



**December 18, 2007**

**A Comparison of Tools Used to Screen for Caregiver Burden:  
a Systematic Review**

**Systematic Review Protocol**

**Systematic Review Title**

A Comparison of Tools used to Screen for Caregiver Burden: a Systematic Review .....

**Centre Conducting Review**

Indiana Center for Evidence Based Nursing Practice  
Purdue University Calumet, Indiana  
United States of America

**Primary Reviewer .....**

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**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 (WHO, 2007). Caregivers are also referred to as carers. Caregivers and carers provide care to family members or friends who are ill or disabled and typically need help with daily tasks (USDHHS, 2006).

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 (Zarit, 2004). The role of being a caregiver can be demanding physically, psychologically, socially and financially. Caregiver burden or strain can result from the role of providing care to one or more individuals over a period of time (Kasuya, Polgar Bailey, & Takeuchi, 2000).

Caregiver burden was originally operationalized by Professor Steven Zarit of Pennsylvania State University in 1980. His tool, the Zarit Burden Interview (ZBI), is used world-wide (Yumiko, 2006). 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 (Lim & Zebrack, 2004); caring for the elderly (Stoltz, Uldén, & Willman, 2004); caring for those with cancer and in need of palliative care (Harding & Higginson, 2003); caring for people with dementia (Thompson, et al., 2007); and caring for those with psychiatric illness (Ostman & Hansson, 2004). Caregiver burden tools have been used in many countries and several caregiver burden tools have been translated into other languages (Brouwer, van Exel, & van Gorp, 2006; Lee, Friedmann, Picot, Thomas, & Kim, 2007; Wancata et al., 2005).

While caregiver burden screening tools exist, clinicians need to be encouraged to use these tools

to screen caregivers of their patients. Although multiple systematic reviews have examined caregiver burden in reference to specific disease entities, to date no systematic review has examined the psychometric properties of caregiver burden screening tools. A systematic review will be undertaken to determine the reliability and validity of caregiver burden screening tools and the feasibility of their being used by clinicians. Reliability will be assessed by examining stability, internal consistency and equivalence of instruments. Statistical conclusion validity, internal validity, construct validity and external validity of instruments will be examined (Polit & Beck, 2008; Shadish, Cook, & Campbell, 2002). Feasibility regarding ease of use, length and appropriate language translation will also be examined. Clinicians are more likely to use screening tools that are psychometrically sound and are easy to use in their place of work.

### **Review Question/Objectives**

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 are 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 Studies**

The quantitative component of the review will consider any randomized controlled trials undertaken in in-patient and out-patient settings. In the absence of RCTs, other research study designs, such as non-randomized or quasi-randomized controlled trials and before-and-after studies, will be considered for inclusion in a narrative summary to enable the identification of current best evidence regarding tools that screen for caregiver burden and strain. If there is insufficient empirical evidence, clinical studies, case control studies, longitudinal studies, cohort studies, descriptive studies, observational studies, prospective studies, case series, case reports and expert opinion/commentary pieces will be appraised and included in the review.

#### **Types of Participants**

The quantitative and narrative component of the review will consider studies that include children or adults providing care to other individuals.

#### **Types of Interventions/Phenomena of Interest**

The quantitative and narrative component of the review will consider studies that evaluate screening tools (i.e. the type of intervention) which measure caregiver burden and strain.

## **Types of Outcomes**

The review will consider studies that include the following outcome measures: reliability, validity and feasibility.

## **Search Strategy for Identification of Studies**

The comprehensive search strategy aims to find both published and unpublished studies from 1980-2007, published only in the English language. A three-step search strategy will be utilized in each component of the review. An initial limited search of MEDLINE and CINAHL will be 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 using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of identified reports and articles will be searched for additional studies.

The databases to be searched include:

CINAHL

The Cochrane Library

Health Source: Nursing/Academic Edition

Elsevier Science Direct

EMBASE

ISI Web of Science

MEDLINE

PubMed

TRIP (Turning Research Into Practice)

BioMed Central

Centre for Reviews and Dissemination (CRD)

ACP Journal

The search for unpublished studies will include:

Dissertations  
Conference Proceedings  
Index to Theses  
New York Academy of Medicine - Grey Literature Report  
Liverpool Health Authority - Grey Literature Bulletin  
AHRQ (Agency for Healthcare Research and Quality)  
Theses Canada Portal  
NLM Gateway  
CEEHD  
GoogleScholar.com  
Clinical Medicine Netprints Collection  
Geneva Foundation for Medication Education and Research  
HTA: Health Technology Assessment  
Institute for Health & Social Care Research (IHSCR)  
National Library of Health (NLH)  
The Open University  
World Health Organization Library (WHOLIT)

Initial keywords to be used will include:

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).

Example of 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

## **Methods of the Review**

### **Assessment of Methodological Quality**

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using two standardized critical appraisal instruments. The Joanna Briggs Institute Critical Appraisal Checklist for Experimental Studies (Appendix A) and the Joanna Briggs Institute Critical Appraisal Checklist for Interpretive & Critical Research (Appendix C) will be used. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

### **Data Collection/Extraction**

Data will be extracted from papers included in the review using standardized data extraction tools. The Joanna Briggs Institute Data Extraction Form for Experimental/Observational Studies (Appendix B) and the Joanna Briggs Institute Data Extraction Form for Interpretive & Critical Research (Appendix D) will be used.

Data extracted from experimental/observational studies will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Data extracted from interpretive and critical research will include specific details about the type of text, representation, position, setting, geographical and cultural information, the logic of the argument and the type of data analysis used to determine conclusions and credibility of evidence.

### **Data Synthesis**

Quantitative papers will, where possible, be pooled in statistical meta-analysis using the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instruments (JBI-MAStARI). All results will be subject to double data entry. Odds ratio (for categorical data) and weighted mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed using the standard Chi-square. Where statistical pooling is not possible the findings will be presented in narrative form using the Joanna Briggs Institute Narrative, Opinion and Text Assessment Review Instruments (JBI-NOTARI).

### **Potential Conflict(s) of Interest**

No potential conflict of interest is anticipated.

### **Acknowledgements**

Purdue University Calumet for support of the project.

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**Appendix A**

**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 B**

**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 C**

**Critical Appraisal Checklist for Interpretive & Critical Research**

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

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

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

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	Yes	No	Unclear
1. Is the source of the opinion clearly identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the source of the opinion have standing in the field of expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the interests of patients/clients the central focus of the opinion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the opinion's basis in logic/experience clearly argued?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the argument developed analytical?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there reference to the extant literature/evidence and any incongruence with it logically defended?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the opinion supported by peers?	<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 D**

**Data Extraction Form for Interpretive & Critical Research**

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

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

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

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**Study Description:**

Type of Text: \_\_\_\_\_

Those Represented: \_\_\_\_\_

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Stated: \_\_\_\_\_

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Allegiance/Position: \_\_\_\_\_

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

Geographical: \_\_\_\_\_

Cultural: \_\_\_\_\_

Logic of Argument: \_\_\_\_\_

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Data Analysis: \_\_\_\_\_

**Author's Conclusions:**

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Conclusions	Illustration from Publication (page number)	Unequivocal	Evidence Credible	Unsupported

**Extraction of findings complete:**       Yes

**Reviewer's Comments:**

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