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**The Reliability, Validity and Feasibility of Tools Used to  
Screen for Caregiver Burden: a Systematic Review**

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## Abstract

**Objective** The overall objective of this review is to quantitatively measure the psychometric properties and the feasibility of caregiver burden screening tools. The more specific objectives were to determine the reliability, validity as well as feasibility of tools that are used to screen for caregiver burden and strain.

**Inclusion criteria** This review considered international quantitative research papers that addressed the psychometric properties and feasibility of caregiver burden screening tools.

**Search strategy** The search strategy aimed to find both published and unpublished studies from 1980-2007 published only in the English language. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract and the index terms used to describe the article. A second search identified keywords and index terms across major databases. Third, the reference list of identified reports and articles was searched for additional studies.

**Methodological quality** Each paper was assessed by two independent reviewers for methodological quality prior to inclusion in the review using an appropriate critical appraisal instrument from the Joanna Briggs Institutes' System for the Unified Management, Assessment and Review (SUMARI) package.

**Limitations** Because burden is a multidimensional construct defined internationally with a multitude of other terms, only those studies whose title, abstract or keywords contained the search terminology developed for this review were identified for retrieval.

**Results** The construct of caregiver burden is not standardized, and many terms are used to describe burden. A caregiver is also identified as a carer. Instruments exist in multiple languages and have been tested in multiple populations. A total of 112 papers, experimental and non-experimental in nature, were included in the review. The majority of papers were non-experimental studies that tested or used a caregiver burden screening tool. Because of the nature of these papers, a meta-analysis of the results was not possible. Instead a table is used to depict the 74 caregiver burden screening tools that meet the psychometric and feasibility standards of this review. The Zarit Burden Interview (ZBI), in particular the 22-item version, has been examined the most throughout the literature. In addition to its sound psychometric properties, the ZBI has been widely used across languages and cultures.

**Implications for Practice and Research** The significant amount of research that has already been done on psychometric testing of caregiver burden tools has provided a solid foundation for additional research. Although some tools have been well tested, many tools have published limited psychometric properties and feasibility data. The clinician needs to be aware of this and may need to team up with a researcher to obtain additional research data on their specific population before using a minimally tested caregiver burden screening tool. Because caregiver burden is multidimensional and many different terms are used to describe burden, both the clinician and researcher need to be precise in their selection of the appropriate tool for their work.

**Keywords:** caregivers, burden, strain, quality of life, psychometrics

## **Background**

Family members and significant others find themselves in the role of caregiver for a multitude of reasons. The demand for caregivers continues to rise worldwide as a result of an increasingly aged population, multiple co-morbidities, people who survive traumatic injuries and the results of the HIV/AIDS epidemic.<sup>1</sup> Caregivers and carers provide care to family members or friends who are ill or disabled and typically need help with daily tasks.<sup>2</sup>

While family members have always played a significant role in caring for other ill family members, changes that have occurred both culturally and medically have made the role of caregiver more difficult.<sup>3</sup> The role of being a caregiver can be demanding. Caregiver burden is defined as "...the physical, psychological or emotional, social and financial problems that can be experienced..." by caregivers.<sup>4</sup> Caregiver burden or strain can result from the role of providing care to one or more individuals over a period of time.<sup>5</sup>

Early caregiver burden screening instruments were typically interview schedules.<sup>6</sup> Self-reporting tools began to be used when Professor Steven Zarit of Pennsylvania State University published his tool in 1980.<sup>7</sup> This tool, the Zarit Burden Interview (ZBI), is now used world-wide.<sup>8</sup> Many other caregiver burden tools exist which health care providers could potentially use to measure caregiver burden. Caregiver burden instruments often focus around the different disease processes of the person being cared for. There are numerous examples of how caregiver burden has been examined by how specific disease entities affect the caregiver. These include: examining caregiver burden that results from caring for an individual with a chronic physical illness;<sup>9</sup> caring for the elderly;<sup>10</sup> caring for those with cancer and in need of palliative care;<sup>11</sup> caring for people with dementia;<sup>12</sup> and caring for those with psychiatric illness.<sup>13</sup> Caregiver burden tools have been used in many countries and several caregiver burden tools have been translated into other languages.<sup>14-16</sup>

Reviews have examined caregiver burden in reference to specific disease entities. One review retrieved studies about informal caregivers from two major databases.<sup>6</sup> To date no systematic review of worldwide literature and grey literature has examined the psychometric properties of caregiver burden screening tools. This systematic review was undertaken to determine the reliability and validity of caregiver burden screening tools and the feasibility of their use. Reliability was assessed by examining stability, internal consistency and equivalence of instruments. Statistical conclusion validity, internal validity, construct validity and external validity of instruments was examined.<sup>17,18</sup> Feasibility regarding ease of use, length and appropriate language translation was also examined.

## **Objectives**

The overall objective of this review was to quantitatively measure the psychometric properties and the feasibility of caregiver burden screening tools.

The more specific objectives were to:

- Determine the reliability of tools that are used to screen for caregiver burden and strain.
- Determine the validity of tools that are used to screen for caregiver burden and strain.
- Determine the feasibility of tools that are used to screen for caregiver burden and strain.

## **Inclusion criteria**

### ***Types of participants***

The quantitative and narrative component of the review considered studies that included children or adults providing care to other individuals.

### ***Types of intervention***

The quantitative and narrative component of the review considered studies that evaluated screening tools which measure caregiver burden and strain.

### ***Types of studies***

The quantitative component of the review examined quantitative research that addressed the reliability, validity and feasibility of caregiver burden screening tools. The review considered experimental, quasi-experimental, pre-experimental and non-experimental studies undertaken in in-patient and out-patient settings.

### ***Types of outcomes***

The review considered studies that included the following outcome measures: reliability, validity and feasibility.

## **Search strategy**

The comprehensive search strategy aimed to find both published and unpublished studies from 1980-2007 published only in the English language. A three-step search strategy was utilized in each component of the review. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract and the index terms used to describe the article. A second search used all identified keywords and index terms across all other included databases (Appendix I). Third, the reference list of identified reports and articles was searched for additional studies.

## **Method of the review**

### ***Methodological quality***

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using a standardized critical appraisal instrument. The Joanna Briggs Institute Critical Appraisal Checklist for Experimental Studies was used (Appendix II). Any disagreements that arose between the reviewers were resolved through discussion.

### ***Data extraction***

Data was extracted from papers included in the review using data extraction tools. The standardized Joanna Briggs Institute Data Extraction Form for Experimental/Observational Studies (Appendix III) was used. For this systematic review a Data Extraction Form for Psychometric and Feasibility Assessment was developed (Appendix IV).

### ***Data synthesis***

Quantitative papers were reviewed for psychometric and feasibility data. Because of the nature of these papers, statistical pooling was not possible so the findings are presented in table form. If the paper had sound psychometric and feasibility data on more than one instrument, each instrument was analyzed separately. Data about the type of instrument used,

the country or countries that the instrument was used in, the caregiver population and the sample size was retrieved from the article. Data on the stability, internal consistency and equivalence reliability measures was retrieved when available. When Cronbach's alpha was given, the total Cronbach's alpha measure was noted. If more than one total Cronbach's alpha was noted, they were both presented. If no total Cronbach's alpha measure was noted, then the subscale Cronbach's alpha measures were noted. Statistical conclusion, construct, internal and external validity were retrieved when available.<sup>18</sup> Data on measurement quality was retrieved when available. Data regarding feasibility of the study including the number of questions, type of questions, who completes the instrument, how long the instrument takes to complete and language translation was retrieved. If the instrument or items from the instrument were available in the text, this was also noted.

## **Results**

### ***Description of studies***

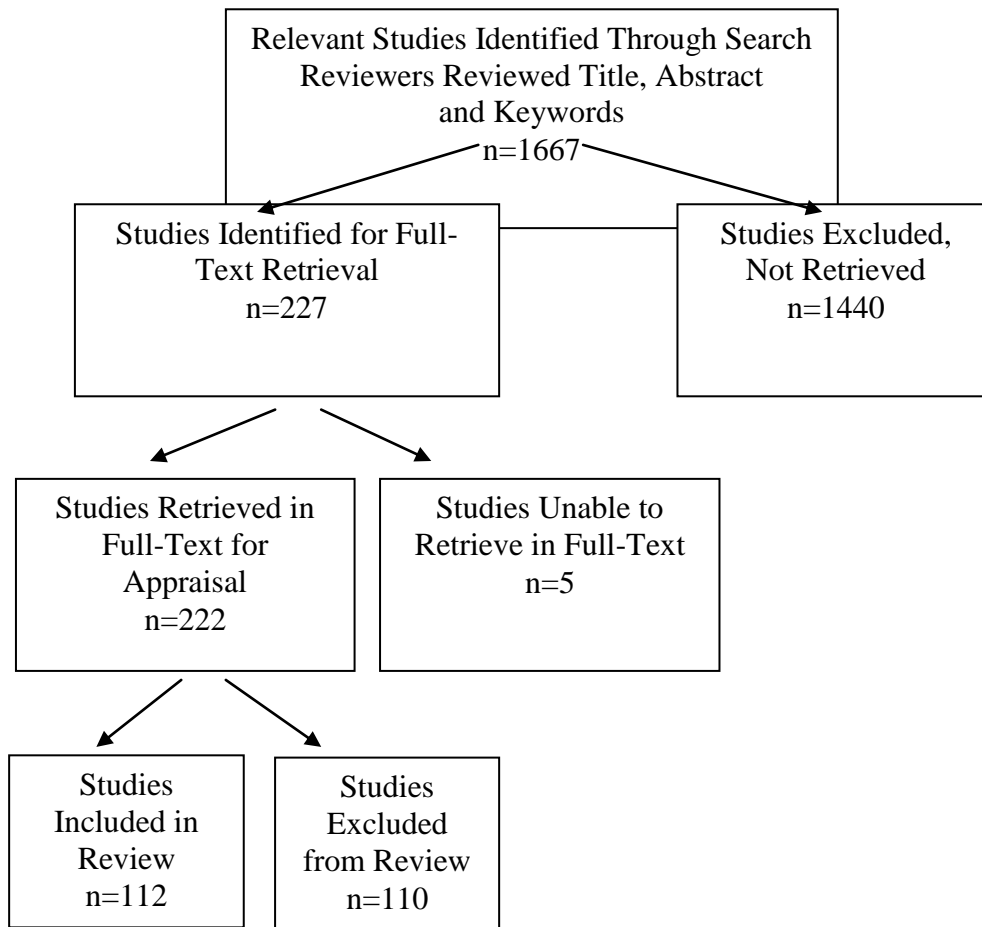
The final search strategy identified 1667 references. Further appraisal resulted in the full-text retrieval of 222 articles. Reviewers analysed the full-text of the 222 articles and determined that 112 contained the appropriate psychometric property and feasibility data for inclusion in this review. Of the 112 articles, only two are randomized control trials or quasi-experimental studies that meet the requirements of Level 2 evidence. All others meet the requirements of Level 3 evidence. A table describing the caregiver burden screening tools, their reported psychometric properties and the reported feasibility data within the included articles is attached in Appendix V. Tools are listed in the table alphabetically by the name of the tool and in reverse chronological order. Included articles are attached in VI.

Within the 112 included articles, 74 caregiver burden screening tools were identified. The Zarit Burden Interview, Caregiver Reaction Assessment and Caregiver Burden Inventory were the most frequently examined and reported tools. Many tools were modified to accommodate specific research needs.

Several articles reported on multiple tools, however, not all articles reported full psychometric data. Of the articles included, 10 reported tools that had 10 or fewer questions, 32 reported tools that had 11-20 questions, and 41 reported tools that had more than 20 questions. The majority of tools (70) included a Likert scale. Seven tools measured nominal responses and 4 tools used visual analogue scales. Not many articles reported the administration of the tool, however 7 reported using self-administered questionnaires and 12 reported using interview-administered questionnaires. Four articles reported that the tools took 10 minutes or less to complete, 7 reported that the tools took 11-20 minutes to complete, and 12 articles reported that the tools took more than 20 minutes to complete. Sample sizes ranged considerably in these studies from 10 to 984, although few studies provided power analysis information. Twenty-eight studies reported having 50 or fewer participants. Thirty studies reported having 51-100 participants. Forty-three studies reported having 101-200 participants. Twenty studies reported having 201-300 participants and 13 studies reported having over 301 participants.

The 110 excluded articles were eliminated for a number of reasons including insufficient psychometric property data or insufficient sample size. Also many of the tools described in the excluded articles did not measure burden as defined for this review. Excluded articles, and the reasons for their exclusion, are provided in Appendix VII.

**Figure 1** Flow chart of search and retrieval process and results



## Discussion

### *Validity*

Caregiver burden is a complex construct. The original roots of caregiver burden research were with mentally ill relatives in the 1960's.<sup>19</sup> Zarit and his colleagues laid significant foundational research on caregiver burden of relatives with dementia in 1980.<sup>7</sup> In the mid-1980's Poulshock and Deimling examined the multidimensional perspective of caregiver burden.<sup>20</sup> Caregiver burden dimensions now include the physical, psychological or emotional, social and financial problems that occur as a result of being a caregiver.<sup>4</sup> Therefore it is not surprising that many different subscales of caregiver burden have been developed over the past three decades.

Within the context of construct validity, concurrent validity was frequently tested in this review of instruments. Most authors were careful to delineate the different tools used for comparison in construct validity. Not surprisingly, a significant number of studies had some

of type of factor analysis completed, often accompanied by extensive tables and figures, providing the reader with clear item subscale information.

One of the most widely used divisions for caregiver burden is objective and subjective burden.<sup>21-25</sup> Objective burden is “the extent of disruptions or changes in various aspects of the caregiver’s life and household”.<sup>24</sup> Subjective burden “reflects the caregiver’s stress and nervousness related to her or his situation and the extent to which the caregiver feels manipulated by the demands of the care receiver”.<sup>24</sup>

Many different tools have been developed to examine caregiver burden. The names given to caregiver burden scales include not only the term burden, but may use other constructs such as outcomes,<sup>26,27</sup> appraisal,<sup>28</sup> inventory,<sup>29</sup> impact,<sup>30</sup> network,<sup>31</sup> quality of life,<sup>32</sup> reaction,<sup>33</sup> risk,<sup>34</sup> strain,<sup>35,36</sup> hassles,<sup>37</sup> cost of care,<sup>38</sup> experiences,<sup>39</sup> and stress.<sup>40</sup> Therefore it is important for the clinician and researcher to review the actual items that are used to measure these various constructs, because many of these instruments do measure the hardships experienced physically, psychologically, emotionally, socially and financially by caregivers. A multitude of instruments measure very specific concepts of caregiver burden such as worry, developmental burden, isolation, guilt, blame, powerlessness, sense of entrapment, scheduling concerns and strain.<sup>21,33,41-46</sup> Many instruments have also been developed that measure the other side of caregiving, the satisfaction that occurs from being a caregiver. There are several instruments that provide subscales for both the positive aspects of caregiving satisfaction as well as the negative aspects of caregiving burden.<sup>28,39,47</sup>

As scales have been tested and developed, different names have been given to the same tool. This is most evident with the widely used “Zarit Burden Interview”. Originally a 29-item tool titled “The Burden Interview” it is now typically a 22-item tool.<sup>7</sup> However researchers have made several modifications to the name of the tool.<sup>48-51</sup> This tool has been modified into shorter and screening versions.<sup>52</sup> Also, the language or country that this scale has been used in has been added to the name such as Spanish, Brazilian and Japanese.<sup>53-56</sup> There are also tools that have the same name, but are actually different tools. An example of this is the “Caregiver Burden Scale”.<sup>42,43,57,58</sup>

Caregiver burden is a construct that is recognized internationally. However the term caregiver is not used synonymously throughout the world. In the United Kingdom and Europe the term carer is used more frequently than caregiver. This is evidenced in part by tools that have been tested in the United Kingdom, Netherlands, Austria, other European countries and New Zealand that have the word ‘carer’ within the tool title.<sup>14,16,46,47,59</sup> In Japan, the term ‘Sekentei’ is used instead of caregiver burden and is a construct that “refers to an individual’s concerns about behaving in a socially acceptable manner as judged by others”.<sup>60,61</sup> Caregiver burden scales have been translated into multiple languages including Asian languages such as Chinese,<sup>62-65</sup> Mandarin,<sup>66</sup> Korean,<sup>15,23</sup> Cantonese,<sup>67</sup> Japanese,<sup>8,49,56,60,68,69</sup> and Hindi;<sup>45</sup> European languages such as Spanish,<sup>53,70</sup> Greek,<sup>47</sup> Italian,<sup>47,71</sup> Polish,<sup>47</sup> Dutch,<sup>14,72</sup> French,<sup>55,73,74</sup> Swedish and Norwegian;<sup>47,75</sup> and the South American language of Portuguese used in Brazil;<sup>76</sup> as well as the African language of Yoruba.<sup>22</sup> The psychometric testing of caregiver burden screening tools has spanned six continents in less than three decades. Although caregiver burden was originally measured in limited caregiver populations, caregiver burden is now measured in multiple populations. These populations include caregivers of the elderly, people with dementia and Alzheimer’s disease, people with various psychiatric illnesses, people that have experienced various neurological diseases or events,



people with chronic illnesses, people that have had a traumatic brain injury and people with developmental disabilities.

### ***Reliability***

Most studies provided reliability data in the form of a Cronbach's alpha for subscale scores and total scores. Over 75% of the reported Cronbach's alpha measures were .80 or greater. For the studies that conducted a test-retest analysis, the majority had results greater than .80. Intra Class Correlation Coefficient measures were reported 7 times and ranged from .66 to .99. Interrater reliability was reported 4 times and ranged from .78 to 1.00.

### ***Feasibility***

The most popular type of measurement used was Likert scales. The Likert scales typically ranged from 4 to 7 response categories. This is useful for researchers because of the higher level of measurement that interval level data provides.<sup>17</sup> Other measurement tools employed dichotomous or other categorical scales to quantify caregiver burden. While nominal data is more limited statistically, it may be easier for some populations to answer. A small number of studies tested visual analogue scales which are becoming increasingly popular for ease of use in the clinical setting. Administration time ranged widely with only half of the tools taking 20 minutes or less to complete. Many of the tools have already been tested in other languages, providing a significant international library of available caregiver burden screening tools. Seventy-two of the articles published complete tools or items from the tool within the text and 3 articles stated that the author be contacted directly for the tool.

### **Conclusion**

#### ***Implications for practice***

In this systematic review there are over 74 instruments that measure caregiver burden as a total scale or subscale of the instrument. Because there is such a plethora of caregiver burden tools to choose from, the clinician has the ability to maintain very high practice standards when choosing which tool to use. Several of these tools have been well tested and have sound psychometric data. However there are tools in the literature that have had minimal testing, especially in regards to external validity. The clinician needs to be aware of this and may need to team up with a researcher to obtain additional research data on their specific population before using a minimally tested caregiver burden screening tool in practice.

Because caregiver burden is multidimensional, and there is a lack of standardization among caregiver burden tools,<sup>77</sup> the clinician needs to carefully examine the subscales and items in each tool to assess if they are measuring the dimension or dimensions of burden they are specifically interested in. Tools vary considerably in length, and the clinician needs to be wary of tools that may take a significant amount of time to complete. Although significant information on caregiver burden screening tools has been published, scant information was provided on literacy levels. Therefore it is likely that the clinician will need to do a literacy assessment of the tool before using it in a practice setting. There are several relatively short scales available that may be useful in the clinical setting but need further psychometric testing before they can be used for intervention work.

The vast majority of studies used in this systematic review were non-experimental studies. Although a significant body of research has been done in intervention research using

caregiver burden screening tools as a way of measuring outcomes, few of these studies had significant psychometric data in the results. Since this systematic review intends to provide a scope of the psychometric and feasibility properties of caregiver burden screening tools, those studies were not included in this review. Also, it is not the purpose of this systematic review to provide the clinician with the “best” caregiver burden screening tool. Instead this review guides the clinician in identifying the caregiver burden screening tool most appropriate for their practice.

### ***Implications for research***

The significant amount of research that has already been done on psychometric testing of caregiver burden tools has provided a solid foundation for additional research. Although some tools have been well tested, many tools have published limited psychometric properties and feasibility data. These latter studies deserve further nonexperimental research work before they are used in experimental studies to determine the outcomes of various interventions used to relieve caregiver burden. Many of the tools are fairly lengthy and while they may be useful in the research setting, they may not be as practical when translated into practice. Some work has been done in examining shortened or screening versions of already existing instruments, and this area continues to deserve further attention for effectiveness of translation of these instruments into practice.<sup>73,78</sup> The researcher needs to be keenly aware that many of the caregiver burden screening tools have very specific areas of burden that they measure. A significant amount of factor analysis work has already been done to determine correct subscale use, especially with language translation, and continues to deserve attention by the researcher when expanding the use of various caregiver burden tools into other cultures.<sup>45,79-81</sup>

In light of the findings of this systematic review, specific populations deserve attention and awareness by caregiver burden researchers. As the needs of caregivers of people with HIV and AIDs continue to expand globally, further psychometric testing should be done on caregiver burden tools applied to this population. Another broad population group that needs continued psychometric study is caregivers of children with health concerns. The same applies for researchers that study children caregivers, in particular children less than 18 years of age who care for an elderly, ill or disabled relative. A child’s specific caregiver burdens are confounded by their own developmental needs and emerging abilities. Countries with rapidly expanding caregiving needs such as India, and several countries in Africa deserve the researcher’s attention, since only minimal psychometric data has been published about caregiver burden screening from these regions. Because the demand for caregivers will continue to rise in the next several decades, and because caregiver burden is a typical result of caregiving, there is an ongoing need for exploratory and interventional research to assess and provide interventions to help alleviate the burden of the caregiver.

### **Conflict of interest**

There are no conflicts of interest.

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## **Appendix I Search Strategy**

The databases searched included:

EBSCO's CINAHL  
The Cochrane Library  
EBSCO's Health Source: Nursing/Academic Edition  
Elsevier's Science Direct  
EMBASE  
ISI Web of Knowledge  
Wiley InterScience  
ProQuest Dissertation and Theses  
FirstSearch Dissertation Abstracts  
MEDLINE  
PubMed  
TRIP (Turning Research Into Practice)  
BioMed Central  
Centre for Reviews and Dissemination (CRD)  
American College of Physicians

The search for unpublished studies included:

Dissertations  
Conference Proceedings  
Index to Theses in Great Britain and Ireland  
New York Academy of Medicine - Grey Literature Report and Grey Literature Collection  
AHRQ (Agency for Healthcare Research and Quality)  
Theses Canada Portal  
NLM Gateway  
Centre for Evidence in Ethnicity, Health and Diversity (CEEHD) from Warwick Medical School  
GoogleScholar.com  
Clinical Medicine (ClinMed) Netprints Collection  
Geneva Foundation for Medication Education and Research  
Health Technology Assessment (HTA)  
Institute for Health & Social Care Research (IHSCR)  
National Library for Health (NLH)  
The Open University  
World Health Organization and Information Networks for Knowledge Database Library (WHOLIS)

Initial keywords used included:

Caregiver burden, caregiver support, caregiver strain, caregiver stress, caregiving, carer, clinical assessment tools, screening tools, instrument, Brief Assessment Scale for Caregivers (BASC), Caregiver Assessment Scale (CAS), Caregiver Quality of Life Index, Experience of Caregiving Inventory, Family Burden Inventory Scale, General Health Questionnaire (GHQ), Neo Five-Factor Inventory, Perceived Burden Scale (PBS), Perceived Caregiver Burden (PCB), Perceived Family Burden Scale (PFBS), Rapid Screen for Caregiver Burden, Relative Stress Scale (RSS), Subjective and Objective Family Burden Interview, Subjective Burden Scale (SCB), and Zarit Caregiver Burden Interview (ZBI).

An example of a CINAHL Search:



1. Explode caregiver burden
2. Explode caregiver support
3. Keyword caregiver strain
4. Explode clinical assessment tools
5. Explode instrument
6. Keywords brief assessment scale for caregivers OR caregiver assessment scale OR caregiver quality of life index OR experience of caregiving inventory OR family burden inventory scale OR general health questionnaire OR neo five-factor inventory OR perceived burden scale OR perceived caregiver burden OR perceived family burden scale OR rapid screen for caregiver burden OR relative stress scale OR subjective and objective family burden interview OR subjective burden scale OR zarit caregiver burden interview
7. Combine 1 or 2 or 3
8. Combine 4 or 5 or 6
9. Combine 7 and 8
10. Keywords Valid\$ or Reliab\$
11. Combine 1 and 6 and 10

## Appendix II

### Critical Appraisal Checklist for Experimental Studies

Reviewer \_\_\_\_\_ Date \_\_\_\_\_  
Author \_\_\_\_\_ Year \_\_\_\_\_  
Record Number \_\_\_\_\_

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	Yes	No	Unclear	N/A
1. Was the assignment to treatment groups random?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were participants blinded to treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was allocation to treatment groups concealed from the allocator?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were those assessing outcomes blind to the treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were the control and treatment groups comparable at entry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were groups treated identically other than for the named interventions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Was there adequate follow-up (>80%)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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**Overall Appraisal:** ☐ Include ☐ Exclude ☐ Seek further info.

**Reviewer's Comments (Including reasons for exclusion):**

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## Appendix III

### Data Extraction Form for Experimental/Observational Studies

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_

Record Number \_\_\_\_\_

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**Study Method:**      ☐ RCT      ☐ Quasi-RCT      ☐ Longitudinal  
                                 ☐ Retrospective      ☐ Observational      ☐ Other

**Participants:**

Setting: \_\_\_\_\_

Population: \_\_\_\_\_

Sample size: \_\_\_\_\_

**Intervention:**

Intervention 1: \_\_\_\_\_

Intervention 2: \_\_\_\_\_

Intervention 3: \_\_\_\_\_

**Clinical Outcome Measures:**

Outcome Description	Scale/Measure

**Study Results:**  
Dichotomous Data

Outcome	Intervention ( ) Number/Total Number	Intervention ( ) Number/Total Number

Continuous Data

Outcome	Intervention ( ) Mean and SD (Number)	Intervention ( ) Mean and SD (Number)

**Author's Conclusions:**

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**Reviewer's Comments:**

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## Appendix IV

### Data Extraction Form for Psychometric and Feasibility Assessment

**Instrument** \_\_\_\_\_

**Article** \_\_\_\_\_ **Year** \_\_\_\_\_

**Reviewer** \_\_\_\_\_ **Date** \_\_\_\_\_

#### **Reliability:**

Stability	Test-Retest Reliability	
Stability	Parallel Forms	
Internal Consistency	Cronbach's alpha	
Internal Consistency	Split Half	
Internal Consistency	Kuder-Richardson	
Equivalence of Instruments	Interrater Reliability	
Equivalence of Instruments	Kappa Statistic	
Equivalence of Instruments	Intraclass Correlation	

#### **Validity:**

Statistical Conclusion Validity		
Construct Validity Translational Validity	Face Validity	
Construct Validity Translational Validity	Content Validity	
Construct Validity Criterion Validity	Concurrent Validity	
Construct Validity Criterion Validity	Predictive Validity	
Construct Validity Criterion Validity	Convergent Validity	
Construct Validity Criterion Validity	Discriminant Validity	

Construct Validity Criterion Validity	Sensitivity	
Construct Validity Criterion Validity	Specificity	
Construct Validity Factor Analysis		

**Study Design:**

Internal Validity	
External Validity	

**Feasibility:**

Number of Questions/Length	
Type of Questions	
Who Completes Instrument	
Time to Complete Instrument	
Literacy level	
Language Translation	
Ease of Administration and Scoring	
Availability of Instrument/Cost	

Other Remarks:

## Appendix V

**Table of Psychometric and Feasibility Assessment of Caregiver Screening Tools**

Name of Tool	Author (Year)	Setting	Caregiver Population	Sample Size	Reliability	Validity	Feasibility	Subscales	Other Remarks	Level of Evidence
Bakas Caregiving Outcomes Scale (BCOS)	Bakas T, Champion V (1999)	USA	Family caregivers of stroke survivors	N=104	Cronbach's alpha = .90	Demonstrated face and concurrent validity; Factor analysis data provided	Tool reduced from 48 to 27 to 12 to 10 items; 7-point Likert scale		12 items listed in Table 3; 10 items listed in Table 5	3
	Bakas T, Champion V, Perkins SM, Farran CJ, Williams LS (2006)	USA	Family caregivers of stroke survivors	N=147	Cronbach's alpha = .90; ICC = .66	Demonstrated concurrent validity; Factor analysis data provided	15-item tool; 7-point Likert Scale		Comparison made between 10-item and 15-item tool; Contact author for tool	3
Brief Assessment Scale for Caregivers (BASC)	Glajchen M, Kornblith A, Homel P, Fraidin L, Mauskop A, Portenoy	USA	Caregivers of patients with chronic illness	N=102	Cronbach's alpha = .70 to .80	Demonstrated concurrent validity	14-item tool; 4-point Likert scale	Negative personal impact	Tool available in the Appendix; The BASC has an 8-item negative personal impact subscale	3

	RK (2005)								(NPI)	
Burden Assessment Scale (BAS)	Reinhard SC, Gubman GD, Horwitz AV, Minsky S (1994)	USA	Caregivers of mentally ill adults	N=94; N=94	Cronbach's alpha = .91 and .89	Demonstrated discriminant validity; Factor analysis data provided	19-item tool; 4-point Likert scale; Can be completed by self or by interviewer	Objective burden; Subjective burden; Worry	Tool available in the Appendix	3
	Ivarsson A, Sidenvall B, Carlsson M (2004)	Sweden	Caregivers of individuals with severe mental disorders	N=256	Cronbach's alpha = .90	Factor analysis data provided	19-item tool; 4-point Likert scale	Activity limitation; Feelings of worry analogue; Social strain		3
Burden Index of Caregivers (BIC)	Miyashita M, Yamaguchi A, Kayama M, Narita Y, Kawada N, Akiyama M et al (2006)	Japan	Caregivers of patients with neurological diseases or stroke	N=646	Cronbach's alpha = .91; ICC = .83	Demonstrated face, concurrent and convergent validity; Factor analysis data provided	11-item tool; 5-point Likert scale; Self-administered questionnaire	Time-dependent burden; Emotional burden; Spiritual burden; Physical burden; Service-related burden; Total care burden	Items listed in English in Table 2; Items listed in Japanese in Figure 2	3
Burden	Roud H,	New	Caregivers	N=45		Demonstrated	18-item	Personal		3



Interview	Keeling S, Sainsbury R (2006)	Zealand	of people with dementia			convergent validity	tool; 5-point Likert scale	Strain; Role Strain		
Burden of Care	Hobbs TR (1997)	USA	Black, caregiving mothers of adult schizophrenic children	N=100		Results of Path Model listed	9-item modified version of "Patient Behavior" Scale			3
Burden on Family Interview Schedule	Pai S, Kapur RL (1981)	India	Family members of psychiatric patients	N=40 N=24	Test-Retest reliability = .72; Interrater reliability = .87 to .99		24-item tool; 3-point scale; Semi-structured interview		Tool listed in the Appendix	3
Burden Questionnaire	Ohaeri JU, Campbell OB, Ilesanmi AO, Omigbodun AO (1999)	Nigeria	Caregivers of female cancer patients	N=73		Demonstrated content and convergent validity	32-item tool; 4-point Likert scale; Yoruba language translation information provided	Objective burden; Subjective burden	Tool available by request to authors	3
Burden Scale – Korean (BS-K)	Lim YM, Ahn Y (2003)	Korea	Family caregivers of schizophrenics	N=37	Cronbach's alpha = .84	Path analysis was used	19-item tool; 5-point Likert scale	Objective burden; Subjective burden	In this study only the 9-item subjective burden subscale used	3

Caregiver Appraisal Scale (CAS)	Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, Sander AM (2002)	USA	Caregivers of adults with Traumatic Brain Injury	N=241	Cronbach's alpha = .91 for Perceived burden	Demonstrated content and concurrent validity; Factor analysis data provided	35-item tool; 7-point Likert scale	Perceived burden; Caregiving relationship satisfaction; Caregiving ideology; Caregiving mastery	Four Factor scales, including a 15-item Perceived burden scale	3
Caregiver Burden Inventory (CBI)	Novak M, Guest C (1989)	Canada	Caregivers of confused or disoriented older people	N=107		Demonstrated content validity; Factor analysis data provided	24-item tool	Time-dependence burden; Developmental burden; Physical burden; Social burden; Emotional burden	Items available in Table 2; Authors constructed a Caregiver Burden Profile on subjects based on CBI scores	3
	Caserta MS, Lund DA, Wright SD (1996)	USA	Caregivers of adults	N=160	Cronbach's alpha = .69 to .87	Demonstrated concurrent validity	24-item tool; 5-point Likert scale	Time-dependence burden; Developmental burden; Physical burden; Social burden; Emotional burden		3

	Chou K (1997)	Taiwan	Primary caregivers of relatives with dementia	N=150	Cronbach's alpha = .82 to .93		24-item tool; 5-point Likert scale; Chinese language translation information provided	Physical burden; Emotional burden; Social burden; Financial burden	Tool listed in Appendix M; Further psychometric data provided in Chou K, LaMontagne LL, Hepworth JT (1999) and Chou K, Chyun L, Chu H (2002)	3
	Schwiebert VL, Giordano FG, Zhang G, Scalander KA (1998)	USA	Caregivers of Alzheimer's disease patients	N=123	Cronbach's alpha = .90	Factor analysis data provided	24-item tool; 5-point Likert scale	Time-dependence burden; Developmental burden; Physical burden; Social burden; Emotional burden; Health burden		3
	Chio A, Gauthier A, Calvo A, Ghiglione P, Mutani R (2005)	Italy	Caregivers of patients with ALS	N=60		Demonstrated convergent validity	24-item tool; 5-point Likert scale	Time-dependence burden; Developmental burden; Physical burden;		3

								Social burden; Emotional burden		
	McCleery A, Addington J, Addington D (2007)	Canada	Family members of psychosis patients	N=113	Cronbach's alpha = .92 to .94	Demonstrated concurrent validity	24-item tool; 5- point Likert scale	Time- dependence burden; Develop- mental burden; Physical burden; Social burden; Emotional burden	Tool available in Appendix A	3
Caregiver Burden Scale – I	Macera CA, Baker ED, Jannarone RJ, Davis DR, Stoskopf CH (1993)	USA	Family members of patients with Alzheimer's disease	N=82	Cronbach's alpha = .87	Demonstrated concurrent validity	15-item tool; Three Yes/No answer columns and a line for 'Why' for each item		Tool available in the Appendix	3
Caregiver Burden Scale – II	Stolarik A, Lindsay P, Sherrard H, Woodend AK (2000)	Canada	Caregivers of patients who had coronary artery bypass grafting	N=124	Cronbach's alpha = .94		15-item tool; 15 items are tasks; 5-point Likert scale		Demands of care were compared at one week and six weeks post discharge	3
Caregiver Burden Scale –	Andren S, Elmstahl S	Sweden	Family members of	N=153		Factor analysis data	22-item tool; 4-	General strain;		3

III	(2005)		patients with dementia living at home			provided	point Likert scale	Isolation; Disappointment; Emotional involvement; Environment		
Caregiver Burden Scale – IV	Kao HS, Acton GJ (2006)	Taiwan	Caregivers of elders with a stroke	N=148	Cronbach's alpha = .92	Demonstrated convergent validity; Factor analysis data provided	20-item tool; Likert scale; 15 minutes to complete	5 factors were reduced to 3 factors: Awareness of degeneration of both care receiver & giver; Time and finance constraints & readjustment; Guilt & blame	Original Caregiver Burden Scale listed in Table 1	3
Caregiver Distress Scale (CDS)	Cifu DX, Carne W, Brown R, Pegg P, Ong J, Qutu-buddin A et al (2006)	USA	Caregivers of Parkinson's patients	N=49		Demonstrated concurrent and convergent validity	Visual Analogue Scale: 1 to 10			3
Caregiver Network Scale	Love A, Street A, Ray R, Harris R,	Australia	Caregivers of people living with ALS	N=75	Cronbach's alpha = .77 to .92	Demonstrated face and content validity	50-item tool; 5-point Likert scale	Receive support; Self-care; Caregiver		3

	Lower R (2005)							satisfaction; Stress on relationships		
Caregiver Quality of Life Index-Cancer (CQOLC)	Weitzner MA, Jacobsen PB, Wagner H, Friedland J, Cox C (1999)	USA	Family caregivers of patients with cancer	N=263	Cronbach's alpha = .91; Test- Retest = .95	Demonstrated face, content, concurrent, convergent and discriminant validly	35-item tool; 5- point Likert scale; 10 minutes to complete		Items listed in Table 1	3
Caregiver Reaction Assessment (CRA)	Given CW, Given B, Stommel M, Collins C, King S, Franklin S. (1992)	USA	Caregivers of elderly patients with physical impair- ments, Alzhiemers' disease or cancer	N=377	Cronbach's alpha = .80 to .90	Demonstrated content and concurrent validity; Factor analysis data provided	Tool reduced from 40 to 24 questions; Likert scale	Caregiver esteem; Impact on finance; Impact on health: Impact on schedule; Lack of family support	Items listed in Table 2	3
	Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA. (1999)	Nether- lands	Partners of colorectal cancer patients	N=181	Cronbach's alpha = .62 to .83	Demonstrated construct validity	24-item tool; 5- point Likert scale; Face-to- face interview; < 10 minutes to	Esteem; Finance; Health; Schedule; Support	Items available in Table 5	3

							complete; Dutch language translation information provided			
	Van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg B, Koopmans- chap MA, van den Bos GA (2004)	Nether- lands	Informal caregivers of stroke patients	N=148		Demonstrated convergent validity	24-item tool	Esteem; Finance; Health; Schedule; Support		3
	de Frias CM, Tuokko H, Rosenberg T (2005)	Canada	Family members of geriatric care services	N=133	Cronbach's alpha = .67 to .86	Factor analysis data provided	24-item tool; 5- point Likert scale	Esteem; Finance; Health; Schedule; Support		3
	Grater JJ (2005)	USA	Older spousal caregivers of oncology patients	N=66	Cronbach's alpha = .83	Demonstrated concurrent validity	24-item tool; 5- point Likert scale	Esteem; Finance; Health; Schedule; Support	Full text available in Appendix B3	3
	Grov EK, Fossa SD, Tonnessen	Norway	Caregivers of cancer patients	N=85	Cronbach's alpha = .74	Demonstrated concurrent validity;	24-item tool; 5- point	Esteem; Finance; Health;	Items available in Table 2	3

	A, Dahl AA (2006)					Factor analysis data provided	Likert scale; Norwegian language translation information provided	Schedule; Support		
	Bachner YG, O'Rourke N, Carmel S (2007)	Israel	Bereaved primary caregivers of recently deceased cancer patients	N=236		Demonstrated concurrent validity; Factor analysis data provided	24-items expanded to 31- items; 5- point Likert scale	Scheduling impact; Social support impact; Health impact; Self-esteem; Financial impact	“The Modified Hebrew Language Version of the CRA” available in Table 2; Evaluated caregiving and post- caregiving reactions	3
Caregiver Risk Screen (CRS)	Huyck MH, Ayalon L, Yoder J (2007)	USA	Family caregivers of impaired elders	N=67	Cronbach's alpha = .85 and .84	Demonstrated convergent validity	12-item tool; 4- point Likert scale		Monitor's family strain; Items available in the Appendix	3
Caregiver Strain Index (CSI)	Robinson BC (1983)	USA	Caregivers of recently hospitalized hip surgery and heart patients aged 65 and	N=81	Cronbach's alpha = .86	Demonstrated concurrent validity	13-item tool; yes/no answers; Interview		Tool available in Table 1	3



			over							
	Van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg B, Koopmanschap MA, van den Bos GA (2004)	Netherlands	Informal caregivers of stroke patients	N=148		Demonstrated convergent validity	13-item tool; yes/no answers		Tool available in Appendix	3
Caregiver Strain Questionnaire	Schwarz KA, Blixen CE (1997)	USA	Caregivers to impaired older adults	N=100	Cronbach's alpha = .92		48-item tool	Exhaustion; Emotional arousal; Discrepancy with ideal states		3
Caregiver Strain Questionnaire (CGSQ)	Brannan AM, Heflinger CA (1997)	USA	Families of children with emotional and behavioral disturbances	N=984	Cronbach's alpha = .93	Demonstrated convergent validity; Factor analysis data provided	21-item tool; 5-point Likert scale; Self-report	Objective caregiver strain; Internalized and externalized subjective caregiver strain; Global measure of caregiver strain	Items listed in Table 1	3

Caregiver Subjective and Objective Burden Scale (CSOB)	Montgomery RJ, Gonyea JG, Hooyman NR (1985)	USA	Caregivers of elderly relatives	N=80	Cronbach's alpha = .85 and .86		22-item tool; 5-point Likert scale	Objective burden; Subjective burden	Items listed in Appendix A and B	3
Caregiving Appraisal	Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A (1989)	USA	Caregivers of disabled older people	N=632 N=239	Cronbach's alpha = .85 and .87; Test-Retest = .78	Demonstrated convergent validity; Factor analysis data provided	Tool reduced from 47 to 28 to 19 items; 5-point Likert scale; 90 minutes to complete; Interview	Subjective burden; Caregiving satisfaction; Impact of caregiving	Original 47 items available in Table 2	3
	Sevick M, Sereika S, Matthews JT, Zucconi S, Wielobob, C, Puczynski, S et al (1994)	USA	Primary family caregivers of home-based ventilator-dependent patients	N=27	Cronbach's alpha = .65 to .87	Demonstrated face validity	43-item tool; 5-point Likert scale; Survey is 20 pages	Burden; satisfaction; Impact; Mastery; Ideology	Tool referred to as "Modified Caregiving Appraisal Scale"	3
Caregiving Burden Scale (CBS)	Fuh J, Wang S, Liu H, Wang H (1999)	Taiwan	Caregivers of Alzheimer's disease patients	N=76	Cronbach's alpha = .85	Demonstrated concurrent validity	20-item tool; 4-point rating scale; Mandarin		Items listed in Table 3	

							language translation information provided			
Caregiving Hassles Scale	Kinney JM, Stephens MA (1989)	USA	Primary family caregivers to Alzheimer's disease patients	N=60	Cronbach's alpha = .91; Test-Retest = .83	Demonstrated concurrent validity	110-item tool reduced to 42 items; 4-point Likert scale	Assistance in basic ADL; Assistance with instrumental ADL; Care-recipient's cognitive status; care-recipient's behavior; Caregiver's support network	Items and subscales listed in Chart 1	3
Caregiving Impact Scale	Orbell S, Hopkins N, Gillies B (1993)	United Kingdom	Caregivers of elderly people	N=108	Cronbach's alpha = .80 and .95	Demonstrated concurrent, predictive and convergent validity	31-item tool	Care work strain; Care work satisfaction; Relationship dis-satisfaction; Care lifestyle satisfaction	Only two of the four factors measure burden	3
Caregiving Stress Appraisal (CSA)	Abe K (2007)	Japan	Family caregivers	N=219		Demonstrated convergent validity	12-item tool; 4-point Likert scale; Self-	Social constraint; Physical exhaustion	Tool available in Appendix A	3

							completed question-naire			
CarerQol Instrument	Brouwer WB, van Exel NJ, van Gorp B, Redekop WK (2006)	Netherlands	Informal caregivers	N=175		Demonstrated concurrent validity	7 broad questions and 1 Visual Analogue Scale question; Dutch language translation information provided	Fulfillment; Relational problems; Mental problems; Problems with daily activities; Financial problems; Support; Physical problems	Tool available in Figure 1	3
Carers Assessment of Difficulties Index (CADI)	Charlesworth GM, Tzimoula XM, Newman SP (2007)	United Kingdom	Family carers of people with dementia	N=232	Cronbach's alpha >.65 for most factors	Factor analysis data provided	30-item tool; 3-point Likert scale; Takes 25 minutes to complete	Impact; Physical help; Relationship; Social life restrictions; Professional support; Family support; Interpersonal demands; Finances	Items listed in Table 1	3
Carers of Older People in Europe (COPE Index)	McKee KJ, Philip I, Lamuri G, Prouskas	Europe	Caregivers of older people	N=577		Demonstrated face, content and discriminant	17 -item version of the COPE Index;	Negative impact; Positive value	Original COPE Index in Table 2. 15-item	3

	C, Oberg B, Krevers B (2003)					validity	4-response categories; Italian, Greek, Swedish and Polish language translation information provided		version of revised index available in Appendix	
	Roud H, , Keeling S, Sainsbury R (2006)	New Zealand	Caregivers of people with dementia	N=45		Demonstrated convergent validity	15-item tool; 4-response categories	Negative impact; Positive value	Items listed in Table 3	3
Carers' Needs Assessment for Dementia (CNA-D)	Wancata J, Krautgartner M., Berner J, Alexandrowicz R, Unger A, Kaiser G (2005)	Austria	Carers of dementia patients	N=45 N=40 N=40	Cronbach's alpha = .70 to .95	Demonstrated content, concurrent and convergent validity	18 problem areas; 3-point and 4-point scales used; Semi-structured research interview		Assesses the needs of dementia caregivers; Items listed in Table 1	3
Child and Adolescent Burden Assessment (CABA)	Messer SC, Angold A, Costello EJ, Burns BJ (1996)	USA	Family caregivers of children with psychiatric disorders	N=349	Cronbach's alpha > .80; ICC = 0.67	Demonstrated convergent validity; Factor analysis data provided	20-items, 3 and 4-point scales; 10 minutes to complete	Economic Burden; Impact on family relationships; Impact on other relationships;	Tool (CABA Parent Interview Version 1.0) available in Appendix	3

								Restrictions on activities; Responsibility for problems; Impact on feelings of well-being		
Cost of Care Index	Kosberg JI, Cairl RE, Keller DM (1990)	USA	Informal caregivers of Alzheimer's disease patients	N=127	Cronbach's alpha = .79		20-item tool; 4-point Likert scale	Personal and social restrictions; Physical and emotional problems; Economic costs; Value investment in caregiving, Care recipient as provocateur	Tool available in Figure 1	3
Cost of Care Index – Chinese Version	Tseh OY, Loke Yuen A, Chan MF, Kwok T (2005)	Hong Kong	Informal caregivers of elderly relatives	N=111	Cronbach's alpha = .93	Demonstrated content and concurrent validity	20-item tool; 5-point scale; 30 to 45 minutes to complete; Tool already translated in Chinese	Personal and social restrictions; Physical and emotion health; Economic costs; Value investment in caregiving; Care recipient	Items listed in Table 1	3

								as provocateur;		
Dementia Caregiving Burden Questionnaire (DCBQ)	O'Donovan ST (2004)	United Kingdom	Carers of people with dementia	N=109	Cronbach's alpha = .84; Split Half = .76	Demonstrated concurrent validity	40-item tool; 5-point Likert scale	Life upset; Personal distress; Negative feelings; Positive feelings	Tool available within paper	3
Experience of Caregiving Inventory (ECI)	Szmukler GI, Burgess P, Herrman H, Benson A, Colusa S, Bloch S (1996)	Australia	Caregivers of relatives with serious mental illness	N=359	Cronbach's alpha = .74 to .91	Demonstrated content validity	66-item tool; 10 to 15 minutes to complete	Difficult behaviors; Negative symptoms; Stigma; Problems with services; Effects on family; Need to provide backup; Dependency; Loss; Positive personal experiences; Good aspects of relationship	Items listed in Table 2	3
	Lemoine O, Lavoie S, Poulin C, Poirier L, Fournier	Canada	Caregivers of persons with a mental health	N=405		Factor analysis data provided	66 items reduced to 45 items; 5-point Likert	Difficult behaviors; Negative symptoms; Stigma;	Items available in Table 3	3

	L (2005)		problem				scale; French language translation information provided	Problems with services; Effects on the family; Need to provide back up; Loss; Positive personal experiences		
	Tarricone I, Leese M, Szmukler GI, Bassi M, Berardi D (2006)	United Kingdom and Italy	Carers of patients suffering from a functional psychiatric disorder	N=164	Cronbach's alpha = .71 to .86	Demonstrated convergent validity	66-item tool; Italian language translation information provided	Difficult behaviors; Negative symptoms; Stigma; Problems with services; Effects on the family; Need to provide backup; Dependency; Loss; Positive personal experiences; Good relationship with the patient		3
Family Appraisal of Caregiving	Cooper B, Kinsella GJ, Picton	Australia	Caregivers of relatives with cancer	N=160	Cronbach's alpha = .73 to .86	Demonstrated content and concurrent	26 items reduced to 25-item	Caregiver strain; Caregiver	Items listed in Table 1	3



Questionnaire for Palliative Care (FACQ-PC)	C (2006)					validity; Factor analysis data provided	tool; 5-point Likert scale	distress; Positive caregiving; Family well-being		
Family Burden Interview Scale – Brazilian version (FBIS-BR)	Bandeira M, Calzavar MG, Freitas LC, Barroso SM (2007)	Brazil	Relatives of psychiatric patients	N=243	Cronbach's alpha = .58 to .90; Test-Retest = .54 to .92		52-item tool; 5-point Likert scale; 60 minutes to complete	Assistance to the patient; Patient supervision; Financial burden; Impact on family routine; Worries about the patient	Measures global objective burden and global subjective burden	3
Family Burden Interview Schedule (FBIS)	Chien W, Norman I (2004)	China	Family caregivers of psychiatric patients	N=185	Cronbach's alpha= .87; Test-Retest = .83; ICC = .87	Demonstrated face, content, concurrent, convergent and discriminant validity	25-item tool; 3-point Likert scale; Semi-structured Interview Schedule; 15 minutes to complete; Chinese language translation information	Family finance; Family routine; Interactions; Leisure activities; Mental health; Physical health	Items in this scale address major issues of family caregiving common to many cultures; Items listed in Table 4	3

							provided			
	Siu BW, Yeung TM (2005)	Hong Kong	Caregivers of patients with Obsessive-compulsive Disorder	N=77	Cronbach's alpha = .90; Test-Retest = .97 to .99; Split Half = .92; Interrater reliability = .98 to .99; Kappa Statistic = .84 to 1.0; ICC = .99	Demonstrated content, concurrent and convergent validity	25-item tool; 3-point Likert scale; 45 minutes to complete; Cantonese language translation information provided	Family finance; Family routine; Interactions; Leisure activities; Mental health; Physical health	Some modified questions listed in Table 3	3
Family Burden of Injury Interview (FBII)	Burgess ES, Drotar D, Taylor HG, Wade S, Stancin T, Yeates KO (1999)	United States	Mothers of school-aged children who experienced traumatic head injuries	N=99	Cronbach's alpha = .90; Test-Retest = .52 to .73; Guttman's = .80	Demonstrated concurrent, predictive and discriminant validity	27-item tool; 5-point Likert scale			3
Family Burden Scale (FBS)	Madianos M, Economou M, Dafni O, Koukia E, Palli A, Rogakou E (2004)	Greece	Relatives of patients with schizophrenia	N=171	Cronbach's alpha = .85; Test-Retest = .88 to .95	Demonstrated content, concurrent and discriminant validity; Factor analysis data provided	Tool reduced from 45 to 35 to 23 items; 3-point Likert scale; 28.5 minutes to	Impact on daily activities/ social life; Aggressiveness; Impact on health; Economic	23 items listed in Table 3	3

							complete	burden		
Family Objective and Subjective Burden Interview – Spanish Version (ECFOS-II)	Vilaplana M, Ochoa S, Martinez A, Villalta V, Martinez-Leal R, Puigdollers E et al (2007)	Spain	Main family caregivers of schizophrenic patients	N=205	Cronbach's alpha = .85	Demonstrated concurrent validity; Factor analysis data provided	4-5 point Likert scale; Self- or hetero-administered interview; 30 minutes to complete	Assistance in daily life activities; Concerns; Impact on daily activities; Supervision	Complete ECFOS-II interviews can be obtained from the author	3
Family Strain Questionnaire (FSQ)	Ferrario SR, Baiardi P, Zotti AM (2004)	Italy	Caregivers	N=296 N=409	Cronbach's alpha = .87	Demonstrated convergent and discriminant validity; Factor analysis data provided	44-item; yes/no answers; semi-structured interview; 20 minutes to complete	Emotional burden; Social involvement; Knowledge of the disease; Family relationships; Thoughts about death	1 <sup>st</sup> and 2 <sup>nd</sup> Versions of the Family Strain Questionnaire are in Appendix A	3
Family Stress and Coping Interview (FSCI)	Nachshen JS, Woodford L, Minnes P (2003)	Canada	Parental caregivers of children and adults with developmental disabilities	N=106	Cronbach's alpha = .89; Test-Retest = .80	Demonstrated face and discriminant validity	23-item quantitative questions, 5-item qualitative questions; 5-point Likert scale; 1 ½ hours to 3 hours to		Measures experiences of parents of children with developmental disabilities; Quantitative and Qualitative tools in	3

							complete		Appendix I and II	
Given's Burden Scale	Gallagher-Thompson D, Areal P, Rivera P, Thompson LW (2001)	USA	Latino family caregivers of dementia patients	N=70			35 items in tool; 5-point Likert scale; Spanish language translation information provided	Scheduling problems; Poorer health; Financial		2
Global Role Strain Scale	Farran CJ, Miller BH, Kaufman JE, Davis L (1997)	USA	Caregivers of persons with dementia	N=215	Cronbach's alpha = .79	Demonstrated concurrent validity	3-item tool; 4-point scale			3
Korean version of the Revised Caregiving Appraisal Scale (K-RCAS)	Lee J, Friedmann E, Picot SJ, Thomas SA, Kim CJ (2007)	Korea	Primary family caregivers of older stroke survivors	N=147	Cronbach's alpha = .86	Demonstrated face validity; Factor analysis data provided	27-item tool; 5-point Likert scale; Self-administered; 30 to 40 minutes to complete; Korean language translation information provided	Burden; Satisfaction; Mastery; Impact; Demand	27-items listed in Table 2	3

Life Situation among Spouses after a Stroke Event (LISS)	Larson J, Franzen-Dahlin A, Billing E, Murray V, Wredling R (2005)	Sweden	Spouses of stroke survives	N=99	Cronbach's alpha = .80	Demonstrated construct and concurrent validity; Factor analysis data provided	13-item tool; 5-point Likert scale	Worries; Powerlessness; Personal adjustment; Social isolation	Modified from the "Care Burden Scale for Relatives"; Items listed in Table 5	3
Modified Caregiver Strain Index (Modified CSI)	Thornton M, Travis SS (2003)	USA	Family caregivers	N=158	Cronbach's alpha = .90; Test-Retest = .88	Demonstrated content validity	13-item tool; 3 nominal answers		Modified Caregiver Strain Index in Table 1	3
Montgomery Borgatta Burden Scale	Montgomery RJ, Borgatta EF (1989)	USA	Family caregivers of impaired elderly persons		Cronbach's alpha = .73 to .94		9-item tool; 5-point scale	Objective burden; Subjective burden		2
Novel Caregiver Burden Scale (CB scale)	Elmstahl S, Malmberg B, Annerstedt L (1996)	Sweden	Family caregivers of stroke patients	N=150	Cronbach's alpha = .70 to .87; Kappa Statistic = .89 to 1.00	Factor analysis data provided	Tool reduced from 24 to 22 items; 4-point Likert scale	General strain; Isolation; Disappointment; Emotional involvement; Environment	22-item tool listed in Appendix	3
Oberst Caregiving Burden Scale (OCBS)	Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT (2004)	USA	Family caregivers of stroke survivors	N=116	Cronbach's alpha = .90 and .94	Demonstrated concurrent and predictive validity; Factor analysis data provided	15-item scale with 2 measures; 5-point Likert scale		Tool available in Figure 1	3

Objective Burden Scale	Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, Sander AM (2002)	USA	Caregivers of adults with Traumatic Brain Injury	N=241		Demonstrated concurrent validity	25-item tool; yes/no answers		Assesses concrete problems that the caregiver perceives	3
Overall Burden	Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA (1999)	Netherlands	Partners of colorectal cancer patients	N=181		Demonstrated concurrent validity	One-item burden question; 5-point answer		Assesses overall burden	3
Parental Illness Impact Scale (Parkinson's Disease) (PIIS-PD)	Schrag A, Morley D, Quinn N, Jahanshahi M (2004)	England	Children of patients with Parkinson's disease	N=89	Cronbach's alpha = .62 to .91	Demonstrated content and concurrent validity; Factor analysis data provided	Tool reduced from 53 to 38 items; 5-point Likert scale	Social development, independence and responsibility; Burden of daily help; Communication and understanding; Impact on personal	38-items listed in Table 2	3

								future; Impact on family functioning; Friend's reactions		
Perceived Caregiver Burden Scale (PCB-12)	Gupta R (2007)	India	Caregivers of elderly people	N=259	Cronbach's alpha = .77 to .82	Demonstrated face and concurrent validity; Factor analysis data provided	Reduced from 31 to 17 to 12 items; 4-point Likert scale; 1-2 hours for interview; Hindi language translation information provided	Impact on finances; Abandonment by extended family; Sense of entrapment	12-items listed in Table 2	3
Perceived Family Burden Scale (PFBS)	Levene JE, Lancee WJ, Seeman MV (1996)	Canada	Caregivers of a mentally ill relative	N=40 N=38	Test-Retest = .53	Demonstrated content, concurrent, predictive and discriminant validity	Increased from 15 to 45 items then reduced to 35 to 24 items; 4-point Likert scale		24-items listed in Table 1	3
	Tsang HW, Chan AS, Chung AW, Lam	Hong Kong	Caregivers of individuals with schizo-	N=21	Cronbach's alpha = .85; Test-Retest =		24-item tool; 4-point Likert; 15		24-items listed in Tables 1, 2 & 3; Tool	3

	EC, Ting SO (2006)		phrenia		.86		to 20 minutes to complete; Tool already translated in Chinese		referred to as “ Chinese version of the Perceived Family Burden Scale” (CPFBS)	
Perceived Stress Scale (PSS)	Schwarz KA, Dunphy G (2003)	USA	Family caregivers of adults age 65 or older with heart failure	N=75	Cronbach’s alpha = .87	Demonstrated concurrent validity; Factor analysis data provided	14-item tool; 5-point Likert scale		14-items listed in Table 3; Assesses perception of global life stress rather than specific stressful events or situations	3
Poulshock and Deimling Burden Measure	Poulshock SW, Deimling GT (1984)	USA	Caregivers of elders	N=614		Demonstrated concurrent validity; Factor analysis data provided				3
	Lim YM, Luna I, Cromwell SL, Phillips LR, Russell CK, de Ardon ET (1996)	USA	Anglo- and Mexican American caregivers of elders	N=39; N=100	Cronbach’s alpha >.80	Demonstrated content validity; Path Model listed	Spanish language translation information provided	Disruptive behavior; Social functioning; Negative changes in relationships; Social activity restriction;	Tool referred to as “Poulshock and Deimling Burden Scale”	3



								Cognitive incapacity; ADL impairment		
	Phillips LR, Brewer BB, de Ardon ET (2001)	USA	Caregivers of elders	N=226 N=127	Cronbach's alpha = .78 to .81	Demonstrated concurrent validity		Activities of daily living; Cognitive incapacity; Social function; Disruptive behavior; Elder-care-giver-family relationship change; Social restriction	Tool referred to as "The Burden Scale"	3
Professional Caregiver Burden Index (PCBI)	McCarty EF, Drebing C (2002)	USA	Caregivers of Alzheimer's disease patients	N=22 N=52 N=43	Cronbach's alpha = .90 to .94; Test-Retest = .72; Split Half = .90 to .94	Demonstrated content and concurrent validity	Reduced from 40 to 24 to 16 items; 4-point response	Physical burden; Emotional burden; Loss of empathy/ Detachment; Development of negative job attitude/ competence	16-items listed in Table 2; Completed by nursing staff	3
Relative Stress Scale (RSS)	Greene JG, Smith R, Gardiner M,	England	Carers of elderly relatives with	N=38	Test-Retest = .85	Demonstrated concurrent validity; Factor	15-item tool; 5-point Likert scale	Personal distress; Domestic upset;	15-items listed in Table II	3

	Timbury GC (1982)		dementia			analysis data provided		Negative feelings		
	Thom-messen B, Aarsland D, Braekhus A, Oksen-gaard AR, Engedal K, Laake K (2002)	Norway	Spouse carers of stroke, mild dementia and Parkinson's disease patients	N=186	Cronbach's alpha = .94	Demonstrated concurrent validity; Factor analysis data provided	15-item tool; 5-point Likert scale	Personal distress; Life upset; Negative feelings	15 items listed in Table 2; 8-items for Psycho-social Burden listed in Table 3	3
	Ulstein I, Wyller TB, Engedal K (2007)	Norway	Carers of patients with dementia	N=196	Cronbach's alpha = .70 to .86	Demonstrated concurrent validity	15-item tool; 5-point Likert scale	Emotional distress; Social distress; Negative feelings	15 items listed in Table 2	3
Screen for Caregiver Burden (SCB)	Vitaliano PP, Russo J, Young HM, Becker J, Maiuro RD (1991)	USA	Spouses of patients with Alzheimers Disease	N=191	Cronbach's alpha = .84 to .89; Test-Retest = .64 to .70	Demonstrated face, content, concurrent and discriminant validity	25-item tool; 5-point Likert scale used, with summated total scores	Objective burden; Subjective burden	25 items available in Table 2	3
	King AC, Brassing-ton G (1997)	USA	Family caregivers	N=22	Cronbach's alpha = .75 and .81	Demonstrated concurrent validity	25-item tool; 4-point Likert scale used with summated total scores	Objective burden; Subjective burden		2

	Chou K (1997)	Taiwan	Caregivers	N=10 N=10 N=21	Cronbach's alpha = .91 to .93; Test-Retest = .81 and .84	Demonstrated concurrent and discriminant validity	25-item tool; 5-point Likert scale used with summated total scores; Chinese language translation information provided	Objective burden; Subjective burden		3
	Hirschman KB, Shea JA, Xie SX, Karlawish JH (2004)	USA	Caregivers of Alzheimer disease patients	N=251	Cronbach's alpha = .86 (shortened scale) and .88 (full scale)	Demonstrated concurrent and discriminant validity	Full scale has 25 items; Shortened scale has 7 items; 5-point Likert scale		Shortened 7 item tool listed in Appendix 1; Full 25 item tool in Table 1; Shortened tool referred to as "Rapid Screen for Caregiver Burden"	3
Self-Rated Burden (SRB)	Van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg	Netherlands	Informal caregivers of stroke patients	N=148		Demonstrated convergent validity	Single question; 100-point visual analogue scale		Tool available in Appendix	3

	B, Koopmans- chap MA, van den Bos GA (2004)									
Sekentei Scale	Asai MO, Kameoka VA (2007)	Japan and USA	Family caregivers of elders	N=266	Cronbach's alpha = .95	Demonstrated face, content, concurrent and discriminant validity	Reduced from 53 to 52 to 43 to 32 items; 4-point Likert scale; Japanese language translation information provided		Tool listed in Appendix; Social construct that causes a person to worry about others' evaluation of their behavior	3
Sekentei Scale for Caregivers (SCC)	Asahara K, Momose Y, Murashima S, Okubo N, Magilvy JK (2001)	Japan	Family caregivers of impaired elders	N=260	Cronbach's alpha = .93	Factor analysis data provided	From 26 to 19 to 12 item tool; 4-point Likert scale;	Conformance to social norms; Worry about being seen; Acceptance of traditional social norms	Structure of 12-item scale listed in Figure	3
Sense of Competence Questionnaire (SCQ)	Scholte op Reimer WJ, de Haan RJ, Pijnenborg JM,	Nether- lands	Partners of stroke patients	N=166	Cronbach's alpha = .83; ICC = .93	Demonstrated content validity; Factor analysis data provided	27 item tool; 4- point Likert scale; 15 to 20 minutes	Satisfaction with care recipient; Satisfaction of performance as caregiver;	27 items listed in Appendix	3

	Limburg M, van den Bos GA (1998)						to complete	Consequences of involvement in care		
	Van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg B, Koopmanschap MA, van den Bos GA (2004)	Netherlands	Informal caregivers of stroke patients	N=148		Demonstrated convergent validity	27-item tool	Satisfaction with care recipient; Satisfaction of performance as caregiver; Consequences		3
Strain Visual Analogue Scale	McPherson, KM, Pentland B, McNaughton HK (2000)	United Kingdom	Primary caregivers of severely brain injured individuals	N=70		Demonstrated convergent and discriminant validity	10 cm visual analogue scale with no strain = 0 cm, severe strain = 10 cm		Addresses how much strain the carer has	3
Subjective and Objective Family Burden Interview (SOFBI)	Montgomery RJ, Gonyea JG, Hooyman NR (1985)	USA	Caregivers of elderly relatives	N=80	Cronbach's alpha = .85 and .86	Demonstrated concurrent validity	22-item tool; 5-point Likert scale; Structured	Objective burden; Subjective burden	Items listed in Appendix A and B	3

							interviews; 45 minutes to complete			
Subjective and Objective Family Burden Interview (SOFBI/ECFOS)	Martorell Pereda A, Salvador-Carulla L, Ochoa S, Ayuso-Mateos JL (2007)	Spain	Caregivers of adults with intellectual disabilities	N=166	Cronbach's alpha = .88; Test-Retest = .48 to .79; Interrater reliability .78 to 1.00	Demonstrated convergent validity; Factor analysis data provided	Semi-structured interview; 30 minutes to complete	Assistance with everyday activities; Behavioural problems; Emotional concerns; Impact on the caregiver's functioning	Items listed in Table 4	3
Subjective Burden Scale	Matsuda O (1999)	Japan	Family caregivers of elderly relatives with dementia	N=255	Cronbach's alpha = .87; Test-Retest = .72; Split-Half = .80	Demonstrated concurrent and predictive validity	14-item tool; 5-point Likert scale; Self-administered; 10 minutes to complete		14 items listed in Appendix	3
Swedish Family Burden and Participation in Care	Ostman M, Hansson L (2000)	Sweden	Caregivers of mentally ill family members	N=27	Test-Retest = .05 to 1.00; Interrater reliability = .98	Demonstrated content validity	59-items; 46-items measured burden and participation; semi-structured interview		46 items listed in Table 1	3
Zarit Burden Interview	Zarit SH, Reever KE,	USA	Primary caregivers	N=29		Demonstrated concurrent	29-item tool; Likert		29 items listed in Table 1;	3

(ZBI)	Bach-Peterson J (1980)		of older relatives with senile dementia			validity	scale		Tool referred to as “The Burden Interview”	
	Anthony-Bergstone CR, Zarit SH, Gatz M (1988)	USA	Caregivers of dementia patients	N=184	Cronbach’s alpha = .79	Demonstrated concurrent validity	22-item tool; 5-point Likert scale		Tool referred to as “The Burden Interview”; Measures perceived impact of caregiving on financial status, physical health, emotional health, and social activities	3
	Buffum MD (1992)	USA	Spouses caring for Alzheimer’s disease patients	N=72	Cronbach’s alpha = .93		22-item tool; 5-point Likert scale		22 items listed in Appendix; Tool referred to as “Caregiver Burden Interview”	3
	Arai Y, Kudo K, Hosokawa T, Washio M, Miura	Japan	Caregivers of disabled elderly	N=66	Cronbach’s alpha = .93; Test-retest = .76	Demonstrated concurrent validity	22-item tool; 5-point Likert scale;		22 items listed in Appendix; Tool referred to as “Zarit Caregiver	3

	H, Hisamichi S (1997)						Japanese language translation information provided		Burden Interview”	
	Uttl B, Santacruz P, Litvan I, Grafman J (1998)	USA	Caregivers of patients with progressive supra- nuclear palsy	N=180	Cronbach’s alpha = .91	Demonstrated discriminant validity	22-item tool; 5- point Likert scale		Tool referred to as “Burden Interview” (BI22)	3
	Arai Y, Washio M (1999)	Japan	Caregivers of elderly	N=45	Cronbach’s alpha = .93	Demonstrated concurrent validity	Tool already translated in Japanese		Tool referred to as “Zarit Caregiver Burden Interview”	3
	Hebert R, Bravo G, Preville M (2000)	Canada	Informal caregivers of community- dwelling older persons with dementia	N=312	Cronbach’s alpha = .92 and .91; Split Half = .90 and .91	Demonstrated concurrent validity; Factor analysis data provided	22-item tool reduced to 12 items for short version; 5-point Likert scale; Tool already translated in French	Personal strain; Role strain	Tool referred to as “Zarit Burden Interview”; Developed short version of the tool; Recommend- ed new cut-off scores to quality level of burden	3
	Bedard M, Molloy DW,	Canada	Caregivers of cognitively	N=413	Cronbach’s alpha = .88 and .78	Demonstrated convergent validity;	12-item short version of		Tool referred to as “Zarit Burden	3



	Squire L, Duboise S, Lever JA, O'Donnell M (2001)		impaired adults			Factor analysis data provided	the tool; 4-item screening version of the tool; 5- point Likert scale		Interview"; Used 12-item short version and developed 4-item screening version; Items provided in Appendix	
	Phillips LR, Brewer BB, de Ardon ET (2001)	USA	Caregivers of elders	N=249	Cronbach's alpha = .90	Demonstrated concurrent validity; Factor analysis data provided				3
	Scazufca M (2002)	Brazil	Carers of people with mental illnesses	N=82	Cronbach's alpha = .87	Demonstrated concurrent validity	22-item tool; 5- point Likert scale; Portuguese language translation information provided		Tool referred to as Portuguese "Burden Interview"; Tool available in Table 1	3
	Rivera- Navarro J, Morales- Gonzalez JM, Benito- Leon J;	Spain	Caregivers of patients with demyelin- ating disease	N=91		Demonstrated concurrent validity	22-item tool; Tool already translated in Spanish		Tool referred to as modified Spanish version of the "Zarit Caregiver	3

	Madrid Demyelinating Diseases Group (GEDMA) (2003)								Burden Interview"	
	Taub A, Andreoli SB, Bertolucci PH, (2004)	Brazil	Informal caregivers of demented patients	N=50	Cronbach's alpha = .77; Test-Retest = .80; ICC = .88		22-item tool; 5-point Likert scale		Tool referred to as "Brazilian version of the Zarit Burden Interview"	3
	Kumamoto K, Arai Y (2004)	Japan	Caregivers of elderly patients	N=51		Demonstrated convergent validity; Factor analysis data provided	8-item tool; Tool already translated in Japanese	Personal strain; Role strain	Tool referred to as short version of the "Japanese version of the Zarit Burden Interview" (J-ZBI_8)	3
	Ankri J, Andrieu S, Beaufils B, Grand A, Henrard JC (2005)	France	Informal caregivers of patients with Alzheimer's disease or related disorders	N=152		Demonstrated concurrent validity; Factor analysis data provided	22-item tool; Tool already translated in French	Effect on social and personal life; Psychological burden; Feelings of guilt	22 items provided in Table 2	3
	Onishi J, Suzuki Y, Umegaki	Japan	Caregivers of patients with	N=116	Cronbach's alpha = .92	Demonstrated convergent validity; Path	21-item tool; 4-point			3

	H, Nakamura A, Endo H, Iguchi A (2005)		dementia			analysis data provided	Likert scale; One item 0-100 self-rated			
	Shurgot GS, Knight BG (2005)	USA	Latino caregivers of patients with dementia	N=48	Cronbach's alpha = .70	Demonstrated concurrent validity	14-item tool; 5-point Likert scale		Tool referred to as "Modified version of the Burden Interview"	3
	Abe K (2007)	Japan	Family caregivers	N=219	Cronbach's alpha = .93	Demonstrated convergent validity	22-item tool		Tool referred to as "Japanese version of the Zarit Burden Interview" (J-ZBI)	3
	Cifu DX, Carne W, Brown R, Pegg P, Ong J, Qutu-buddin A et al (2006)	USA	Caregivers of Parkinson's patients	N=49		Demonstrated concurrent and convergent validity	22-item tool; 4-point Likert scale; 15 minutes to complete			3
	Kim S, Kim J, Stewart R, Bae K, Yang S,	South Korea	Co-habiting caregivers of elders	N=484	Cronbach's alpha = .89	Demonstrated concurrent validity	22-item tool; 5-point Likert scale			3

	Shin Hj et al (2006)									
	Schreiner AS, Morimoto T, Arai Y, Zarit S (2006)	Japan	Family caregivers of older adults, stroke caregivers and chronic obstructive pulmonary disease caregivers	N=198		Demonstrated predictive validity	22-item tool; 5- point Likert scale			3
	Martinez- Martin P, Forjaz MJ, Frades- Payo B, Rusinol AB, Fernandez- Garcia JM, Benito- Leon J et al (2007)	Spain	Caregivers of patients with Parkinson's Disease	N=79	Cronbach's alpha = .93	Demonstrated convergent validity	22-item tool; 5- point Likert scale; Tool already translated in Spanish	Personal strain; Role strain	Tool referred to as "Zarit CB Inventory" (ZCBI)	3

## Appendix VI Included studies

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## Appendix VII - Excluded studies

Antonucci TC, Sherman AM. Measures of social support and caregiver burden. *Generations* 1997;**21**(1):48-52.

**Reason for exclusion:** Used only as reference. Retrieved relevant primary sources.

Arai Y. Family caregiver burden and quality of home care in the context of the Long-Term Care insurance scheme: an overview. *Psychogeriatrics* 2006;**6**:134-8.

**Reason for exclusion:** Review of previous studies. No psychometric properties of burden tools reported.

Arai, Y, Sugiura M, Miura H, Washio M, Kudo K. Undue concern for others' opinions deters caregivers of impaired elderly from using public services in rural Japan. *Int J Geriatr Psychiatry* 2000;**15**:961-8.

**Reason for exclusion:** No psychometric properties of tool reported.

Arguelles A, Loewenstein DA, Eisdorfer C, Arguelles T. Caregivers' judgments of the functional abilities of the Alzheimer's disease patient: impact of caregivers' depression and perceived burden. *J Geriatr Psychiatry Neurol* 2001;**14**(2):91-8.

**Reason for exclusion:** No psychometric properties of tool reported.

Aubeeluck A, Buchanan H. The Huntington's Disease quality of life battery for carers: reliability and validity. *Clin Genet* 2007;**71**:434-445.

**Reason for exclusion:** Neither tool nor subscale measures burden.

Bachner YG, O'Rourke N. Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging Ment Health* 2007;**11**(6):678-685.

**Reason for exclusion:** Meta-analysis of previous studies.

Bairdi JM. The influence of health status, burden, and degree of cognitive impairment on the self-care agency and dependent-care agency of caregivers of elders. [Dissertation]. Detroit (MI): Wayne State University; 1997.

**Reason for exclusion:** Montgomery Borgatta Burden Scale used. Insufficient psychometric properties reported.

Baronet AM. Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clin Psychol Rev* 1999;**19**(7):819-841.

**Reason for exclusion:** Detailed review of burden but not about tools used to measure burden.

Battista MA, Pate DS, Hierholzer R, Howsepian AA, Mogelof J. Caregiver reports: a systematic method of comparison with clinical impressions. *Clin Gerontol* 2004;**27**(4):52-70.

**Reason for exclusion:** No psychometric properties of the tool measuring burden reported.

Bautz-Holter E, Sveen U, Rygh J, Rodgers H, Wyller TB. Early supported discharge of patients with acute stroke: a randomized controlled trial. *Disabil Rehabil* 2002;**24**(7):348-355.

**Reason for exclusion:** Randomized control trial of an intervention. No psychometric properties of a tool measuring burden reported.

Beland F, Bergman H, Lebel P, Clarfield AM, Tousignant P, Contandriopoulos, AP et al. A

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Bell CM, Araki SS, Neumann PJ. The association between caregiver burden and caregiver health-related quality of life in Alzheimer disease. *Alzheimer Dis Assoc Disord* 2001;**15**(3):129-136.

**Reason for exclusion:** No psychometric properties of the tool measuring burden reported.

Blake H, Lincoln ND, Clarke DD. Caregiver strain in spouses of stroke patients. *Clin Rehabil* 2003;**17**:312-7.

**Reason for exclusion:** Caregiver Strain Index tool was used but no psychometric properties were reported.

Boling W. The health of chronically ill children: lessons learned from assessing family caregiver quality of life. *Fam Community Health* 2005;**28**:176-183.

**Reason for exclusion:** Tool used did not extrapolate burden.

Caap-Ahlgren M, Dehlin O. Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging Clin Exp Res* 2002;**14**(5):371-7.

**Reason for exclusion:** Caregiver Burden Scale tool was used but insufficient psychometric properties reported.

Cafferata GL, Stone R. The caregiving role: dimensions of burden and benefits. *Compr Gerontol A* 1989;**3**:57-64.

**Reason for exclusion:** Informal Caregivers Survey tool used but insufficient psychometric properties reported.

Chadda RK, Singh TB, Ganguly KK. Caregiver burden and coping: a prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Soc Psychiatry Psychiatr Epidemiol* 2007;**42**:923-930.

**Reason for exclusion:** Burden Assessment Scale tool was used but insufficient psychometric properties reported.

Chan RC, Lee PW, Lieh-Mak F. Coping with spinal cord injury: personal and marital adjustment in the Hong Kong Chinese setting. *Spinal Cord* 2000;**38**:687-696.

**Reason for exclusion:** Insufficient psychometric properties reported.

Chen H, Chen M, Shyu Y, Tang W. Development and testing of a scale to measure caregiving load in caregivers of cancer patients in Taiwan, the Care Task Scale – Cancer. *Cancer Nurs* 2007;**30**(3):223-231.

**Reason for exclusion:** Care Task Scale - Cancer tool used measures tasks not burden.

Chen M, Hu L. The generalizability of caregiver strain index in family caregivers of cancer patients. *Int J Nurs Stud* 2002;**39**:823-9.

**Reason for exclusion:** Caregiver Strain Index tool used. Insufficient sample size.

Chiou C, Chen I, Wang H. The health status of family caregivers in Taiwan: an analysis of gender differences. *Int J Geriatr Psychiatry* 2005;**20**:821-6.

**Reason for exclusion:** Insufficient psychometric properties reported for tools used. Analysis not focused on measuring burden

Chou K, Jiann-Chyun L, Chu H. The reliability and validity of the Chinese version of the Caregiver Burden Inventory. *Nurs Res* 2002; **51**(5):324-331.

**Reason for exclusion:** Data from study was reported in Chou's 1997 dissertation. Data and dissertation are already included in this review.

Chou K, LaMontagne LL, Hepworth JT. Burden experienced by caregivers of relatives with dementia in Taiwan. *Nurs Res* 1999;**48**(4):206-214.

**Reason for exclusion:** Data from study was reported in Chou's 1997 dissertation. Data and dissertation are already included in this review.

Claar RL, Parekh PI, Palmer SM, LaCaille RA, Davis RD, Rowe SK et al. Emotional distress and quality of life in caregivers of patients awaiting lung transplant. *J Psychosom Res* 2005;**59**:1-6.

**Reason for exclusion:** Scale for Caregiver Burden (SCB) tool used but insufficient psychometric properties reported.

Cooper C, Robertson MM, Livingston G. Psychological morbidity and caregiver burden in parents of children with Tourette's disorder and psychiatric comorbidity. *J Am Acad Child Adolesc* 2003;**42**(11):1370-5.

**Reason for exclusion:** Child and Adolescent Impact Assessment tool was used but insufficient psychometric properties reported.

Courtney LJ. Post-traumatic stress disorder symptomatology in family caregivers of persons with recent traumatic brain injuries: an exploratory study [Dissertation]. Houston (TX): University of Houston; 1997.

**Reason for exclusion:** Study about post-traumatic stress disorder. Not relevant to burden tools.

Cousins R, Davies AD, Turnbull CJ, Playfer JR. Assessing caregiving distress: a conceptual analysis and a brief scale. *Br J Clin Psychol* 2002;**41**:387-403.

**Reason for exclusion:** Caregiver Distress Scale tool was used. Insufficient psychometric properties reported.

Daly MP, Fredman L. A simple function-based scale for practitioners to assess the patient-caregiver dyad. *Top Geriatr Rehabil* 1998;**14**(1):45-53.

**Reason for exclusion:** Patient-Caregiver Functional Unit Scale, Burden Interview Scale, Perceived Stress Scale and Geriatric Depression tool were used. Burden was associated with function but insufficient psychometric properties of tools used reported.

Davis LL, Weaver, M, Zamrini E, Stevens A, Kang D, Parker CR. Biopsychological markers of distress in informal caregivers. *Biol Res Nurs* 2004;**6**:90-99.

**Reason for exclusion:** Not relevant to burden tools. Article about cortisol production.

Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *J Pain Symptom Manage* 2004;**26**(4):922-953.

**Reason for exclusion:** Review of previous studies. Some tools described measure burden and report their psychometric properties. Relevant primary sources retrieved.

Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. *Chest* [serial online] 2003 [cited 2008 Apr 3];123:1073-1081. Available from: [URL:http://www.chestjournal.org/content/123/4/1073.full.pdf+html](http://www.chestjournal.org/content/123/4/1073.full.pdf+html)

**Reason for exclusion:** Center for Epidemiologic Studies Depression Scale used but insufficient psychometric properties for the measurement of burden reported.

Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. *Heart Lung* 2004;**33**(6):354-361.

**Reason for exclusion:** Caregiver Appraisal Tool was used but insufficient psychometric properties of the subscales that measure burden reported.

Draper B, Bowring G, Thompson C, Van Heyst J, Conroy P, Thompson J. Stress in caregivers of aphasic stroke patients: a randomized controlled trial. *Clin Rehabil* 2007;**21**:122-130.

**Reason for exclusion:** Relative Stress Scale was used but insufficient psychometric properties of burden measurement reported.

Draper BM, Poulos CJ, Cole AM, Poulos RG, Ehrlich F. A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc* 1992;**40**:896-901.

**Reason for exclusion:** Relative Stress Scale was used but insufficient psychometric properties of burden measurement reported.

Edwards B, Ung L. Quality of life instruments for caregivers of patients with cancer: a review of their psychometric properties. *Cancer Nurs* 2002;**25**(5):342-9.

**Reason for exclusion:** Review of literature describing Caregiver Quality of Life Index - Cancer Scale, the Caregiver Quality of Life Index, the Quality of Life Tool and the Quality of Life Index - Cancer Version tools. Insufficient psychometric properties of burden measurements reported.

Edwards NE, Ruettiger KM. The influence of caregiver burden on patients' management of Parkinson's disease: implications for rehabilitation nursing. *Rehabil Nurs* 2002;**27**(5):182-6.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

England M, Roberts B. Theoretical and psychometric analysis of caregiver strain. *Res Nurs Health* 1996;**19**:499-510.

**Reason for exclusion:** Parent Caregiver Burden Index used to measure response to burden not burden itself.

Fredman L, Daly MP. Weight change: an indicator of caregiver stress. *J Aging Health* 1997;**9**(1):43-69.

**Reason for exclusion:** Zarit Burden Interview used but insufficient psychometric properties reported. Variable measured was weight change.

Freyne A, Kidd N, Coen R, Lawlor BA. Burden in carers of dementia patients: higher levels in carers of younger sufferers. *Int J Geriatr Psychiatry* 1999;**14**:748-788.



**Reason for exclusion:** Zarit Burden Interview used but insufficient psychometric properties reported.

Gallego CF, Roger MR, Bonet IU, Vinets LG, Ribas AP, Pisa RL et al. Validation of a questionnaire to evaluate the quality of life of nonprofessional caregivers of dependent persons. *J Adv Nurs* 2001;**33**(4):548-554.

**Reason for exclusion:** ICUB97 tool used. Insufficient psychometric properties reported for burden measurement.

Gauthier A, Vignola A, Calvo A, Cavallo E, Moglia C, Selliti L et al. A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology* 2007;**68**:923-926.

**Reason for exclusion:** Caregiver Burden Inventory used but study not actually about burden. Insufficient psychometric properties reported.

Gopinath PS, Chaturvedi SK. Measurement of distressful psychotic symptoms perceived by the family: preliminary findings. *Indian J Psychiatry* 1986;**28**(4):343-5.

**Reason for exclusion:** Tool used to measure distress not burden. Author's definition of distress not appropriate for this review.

Grant JS, Weaver M, Elliott TR, Bartolucci AR, Giger JN. Sociodemographic, physical and psychosocial factors associated with depressive behaviour in family caregivers of stroke survivors in the acute care phase. *Brain Inj* 2004;**18**(8):797-809.

**Reason for exclusion:** Caregiving Burden Scale was used. Insufficient psychometric properties reported.

Gupta R. Impact of mental health on perceived caregiver burden in South Asian families. *J of Ment Health and Aging* 2002;**8**(1):45-57.

**Reason for exclusion:** Perceived Caregiver Burden Scale used. Insufficient psychometric properties reported.

Hartnick CJ, Bissell C, Parsons SK. The impact of pediatric tracheotomy on parental caregiver burden and health status. *Arch Otolaryngol Head Neck Surg* 2003;**129**:1065-9.

**Reason for exclusion:** Pediatric Tracheotomy Health Status Instrument used. Domain 4 of the tool included parental rating of their own caregiving burden. Insufficient psychometric properties for domain reported.

Hirakawa Y, Kuzuya M, Masuda Y, Enoki H, Iwata M, Hasegawa J et al. Evaluation of gender differences in caregiver burden in home care: Nagoya Longitudinal Study of the Frail Elderly (NLS-FE). *Psychogeriatrics* 2006;**6**:91-9.

**Reason for exclusion:** Japanese version of the Zarit Burden Interview used to study gender differences in caregiving. Insufficient psychometric properties reported.

Im K, Belle SH, Schulz R, Mendelsohn AB, Chelluri L. Prevalence and outcomes of caregiving after prolonged (> 48 Hours) mechanical ventilation in the ICU. *Chest* 2004;**125**(2):597-606.

**Reason for exclusion:** Patient Behavior Frequency and Caregiver Reaction to These Behaviors tool was used. Insufficient psychometric properties of the measurement of burden reported.

Jones PS, Jaceldo KB, Lee JR, Zhang XE, Meleis AI. Role integration and perceived

health in Asian American women caregivers. *Res Nurs Health* 2001;**24**:133-144.

**Reason for exclusion:** Tool used measured role integration, role satisfaction and role stress not burden as defined for this review.

Jones SL, Jones PK. Caregiver burden: who the caregivers are, how they give care, and what bothers them. *J Health Soc Policy* 1994;**6**(2):71-89.

**Reason for exclusion:** Review of burden but not about tools used to measure burden. No psychometric properties of tools reported.

Juarez G. Perceptions of the caregiving experience and quality of life: Mexican/Mexican-American caregivers providing care to adults with advanced cancer [Dissertation]. Los Angeles (CA): University of California Los Angeles; 2003.

**Reason for exclusion:** Study was of quality of life. No psychometric properties of tools used to measure burden reported.

Kirschling JM, Pittman JF. Measurement of spiritual well-being: a hospice caregiver sample. *Hosp J* 1989;**5**(2):1-11.

**Reason for exclusion:** Spiritual Well-Being Scale used does not measure burden.

Kleinman L, Frank L, Ciesla G, Rupnow M, Brodaty H. Psychometric performance of an assessment scale for strain in nursing care: The M-NCAS. *Health Qual Life Outcomes* [serial online] 2004 [cited 2009 Mar 27];**2**(62):[10 screens]. Available from: URL:

<http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=535543&blobtype=pdf>

**Reason for exclusion:** Modified Nursing Care Assessment Scale measured burden felt by nurses as the formal caregivers. Insufficient psychometric properties reported.

Kosberg JI, Cairl RE. The Cost of Care Index: a case management tool for screening informal care providers. *Gerontologist* 1986;**26**(3):273-8.

**Reason for exclusion:** Insufficient psychometric properties reported.

Koukia E, Madianos MG. Is psychosocial rehabilitation for schizophrenic patients preventing family burden? A comparative study. *J Psychiatr Ment Health Nurs* 2005;**12**:415-422.

**Reason for exclusion:** Study measures psychosocial rehabilitation. No psychometric properties of the tools used to measure burden reported.

Lane AB, Dede DE, Chandra SP, Gilmore R. Continued caregiver burden: seizure-free may not equal burden-free. *J Epilepsy* 1998;**11**:361-7.

**Reason for exclusion:** Caregiver Strain Index used. Insufficient psychometric properties reported.

Lauderdale SA. The intraindividual dimensional structure and discriminant validity of subjective caregiver burden and depression [Dissertation]. Lubbock (TX): Texas Tech University; 2002.

**Reason for exclusion:** Only three caregivers participated. Insufficient sample size.

Lee EE, Farran CJ, Tripp-Reimer T, Sadler GR. Assessing the cultural appropriateness of the finding meaning through caregiving scale for Korean caregivers. *J Nurs Meas* 2003;**11**(1):19-28.

**Reason for exclusion:** Finding Meaning Through Caregiving Scale used measured cultural appropriateness not burden. Insufficient sample size of 10 participants.

Livingston G, Mahoney R, Regan C, Katona C. The Caregivers of Alzheimer's Disease Problems Scale (CAPS): development of a new scale within the LASER-AD study. *Age Ageing* 2005;**34**:287-290.

**Reason for exclusion:** Caregivers for Alzheimer's Disease Problems Scale used did not measure burden.

Longo CJ, Fitch M, Deber RB, Williams AP. Financial and family burden associated with cancer treatment in Ontario, Canada. *Support Care Cancer* 2006;**14**:1077-1085.

**Reason for exclusion:** Tool was administered to patients not caregivers. No information relevant to review.

Marwit SJ, Meuser TM. Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *Gerontologist* 2002;**42**:751-765.

**Reason for exclusion:** Caregiver Grief Inventory used did not measure burden.

McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 2005;**36**:2181-6.

**Reason for exclusion:** Caregiver Burden Score used. Insufficient psychometric properties reported.

Mets T, Vandewoude M, Jacquy J, Deblander A, MacDonald K, Sloesen A. Patient and caregiver outcomes after 6 + 1.5 months of rivastigmine therapy for mild-to-moderate Alzheimer's disease: the Belgian FExT study. *Curr Med Res Opin* 2007;**23**:2485-2501.

**Reason for exclusion:** Zarit Caregiving Burden Scale used. Insufficient psychometric properties reported.

Miyamoto Y, Ito H, Otsuka T, Kurita H. Caregiver burden in mobile and non-mobile demented patients: a comparative study. *Int J Geriatr Psychiatry* 2002;**17**:765-773.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

Montgomery RJ, Stull DE, Borgatta EF. Measurement and the analysis of burden. *Res Aging* 1985;**7**(1):137-152.

**Reason for exclusion:** Review of burden but not about tools used to measure burden. No information relevant to review.

Murray PD, Lowe JD, Anderson HN, Horne HL, Lott WC, Macdonald S. Validity studies of the Filial Anxiety Scale. *Gerontologist* 1996;**36**(1):110-2.

**Reason for exclusion:** Filial Anxiety Scale used does not measure burden.

Nagatomo I, Akasaki Y, Uchida M, Tominaga M, Hashiguchi W, Takigawa M. Gender of demented patients and specific family relationship of caregiver to patients influence mental fatigue and burdens on relatives as caregivers. *Int J Geriatr Psychiatry* 1999;**14**:618-625.

**Reason for exclusion:** An unnamed caregiver burden scale was developed and used. Insufficient psychometric properties reported.

O'Rourke N, Cappeliez P, Guindon S. Depressive symptoms and physical health of

caregivers of persons with cognitive impairment: analysis of reciprocal effects over time. *J Aging Health* 2003;**15**:688-712.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported. Study measures depression and physical symptoms.

Ohaeri JU. Caregiver burden and psychotic patients' perception of social support in a Nigerian setting. *Soc Psychiatry Psychiatr Epidemiol* 2001;**36**:86-93.

**Reason for exclusion:** Original burden questionnaire and Goldberg's General Health Questionnaire used. Insufficient psychometric properties reported.

Osterkamp MB, Jess J, Welborn A. Measuring the impact of a community workshop on family caregivers. Proceedings of the 36th Annual Scientific Meeting of the Gerontological Society 1983; Nov 17-22.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

Pakenham KI. Development of a measure of coping with multiple sclerosis caregiving. *Psychol Health* 2002;**17**(1):97-118.

**Reason for exclusion:** Caregiver Reaction Assessment used. Tool assesses coping strategies not burden.

Pearce K, McGovern J, Barrowclough C. Assessment of need for psychosocial interventions in an Asian population of carers of patients with schizophrenia. *J Adv Nurs* 2006;**54**:284-292.

**Reason for exclusion:** Relatives' Cardinal Needs Schedule used does not measure burden.

Picot SJ, Youngblut J, Zeller R. Development and testing of a measure of perceived caregiver rewards in adults. *J Nurs Meas* 1997;**5**(1):33-52.

**Reason for exclusion:** Picot Caregiver Rewards Scale measures perceived rewards not burden.

Pirraglia PA, Bishop D, Herman DS, Trisvan E, Lopez RA, Torgersen CS, et al. Caregiver burden and depression among informal caregivers of HIV-infected individuals. *J Gen Intern Med* 2005;**20**:510-514.

**Reason for exclusion:** Caregiver Strain Index used. Insufficient psychometric properties reported.

Porock D, Oliver DP. Commentary on Schneider RA (2004) assessing the Fatigue Severity Scale for use among caregivers of chronic renal failure patients. *J Clin Nurs* 2005;**14**:1153-4.

**Reason for exclusion:** Manuscript about fatigue related to caregiving, not about burden.

Reinhard SC. Living with mental illness: effects of professional contacts and personal control on caregiver burden [Dissertation]. New Brunswick (NJ): Rutgers The State University of New Jersey; 1991.

**Reason for exclusion:** Original tool developed for this study. Insufficient psychometric properties reported.

Rodgers H, Soutter J, Kaiser W, Pearson P, Dobson R, Skilbeck C et al. Early supported hospital discharge following acute stroke: pilot study results. *Clin Rehabil* 1997;**11**:280-7.

**Reason for exclusion:** General Health Questionnaire used. Insufficient psychometric properties reported.

Rosenfarb IS, Bellack AS, Aziz N. A sociocultural stress, appraisal, and coping model of subjective burden and family attitudes toward patients with schizophrenia. *J Abnorm Psychol* 2006;**115**(1):157-165.

**Reason for exclusion:** Global Self Report Rating of Family Burden used. Insufficient psychometric properties reported.

Rubio DM, Berg-Weger, M, Tebb SS. Assessing the validity and reliability of well-being and stress in family caregivers *Soc Work Res* 1999;**23**(1):54-63.

**Reason for exclusion:** Caregiver Well-Being Scale and Caregiver Strain Index were analyzed using structural equation modeling. Insufficient psychometric properties reported.

Rudd AG, Wolfe CD, Tilling K, Beech R. Randomised controlled trial to evaluate early discharge scheme for patients with stroke. *Br Med J* 1997;**315**:1039-1044.

**Reason for exclusion:** Caregiver Strain Index used. Insufficient psychometric properties reported.

Samuelsson AM, Annerstedt L, Elmstahl S, Samuelsson S, Grafstrom M. Burden of responsibility experienced by family caregivers of elderly dementia sufferers. *Scand J Caring Sci* 2001;**15**:25-33.

**Reason for exclusion:** Caregivers reported their experience with burden but no tools were used to measure burden.

Schene AH, Tessler RC, Gamache GM. Instruments measuring family or caregiver burden in severe mental illness. *Soc Psychiatry Psychiatr Epidemiol* 1994;**29**:228-240.

**Reason for exclusion:** Review of burden tools used in severe mental illness. Relevant primary sources retrieved.

Schott-Baer D. Dependent care, caregiver burden, and self-care agency of spouse Caregivers. *Cancer Nurs* 1993;**16**(3):230-6.

**Reason for exclusion:** Burden Scale used. Insufficient psychometric properties reported.

Schure LM, van den Heuvel E, Stewart RE, Sanderman R, de Witte LP, Meybom-de Jong B . Beyond stroke: description and evaluation of an effective intervention to support family caregivers of stroke patients. *Patient Educ Couns* 2006;**62**:46-55.

**Reason for exclusion:** Randomised control trial of an intervention. Tools used did not measure burden. No information relevant to review.

Sherwood PR, Given CW, Given BA, Von Eye A. Caregiver burden and depressive symptoms: analysis of common outcomes in caregivers of elderly patients. *J Aging Health* 2005;**17**(2):125-147.

**Reason for exclusion:** Caregiver Reaction Assessment used correlated relationship of burden to depression. Insufficient psychometric properties reported.

Shigenobu K, Ikeda M, Fukuhara R, Maki N, Hokoishi K, Nebu A et al. Reducing the burden of caring for alzheimer's disease through the amelioration of 'delusions of theft' by drug therapy. *Int J Geriatr Psychiatry* 2002;**17**:211-7.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

Shikar R, Shakespeare A, Sagnier P, Wilkinson D, McKeith I, Dartigues J et al. The Impact of metrifonate therapy on caregivers of patients with Alzheimer's disease: results from the MALT Clinical Trial. *J Am Geriatr Soc* 2000;**48**:268-274.

**Reason for exclusion:** Did not measure psychometric properties of screening tools.

Shyu YL, Lee H, Chen M. Development and testing of the Family Caregiving Consequences Inventory for home nursing assessment in Taiwan. *J Adv Nurs* 1999;**30**(3):646-654.

**Reason for exclusion:** Family Caregiving Consequences Inventory used does not measure burden.

Simmons LA. Self-perceived burden in cancer patients. *Cancer Nurs* 2007;**30**(5):405-411.

**Reason for exclusion.** Self-perceived Burden Scale used measures burden perceived by patient not by caregiver. No information relevant to the review.

Sisk RJ. Caregiver burden and health promotion. *Int J Nurs Stud* 2000;**37**(1):37-43.

**Reason for Exclusion:** Objective and Subjective Burden Scales used. Insufficient psychometric properties reported.

Smith AM, Schwirian PM. The relationship between caregiver burden and TBI survivors' cognition and functional ability after discharge. *Rehabil Nurs* 1998;**23**(5):252-7.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

Son G, Zauszniewski JA, Wykle ML, Picot SJ. Translation and validation of Caregiving Satisfaction Scale into Korean. *West J Nurs Res* 2000;**22**(5):609-622.

**Reason for exclusion:** Caregiving Satisfaction Scale used does not measure burden.

Takahashi M, Tanaka K, Miyaoka H. Depression and associated factors of informal caregivers versus professional caregivers of demented patients. *Psychiatry Clin Neurosci* 2005;**59**:473-480.

**Reason for exclusion:** Zarit Burden Interview used. Insufficient psychometric properties reported.

Tebb S. An aid to empowerment: a caregiver well-being scale. *Health Soc Work* 1995;**20**(2):87-92.

**Reason for exclusion:** Well-being scale used does not measure burden.

Teschendorf B, Schwartz C, Ferrans CE, O'Mara A, Novotny P, Sloan J. Caregiver role stress: when families become providers. *Cancer Control* 2007;**14**(2):183-9.

**Reason for exclusion:** Caregivers described their experiences with stress and burden. No psychometric properties of tools measuring burden were reported.

Teunisse S, Mayke MA, Derix MM, van Crevel H. Assessing the severity of dementia: patient and caregiver. *Arch Neurol* 1991;**48**:274-7.

**Reason for exclusion:** Original tool used to measure burden. Insufficient psychometric properties reported.

The 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries, *Int J Geriatr Psychiatry* 2004;**19**:170-7.

**Reason for exclusion:** Insufficient psychometric properties reported.

Thompson C, Spilsbury K. Support for carers of people with Alzheimer's type dementia [review]. The Cochrane Collaboration in The Cochrane Library 2008.

**Reason for exclusion:** Full-text of this systematic review was withdrawn from The Cochrane Collaboration. No information available for review.

Thompson EH, Futterman AM, Gallagher-Thompson D, Rose JM, Lovett SB. Social support and caregiving burden in family caregivers of frail elders. *J Gerontol* 1993;**48**(5):245-254.

**Reason for exclusion:** Three original tools, the Zarit Burden Interview and Activities of Daily Living tools used.

Todtman KL. A financial impact scale for long-term caregivers: application to Alzheimer family caregivers [Dissertation]. Lubbock (TX): Texas Tech University; 1989.

**Reason for exclusion:** Financial Impact Scale did not measure burden.

Ulstein I, Wyller TB, Engedal K. High score on the Relative Stress Scale, a marker of possible psychiatric disorder in family carers of patients with dementia. *Int J Geriatr Psychiatry* 2007;**22**:195-202.

**Reason for exclusion:** Data from study was reported in Ulstein's other 2007 article. Data and analysis already included in this review.

Visser-Meily JM, Post MW, Riphagen II, Lindeman E. Measures used to assess burden among caregivers of stroke patients: a review. *Clin Rehabil* 2004;**18**:601-623.

**Reason for exclusion:** Meta-analysis of previous studies. Relevant primary sources retrieved.

Vitaliano PP, Young HM, Russo J. Burden: a review of measures used among caregivers of individuals with dementia. *Gerontologist* 1991;**31**(1):67-75.

**Reason for exclusion:** Meta-analysis of previous studies. Relevant primary sources retrieved.

Vrabec NJ. Literature review of social support and caregiver burden 1980-1995. *J Nurs Scholarsh* 1997;**29**(4):383-8.

**Reason for exclusion:** Literature review of previous burden studies and instruments.

Watanabe Y, Shiel A, McLellan DL, Kurihara M, Hayashi K. The impact of traumatic brain injury on family members living with patients: a preliminary study in Japan and the UK. *Disabil Rehabil* 2001;**23**(9):370-378.

**Reason for exclusion:** Original family experiences and attitudes questionnaire, family stress, family problems and solutions questionnaire and family needs questionnaire used. Insufficient psychometric properties reported.

Weitzner MA, Meyers CA, Steinbruecker S, Saleeba AK, Sandifer SD. Developing a care giver quality-of-life instrument. *Cancer Practice* 1997;**5**(1):25-31.

**Reason for exclusion:** Quality-of-Life instrument used did not measure burden. Insufficient psychometric properties reported.

Whitney J, Haigh R, Weinman J, Treasure J. Caring for people with eating disorders: factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *Br J Clin Psychol* 2007;**46**:413-428.

**Reason for exclusion:** Experience of Caregiving Inventory does not separate out subscale for burden.

Winter L, Gitlin LN. Evaluation of a telephone-based support group intervention for female caregivers of community-dwelling individuals with dementia. *Am J Alzheimers Dis Other Demen* 2006;**21**(6):391-7.

**Reason for exclusion:** Randomised control trial of an intervention. Zarit Burden Inventory used but insufficient psychometric properties reported.

Wolfe CD, Tilling K, Rudd AG. The effectiveness of community-based rehabilitation for stroke patients who remain at home: a pilot randomized trial. *Clin Rehabil* 2000;**14**:563-9.**Reason for exclusion:** Randomised controlled trial of an intervention. No psychometric properties of tools measuring burden reported.

Wyller TB, Thommessen B, Sodring KM, Sveen U, Pettersen AM, Bautz-Holter E et al. Emotional well-being of close relatives to stroke survivors. *Clin Rehabil* 2003;**17**:410-7.

**Reason for exclusion:** General Health Questionnaire (GHQ-20) and Caregiver Strain Index used. Insufficient psychometric properties reported.

Yeh S, Johnson MA, Wang S. The changes in caregiver burden following nursing home placement. *Int J Nurs Stud* 2002;**39**:591-600.

**Reason for exclusion:** A modified Caregiver Reaction Assessment was used. Insufficient psychometric properties reported.