. This automatically resulted in ratings of “doubtful” or worse methodological quality. Since measure development cannot be optimized retroactively, it is not possible to improve this characteristic of existing measures. Furthermore, in the COSMIN guidelines, content validity is considered as the most important property. For the measures described in the present study this would mean that none of the measures can be recommended for use. However, with the awareness of changing insights over time, we instead recommend to interpret the quality ratings regarding measure development and content validity with caution and also take into account findings regarding other (clinimetric) characteristics of measures.

The need of closing gaps

Our study showed substantial knowledge gaps regarding clinimetric properties of – sometimes extensively – applied measures to assess caregiver impact. For recently developed measures it could be argued that there was less time and opportunity to be carefully tested. However, also for the older measures information on some clinimetric properties is largely lacking. Especially, responsiveness and measurement error have rarely been investigated. This is alarming since reliable and responsive measures are needed to successfully monitor caregiver impact and low responsiveness may result in incorrectly assessing interventions as ineffective. Therefore, we want to emphasize the importance to conduct future research, in line with current standards, to be able to close the existing knowledge gaps regarding clinimetric properties.

Development of new measures

In the last two decades, many caregiving measures were developed (23 of the 48 found measures found in RQ1 were developed

in 2000 or later). This would not be a problem in a highly developed field in which new constructs are being investigated and when measures are developed and tested regarding the current standards. However, in accordance with a previous review, our results showed that recently developed measures assess highly similar constructs (e.g., burden) compared to older measures, that many measures were used only once or just a few times, and that many clinimetric shortcomings exist [2]. We recommend researchers who develop and publish new measures to always compare their newly developed measure with more established measures, to show what their new measure adds. Furthermore, with the recent description of clear guidelines, it is now possible to report scale development and to evaluate measurement properties of existing measures in a standardized way. We strongly recommend researchers to use such guidelines. This makes it easier for other researchers and clinicians to objectively assess the quality aspects of a measure. At this moment, low-quality evidence often relates to incomplete descriptions, which limits objective evaluation.

Measure selection

Our study provided a clear overview of the currently available knowledge with regard to measure development, content validity, and measurement properties of measures used to assess caregiver impact among caregivers of persons with stroke, spinal cord injury, or amputation. Since most publications describing measure development or investigation of measurement properties did not meet the current high reporting standards, we cannot clearly recommend a specific measure to evaluate caregiver impact. However, taken this into account, we think that the overview is nevertheless valuable and useful, because it does help to distinguish measures based on a comprehensive quality assessment. For measures evaluating negative caregiver impact, we found most supportive evidence for the Zarit Burden Interview Short Form [126] and the Caregiver Burden Scale [130]. The Positive Aspects of Caregiving Questionnaire [241] revealed to be a relatively good measure to evaluate positive caregiving impact. Hopefully, our overview will help researchers and clinicians in their selection of measures in addition to consideration of other important aspects, e.g., conceptual considerations, practical aspects like feasibility (e.g., completion time, costs, ease of administration), and interpretability (degree to which one can assign qualitative meaning to quantitative scores or change in scores) [15–17,339].

Limitations

In RQ1, we decided to focus on caregiving impact among caregivers of persons with stroke, spinal cord injury and amputation, because these groups comprise the largest part of the adult inpatient rehabilitation population [1]. Therefore, we missed caregivers of persons with progressive disabilities, like Multiple Sclerosis and Amyotrophic Lateral Sclerosis. In RQ2 we did not limit our search to specific diagnostic groups because we wanted all available clinimetric information. In the interpretation of the results, caution is advised when transferring results to specific subgroups. Furthermore, in RQ2, we only searched for clinimetric properties of the measures which were used in at least two empirical studies in the last decade (RQ1). Therefore, recently developed measures were less likely to be selected. In RQ2 we only included publications which primarily focused on clinimetric properties. However, sometimes results of empirical studies, e.g., randomized controlled trials or longitudinal studies, can be used

as evidence of certain clinimetric properties. In our search, we missed these publications. However, it was practically not achievable to screen all empirical studies in which one of the selected measures was used for information that could be relevant from a clinimetric point of view. Finally, in our evaluation of measurement properties in RQ2, we did not report results for individual subscales or items. The COSMIN guidelines describe that each subscale of a multi-dimensional measure should be considered separately [15–17]. We chose to report results at measure level because most validation studies also report their findings only on the level of total measures.

Strengths

By conducting this review, we obtained a clear overview of the different measures used in the last decade to measure caregiver impact among caregivers of persons with stroke, spinal cord injury, or amputation, three main groups in clinical adult rehabilitation. Second, we used the COSMIN guidelines [15–17] in order to evaluate clinimetric properties in a comprehensive and systematic way. By using this method, not only the findings itself but also the quality of evidence underlying the findings are taken into account, which resulted in weighted conclusions about clinimetric properties.

Conclusions

Many measures have been developed and used in empirical research to evaluate caregiver impact among caregivers of persons with stroke, spinal cord injury, or amputation. The present study provided a detailed overview of what is known about clinimetric characteristics of 18 different measures repeatedly used in research. The overview provides clinicians a guidance of appropriate measure selection.

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Disclosure statement

The authors report no conflicts of interest.

Ethical approval

We certify that we followed all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research.

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