

Development and Validation of the Burden Scale for Family Caregivers (BSFC)

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Printed in Canada

First printing, Toronto, 2003

Preface

This manual describes the Burden Scale for Family Caregivers (BSFC), a global measure of perceived burden resulting from home care. The BSFC is designed for use in both clinical practice and research studies.

The original author developed the BSFC in the early 1990's in Erlangen (Bavaria, Germany), followed by a series of studies with the BSFC in Germany. In 1999, the English version of the BSFC was introduced as an outcome measure to Toronto (Ontario, Canada) at COTA Comprehensive Rehabilitation and Mental Health Services. Further studies were conducted in Toronto.

The BSFC manual was originally written in German. Following the use of the BSFC at COTA, it has become apparent that an English version of the manual would be needed.

We have written this manual with two main purposes. First, to summarize the tool development and studies undertaken in the past 10 years; second, to provide the information necessary for readers to administer the BSFC.

This manual is written to provide information to a diverse audience. It is suitable for practitioners who work with individuals who give care to their family members at home. We have also provided information for researchers, evaluators, educators, and students.

We have divided the manual into four chapters. Chapter one summarizes the background and development of the BSFC. Chapter two describes the administration procedures. Chapter three explains how to score the BSFC and interpret the BSFC score. Chapter four reviews the research undertaken to study the psychometric properties of the BSFC.

The authors of this manual would like to extend thanks to Michelle Patterson and Michelle Martinez, members of the Psychogeriatric Outcome Working Group, who contributed to the revision of the English version of the BSFC at COTA. We appreciate the help from Barbara Cawley and Marilyn Gruneir who reviewed the draft of this manual and provided valuable feedback. Special thanks go to Rosa Chiu who designed the cover page.

Table of Content

Chapter 1. Background.....	1
Subjective Burden of Family Caregivers: a Central Feature of Caregiving at Home.....	1
Development of the BSFC	3
Chapter 2. Administration.....	4
Questionnaire.....	4
Intended Purpose.....	4
Completing the BSFC	5
Chapter 3. Scoring and Interpretation	6
Scoring Method	6
Incomplete or Unclear Answers.....	6
Interpretation	7
Clinical Uses	8
Chapter 4. Psychometric Studies.....	10
Inter-item Correlation	10
Factor Analysis.....	10
Split-Half Reliability	14
Test-Retest Reliability	14
Construct Validity	15
Criterion-Oriented Validity.....	15
Sensitivity to Change	16
Chapter 5. Conclusion	19
 Appendix Burden Scale for Family Caregivers.....	 20
References.....	23

Chapter 1. Background

The Burden Scale for Family Caregivers (BSFC) is a 28-item questionnaire developed to measure the levels of perceived burden of family caregivers. The BSFC is designed for use

- ♦ to identify individual caregiver service needs, plan intervention, and evaluate progress in clinical practice,
- ♦ to evaluate service effectiveness of a program and to predict caregiver health and caregiving situation in research studies.

The BSFC is primarily designed for family members who take care of individuals at home. The reason for caregiving can be due to neurological disorders such as dementia, stroke, Parkinson Disease or other health or functional problems (e.g. internal-medicine geriatric diseases).

Subjective Burden of Family Caregivers: a Central Feature of Caregiving at Home

The subjective burden of family caregivers is a central feature of the home care situation. The extent to which the family caregiver feels burdened, whether not at all, a little, fairly, much or very much, has a significant influence upon the "caring style", on the health, and even on the mortality risk of caregivers, as well as upon the continuation of home care (Figure 1):

- ♦ **Caring Style:** More greatly burdened caregivers are more often aggressive in their behavior towards the person being cared for than are less burdened caregivers (Grafström et al., 1993).
- ♦ **Physical Health of Caregiver:** The greater the subjective burden of the caregiver manifests the more pronounced are the caregiver's somatic symptoms (Gräsel, 1998b).
- ♦ **Mortality Risk:** A comparison with a non-caregiving control group shows that over a period of 4.5 years the risk of death for spouses burdened with caregiving is 63% greater (Schulz & Beach, 1999). In the case of caregiving spouses who feel that home care is not a burden, there is no increased mortality risk.
- ♦ **Give up Home Care:** More greatly burdened caregivers are more likely both to change from home care to institutional care and to do so sooner than less burdened caregivers (Gräsel, 1999; Yaffe et al., 2002).

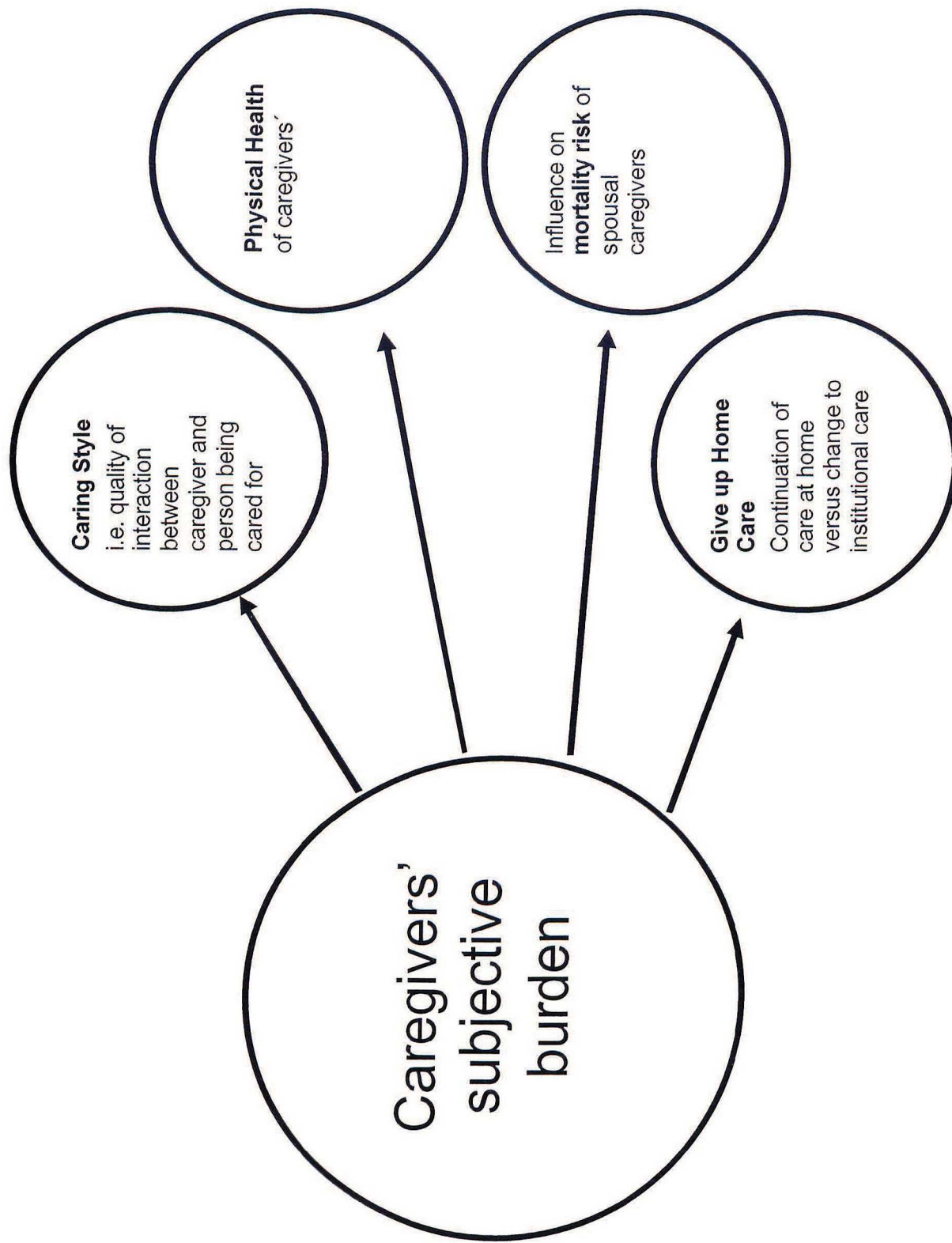


Figure 1 Effects of subjective burden on family caregivers and the caregiving situation

Development of the BSFC

The BSFC was initially developed in German in 1993, with the goal of developing a scale that measures caregiving burden as a sum score. It was translated into English in 1995 (Gräsel, 1995). The author attempted to relate the scale specifically to caregiving as the reason for burden and discriminate clearly between caregiving burden and other sources of burden.

In order to minimize the suggestion of a negative view of the caregiving situation and to guarantee the general comprehensibility of the questionnaire, only 12 items were reverse scored (not 14 which would be 50% of the total of 28 items), thus avoiding formulations containing double negations. The formulation of the BSFC items was completed through seven steps.

1. Observation

A discussion circle for caregiving relatives was observed, and spontaneous statements made by family caregivers concerning important aspects of home care were collected.

2. Qualitative Interviews

Qualitative interviews with family caregivers about positive and negative effects of home care were made in a support group.

3. Formulation of Items

Extracts from the statements collected and collated in step one and two were formulated as items. These items formed the initial prototype of BSFC.

4. Comparison with Other Burden Scales

The initial prototype was compared with burden scales published internationally (Zarit et al., 1980; Robinson, 1983; Kosberg et al., 1990). This led to the modification of some items.

5. Expert Panel Review

A panel of experts assessed the relevance of the statements in the prototype. This process involved item-concretization and augmentation or removal.

6. Pilot Testing

Comprehensibility and acceptance of each item was checked on a test-run.

7. Translation and More Testing

The BSFC was translated into English, with further psychometric testing (Gräsel, 1995).

Chapter 2. Administration

Questionnaire

The BSFC consists of 28 items (Appendix). Each item has four graded responses:

- ◆ yes, definitely
- ◆ yes, generally
- ◆ no, not really
- ◆ no, definitely not

Twelve of the 28 items are inversely presented. In other words, the degree of subjective burden is expressed by the degree of disagreement with the statement. This structuring of the questionnaire has the advantage of minimizing the "Yes-saying" effect which has the potential to falsify findings.

Intended Purpose

The Burden Scale for Family Caregivers (BSFC) is designed for use both at the level of each individual item (the response to individual statements) and the sum score (the total value of all items). This means the BSFC can be used both in practice and in research.

In practice:

- ◆ **Quick Overview:** By looking at the responses to individual items, all those concerned with family caregivers and wishing to provide them with targeted help and support can use the BSFC to obtain a quick overview of where help should be offered. Specific needs can be quickly identified from the level of subjective burden of each item.
- ◆ **Urgency of Need for Relief:** The BSFC score can be used to identify caregivers at risk of physical complaints. This makes it possible to judge the urgency of the need for relief. The principal complaints arising from caregiving centre on symptoms of physical exhaustion (e.g., rapid fatigue), aching joints and stomach complaints.
- ◆ **Evaluate Effectiveness:** Repeated use of the questionnaire makes it possible to assess the effectiveness of the intervention provided in lowering the level of subjective burden.

In scientific research:

- ◆ **Significant Predictor:** Caregiver's subjective burden is a significant predictor of four caregiving outcomes (Chapter 1). They are a) the physical health of the family caregiver, b) the mortality risk for caregiving spouses, c) the "caring style", and d) the further development of the care situation (at home or in a nursing home).
- ◆ **Intervention Studies:** Subjective burden is an important outcome variable in intervention studies targeted on family caregivers. The measurement of the total subjective burden has been proven to be a suitable outcome measure to evaluate changes of subjective burden before and after intervention.

Completing the BSFC

You can administer the BSFC to caregivers individually or in group situations. In any case, ensure the caregivers completing the BSFC are able to complete the questionnaire without interruption and with minimal distractions.

Determine if the caregivers want to complete the BSFC on their own or with you. Some caregivers prefer to do it in their own time; some need assistance with completing it.

Give neither additional instructions nor any further explanations. In particular, no mention should be made of the fact that the aim of the questionnaire is to discover the level of burden caused by care.

When caregivers need your help to complete the BSFC, do not rephrase or reword the questions and answers. Repeat the questions as they are written.

When completing the BSFC in a group setting, you may read the instructions loudly to the group before handing out the questionnaire (Appendix). Doing this has proven useful in practice.

While completing the questionnaire, some caregivers may move into conversations based on the questions and lose their focus. Gently remind them to complete all questions.

After the BSFC has been finished, check the answers for completeness and clarity. Clarify if necessary and obtain responses for questions with missing answers. Completion of the BSFC takes approximately 5 to 10 minutes.

Chapter 3. Scoring and Interpretation

Scoring Method

Score each item using Table 1. Calculate a BSFC sum score by adding all item scores. The minimum BSFC sum score is 0, and the maximum is 84.

Table 1 Item scores of BSFC

Item number	Response	Score
1, 6, 7, 8, 9, 11, 14, 15, 17, 19, 22 and 28	Yes, definitely	0
	Yes, generally	1
	No, not really	2
	No, definitely not	3
2, 3, 4, 5, 10, 12, 13, 16, 18, 20, 21, 23, 24, 25, 26 and 27	Yes, definitely	3
	Yes, generally	2
	No, not really	1
	No, definitely not	0

Incomplete or Unclear Answers

Where responses to individual items are missing or are unclear (such as multiple selections), contact the family caregiver directly and ask the caregiver to complete or clarify those answers that are incomplete or unclear. If it is not possible to obtain such feedback from the caregiver, calculate the BSFC sum score following the instruction below.

One or two missing items: Calculate a weighted sum score if there are only one or two incomplete or unclear responses. Calculate an average using the remaining 26 or 27 questions that have complete answers. Use the average score as the score of the missing item(s). For example, if the answers of items “8” and “12” are missing and the sum score of the remaining 26 items is 39, the average score of the remaining items will be 1.5 (39 divided by 26). Therefore, the score of the missing items “8” and “12” will be 1.5. Then the weighted sum score for the total scale is $39 + 2 \times 1.5 = 42$.

More than two missing items: Do not calculate the sum score when there are more than two incomplete or unclear answers. This would constitute more than 10% of missing items and the estimated sum score would not have a sufficient degree of certainty. In this situation, a total BSFC score will not be available.

Interpretation

The BSFC sum score is assigned to three Subjective Burden Categories: mild, moderate and severe. The assignment is based on the associated risk of psychosomatic symptoms arising primarily from the subjective feelings of burden caused by the home care situation (Gräsel, 2001). Physical complaints are measured using the total score of the Giessen Symptom List, GSL (Brähler & Scheer, 1995).

In the standardization sample (N = 1911; Gräsel, 2002), the average BSFC sum score for family caregivers caring for a patient with dementia was 41.9 (N = 1253, standard deviation SD = 14.8). In the non-dementia group the subjective burden on the family caregivers was 36.6 (N = 612, SD = 16.0). The non-dementia group had a lower perceived burden, and the difference was statistically significant ($p < .001$). The interpretation of the sum score is therefore dependent upon whether the care-receiver has dementia or not.

Refer to the section of “Care-receivers with Dementia” if the caregivers take care of someone with dementia to determine their risk of psychosomatic symptoms. Otherwise, refer to the section of “Care-receivers without Dementia” to interpret the BSFC score.

Care-receivers with Dementia

Table 2 shows the three Subjective Burden Categories, the corresponding BSFC sum score ranges and risks of psychosomatic symptoms for caregivers of individuals with dementia.

Table 2 Assessment of the BSFC sum score for caregivers of individuals with dementia

BSFC SCORE	SUBJECTIVE BURDEN CATEGORIES	RISK OF PSYCHOSOMATIC SYMPTOMS	SAMPLE PERCENTAGE (N = 1236)
0 – 35	none to mild	not at risk ¹	33.8 %
36 – 45	moderate	increased risk ²	25.3 %
46 – 84	severe to very severe	at very high risk ³	40.9 %

- ◆ **None to mild burden:** if the BSFC score ranges from 0 to 35, the subjective burden of the caregiver is none to mild, and the caregiver is not at risk of physical psychosomatic symptoms.

¹ Caregivers were identified as not at risk of psychosomatic symptoms when 50% of the caregivers showed a more than average degree of physical complaints and the other 50% showed an average degree or a lower than average degree of physical complaints

² Caregivers were identified as having increased risk of psychosomatic symptoms when more than 50% of the caregivers showed a more than average degree of physical complaints (percentile norm greater than 50)

³ Caregivers were identified as at very high risk of psychosomatic symptoms when 90% of the caregivers showed a more than average degree of physical complaints (percentile norm greater than 50)

- ♦ **Moderate burden:** if the BSFC score ranges from 36 to 45, the caregiver has a moderate level of subjective burden and an increased risk of physical psychosomatic symptoms.
- ♦ **Severe to very severe burden:** if the BSFC score ranges from 46 to 84, the caregiver is suffering from severe to very severe burden and at a very high risk of physical psychosomatic symptoms.

Care-receivers without Dementia

Table 3 shows the three Subjective Burden Categories, the corresponding BSFC sum score ranges and risks of psychosomatic symptoms for caregivers of individuals without dementia.

- ♦ **None to mild burden:** if the BSFC score ranges from 0 to 41, the subjective burden of the caregiver is none to mild, and the caregiver is not at risk of physical psychosomatic symptoms.
- ♦ **Moderate burden:** if the BSFC score ranges from 42 to 55, the caregiver has a moderate level of subjective burden and an increased risk of physical psychosomatic symptoms.
- ♦ **Severe to very severe burden:** if the BSFC score ranges from 56 to 84, the caregiver is suffering from severe to very severe burden and at a very high risk of physical psychosomatic symptoms.

Table 3 Assessment of BSFC sum score for caregivers of individuals without dementia

BSFC SCORE	SUBJECTIVE BURDEN CATEGORIES	RISK OF PSYCHOSOMATIC SYMPTOMS	SAMPLE PERCENTAGE (N = 591)
0 - 41	none to mild	not at risk ⁴	61.4 %
42 - 55	moderate	increased risk ⁵	24.4 %
56 - 84	severe to very severe	at very high risk ⁶	14.2 %

Clinical Uses

As a Clinical Assessment

After completion, review the items with the caregiver to understand the caregiving situation. This will help both the caregivers and the BSFC administrator to gain a better

⁴ Caregivers were identified as not at risk of psychosomatic symptoms when 50% of the caregivers showed a more than average degree of physical complaints and the other 50% showed an average degree or a lower than average degree of physical complaints

⁵ Caregivers were identified as having increased risk of psychosomatic symptoms when more than 50% of the caregivers showed a more than average degree of physical complaints (percentile norm greater than 50)

⁶ Caregivers were identified as at very high risk of psychosomatic symptoms when 90% of the caregivers showed a more than average degree of physical complaints (percentile norm greater than 50)

understanding of the caregiving situation and identify areas of concerns. Set service goals together to address specific needs. Use the BSFC sum score to determine the severity of the perceived burden and plan appropriate interventions accordingly.

As an Outcome Measure

You can use the BSFC as an outcome measure to evaluate changes of subjective caregiver burden after intervention. Administer the BSFC at least twice, once before and once after intervention to measure outcome. For longer-term services, repeat the BSFC during the service period to monitor changes over time.

Encourage caregivers to complete the re-assessment without referring back to the previously completed BSFC. Compare the BSFC sum score of the two assessments to determine changes. Because a lower BSFC score indicates less subjective burden, a reduction of sum score indicates a positive outcome following intervention.

Chapter 4. Psychometric Studies

One pilot study (Gräsel, 1995) and five full studies (Chiu, 2003; Gräsel, 1998a; Gräsel, 2001; Hecht et al., 2003; Holz, 1999) were conducted to examine the psychometric properties of the BSFC or give substantial information on psychometric criteria. Table 4 describes the study design, sample size, family caregiver characteristics, and purpose of each study.

In the following, the findings from these studies about the BSFC's inter-item correlation, factor analysis, internal consistency, reliability, validity, and sensitivity to changes are reported.

Inter-item Correlation

The inter-item correlation and the factor structure of the BSFC were tested in Study 2 (Gräsel, 1998a). The results supported a procedure of creating only one cumulative value rather than any subscores.

The analysis was conducted using two study groups, a group of caregivers who took care of individuals with dementia and a group of caregivers of non-dementia care-receivers.

In the dementia group the inter-item correlation lied in the range of minus .21 and plus .55. Only 1.6% of all correlation coefficients were negative, and 63.5% were positive with a value of greater than .20.

In the non-dementia group the inter-item correlation range stretched from minus .13 to plus .57. Among the coefficients, 3.5% were negative, while 76.5% were positive with a value of greater than .20.

Study 6 also examined the inter-item correlation of the BSFC. The results showed that the inter-item correlation ranged from minus .10 to plus .69. Only .8% of the correlation coefficients were negative, and 74.9% were positive with a value greater than .20.

Factor Analysis

A factor analysis of the correlation structure of the BSFC items was conducted in Study 2 (Gräsel, 1998a). The analysis was conducted in two caregiver groups, one for caregivers of individuals with dementia and the other for caregivers of care-receivers without dementia.

In the dementia group, the one factor solution resulted in 16 high-loading items, with a factor loading greater than .50 and 6 moderate-loading items, with a factor loading greater than .45 and less than .50 (Table 5). In the non-dementia group the one factor solution had 19 high-loading and 3 moderate-loading items.

Table 4 Designs of the BSFC studies

STUDY DESIGN	SAMPLE SIZE BY REASON OF CAREGIVING			CHARACTERISTICS OF CAREGIVER			TESTING
	Dementia	Non-dementia	Total	Age ⁷	% female	Mean years as caregiver	
1 Cross-sectional survey (Gräsel, 1995)	51	69	120	59 ± 13	61	3 ± 1	Reliability Validity
2 Cross-sectional (Gräsel, 1998a; Gräsel, 1998b)	1272	639 neurological (n=354) geriatric (n=277)	1911	58 ± 12	83	3 ± 2	Inter-item correlation Factor analysis Reliability
3 Longitudinal study (Holz, 1999)	42	65	107	58 ± 12	91	8	Sensitivity to change Validity
4 Test retest (Gräsel, 2001)	12	11	23	51 ± 6	91	3 ± 2	Reliability
5 Cross-sectional survey (Hecht et al., 2003)	0	37 ⁸	37	57 ± 13	73	2 ± 2	Validity
6 Outcome study (Chiu, 2003)	63	36	99	NA ⁹	NA	NA	Inter-item correlation Factor analysis, Validity Sensitivity to change

⁷ Mean ± standard deviation

⁸ Probable or definite Amyotrophic Lateral Sclerosis

⁹ not assessed

Table 5 Factor loadings of the BSFC items (principal components factor analysis without rotation)

ITEM	Factor matrix (one factor solution)	
	DEMENTIA GROUP (N = 1143)	NON-DEMENTIA GROUP (N = 548)
Tiredness	.49	.51*
Discontentment	.70*	.72*
Physical exhaustion	.66*	.68*
Desire to escape	.66*	.70*
Communication deficit	.49	.48
Lack of time for own interests	.45	.58*
Feeling of being used	.57*	.56*
Inability to relax	.52*	.56*
Difficulty in providing care	.48	.47
Feelings of depersonalization	.71*	.73*
Too little recognition for care given	.42	.44
Decrease in living standard	.56*	.60*
Pressurized into caregiver role	.46	.49
Inappropriate demands/expectations	.37	.44
Not in control of care-situation	.37	.40
Negative effect on health	.70*	.70*
Lack of joy	.53*	.53*
Relinquishment of future plans	.48	.53*
Discomfort at outsiders witnessing care-situation	.21	.06
Emotionally drained from caring	.62*	.65*
Being torn between conflicting demands	.67*	.68*
Diminished relationship with patient	.35	.37
Problems with family	.50*	.53*
Need to take a break	.61*	.61*
Anxiety about future	.64*	.65*
Relationship to others are suffering	.67*	.67*
Sadness about patient	.21	.30
Difficulty in fulfilling other daily obligations	.54*	.55*
Percent of the total variance	29.1%	31.5%

* values $\geq .50$

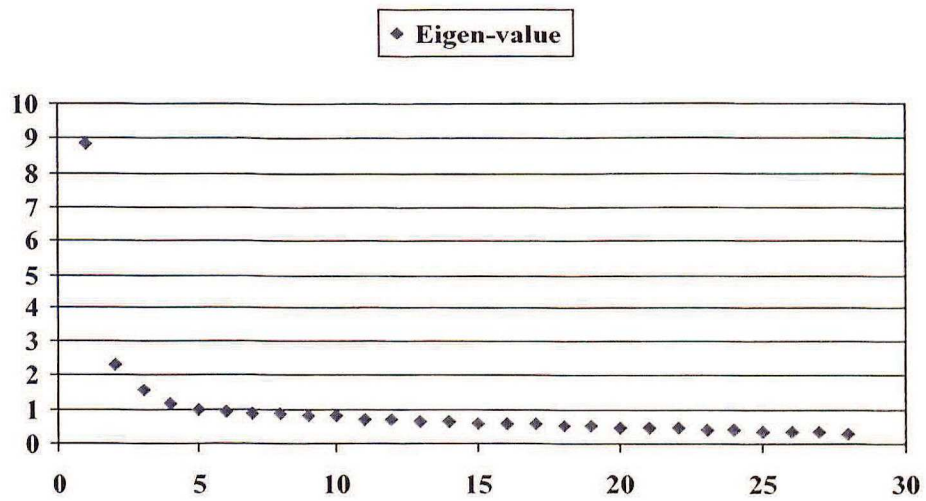


Figure 2 Diagram of factors ordered according to the size of their Eigen-value (non-dementia group)

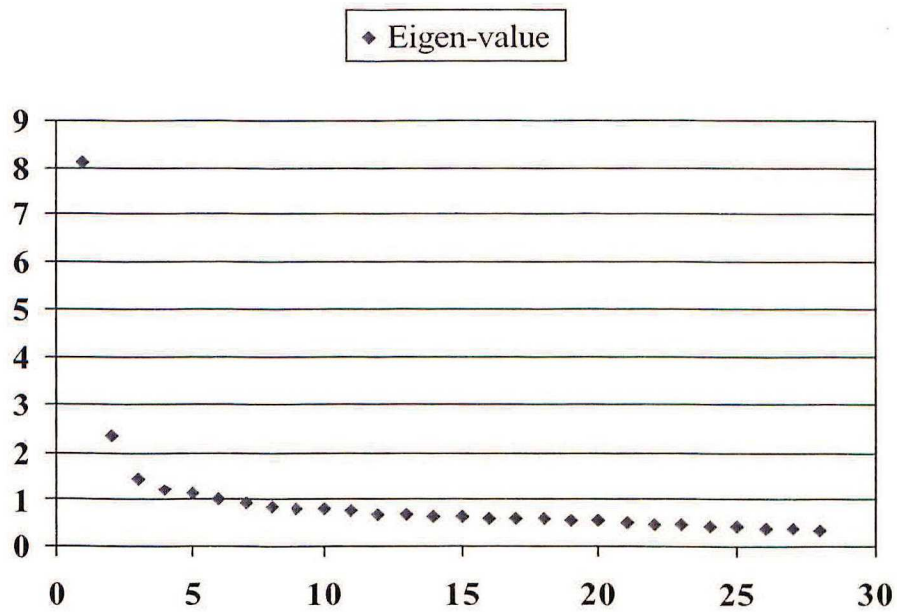


Figure 3 Diagram of factors ordered according to the size of their Eigen-value (dementia group)

The findings indicated that the same 22 items were loaded to one factor in both groups. It incorporated almost 4/5 of all items. The results produced one conspicuous factor - a "general factor" of subjective burden in both caregiver groups (Figures 2 and 3).

Similar results were found in the factor analysis in Study 6. A one-factor solution that explained 35% of variance was extracted. There were 18 high-loading items, with a factor loading greater than .50 on the one-factor solution; and 2 moderate-loading items, with a factor loading greater than .45 and less than .50.

Split-Half Reliability

In Study 1 (Gräsel, 1995), split-half reliability was calculated from 120 survey respondents who were caregivers of individuals with dementia and other health problems (stroke, Parkinson's disease, multiple sclerosis, and internal-medical geriatric diseases). In Study 2 (Gräsel, 1998a; Gräsel, 1998b) these coefficients were based upon data of 1911 caregivers of dementia and non-dementia patients. Table 4 shows the characteristics of the caregivers.

The split-half reliability attained values higher than .80. The Cronbach's alpha ranged from .90 to .91 (Table 6). Out of the 28 items, 27 discriminated significantly between caregivers with low and high burden because Spearman's correlation coefficient between item score and summed score if item deleted was significant. Only in the case of item 19 (Discomfort at outsiders witnessing care-situation) the Cronbach's alpha if item 19 was deleted was higher than the Cronbach's alpha if item 19 was not deleted.

Table 6 Split-half reliability of the BSFC

STUDY	CRONBACH'S ALPHA	SPLIT-HALF COEFFICIENT (odd-even method)
1	.91	.80
2	.90 (dementia group)	.88 (dementia group)
	.91 (non-dementia group)	.90 (non-dementia group)

Test-Retest Reliability

Study 4 (Gräsel, 2001) examined the test-retest reliability. This test criterion of the BSFC was obtained based on two self-help groups for family caregivers (Table 4). A total of 23 individuals participated in the repeated tests immediately prior to group meetings¹⁰. When, after fourteen days, the test was repeated with the initial respondents, the test-retest reliability proved to be .94.

¹⁰ Three of the respondents had to be excluded from calculation of the reliability coefficient. In these cases, serious changes in the caring situation had taken place between the first and the second test (the death of the care-receiver, suicidal intentions of the care-receiver, retirement of the caregiver).

Construct Validity

The construct validity of the BSFC was examined in Study 1. The hypothesis of the construct validity was: a positive relationship exists between perceived stress and perceived burden since burden as a result of caregiving represents a specific stressor. Perceived stress was measured using the Perceived Stress Scale, PSS (Cohen et al., 1983). The results showed that the PSS scores of 117 caregivers were positively correlated to the BSFC sum score. Pearson's correlation coefficient was .56 ($p < .001$) (Gräsel, 1995).

Criterion-Oriented Validity

In the literature, there is general agreement that disturbances in the patient's social behavior (for example, restlessness, aggressiveness) create significant levels of stress for family caregivers (Gold et al., 1994; Reis et al., 1994). The following hypothesis was tested in Study 2 (Gräsel, 1998a): the extent of disturbance in the patient's social behavior is positively correlated with the caregiver's subjective burden. Behavioral disturbances were measured with the Sandoz Clinical Assessment - Geriatric, SCAG (Shader et al., 1974). The results showed that the SCAG sum score was significantly correlated with the BSFC sum score in two caregiver groups, the dementia and the non-dementia group. Table 7 shows the univariate and multivariate coefficients.

In the literature, there is however also general agreement that there is no significant correlation in multivariate analyses between the extent of subjective burden and the number of years as caregiver (Kramer & Kipnis, 1995; Thompson et al., 1993). Table 7 shows the very low correlation between years as caregiver and BSFC sum score, which supports (for both groups) the literature findings.

Table 7 Aspects of criterion-oriented validity of the BSFC score in the dementia and in the non-dementia group

GROUP	RELATIONSHIP BETWEEN BSFC SCORE AND			
	Behavioral disturbances		Years as caregiver	
	univariate ^{a)}	multivariate ^{b)}	univariate ^{a)}	multivariate ^{b)}
	R	β	R	β
Dementia	.39***	.34***	.10***	.07
Non-dementia	.44***	.34***	.03	.02

* $p < .05$ ** $p < .01$ *** $p < .001$

^{a)} Pearson's correlation coefficient

^{b)} stepwise multiple regression analysis with the BSFC score as dependent variable and 26 independent variables (Gräsel, 1998a)

In Study 5 (Hecht et al., 2003) only patients with Amyotrophic Lateral Sclerosis (ALS) were included. ALS is a neurodegenerative disorder with unique clinical signs and symptoms. It is characterised by progressive immobility and weakness leading to death

by respiratory insufficiency. Functional disability (mobility, activities of daily living, and respiratory status) was measured with the ALS Functional Rating Scale, ALS-FRS (ALS CTNF Treatment Study Group, 1996). Spearman's correlation coefficient between ALS-FRS sum score and BSFC sum score was minus .47 ($p = .003$). The heavier the functional disability of the ALS patient occurred the greater the subjective burden of the caregiver resulted.

In the same study the Cost of Care Index, CCI (Kosberg et al., 1990) was used to measure specific components of subjective burden. The BSFC sum score correlated significantly with four of the five burden components of the CCI (Table 8). Thus it shows a high comparability of the BSFC sum score with the burden scores of the CCI (Hecht, 2003, personal communication).

Table 8 Correlation coefficients of the BSFC sum score with the Cost of Care Index

COST OF CARE INDEX SUBSCORES	SPEARMAN'S CORRELATION COEFFICIENT WITH THE BSFC SUM SCORE	
	r	p
Physical and emotional problems	.86	< .0005
Perception of the cared person as a provocateur ¹¹	.80	< .0005
Personal and social restrictions	.80	< .0005
Economic costs	.46	= .005
Value investment in caregiving	.34	= .038

In Study 6, the relationship between perceived caregiver competence and BSFC sum score was examined. Caregiver competence was measured using the one-item Caregiver Competence Scale (CCS) developed for this study. It was hypothesized that caregivers who perceive themselves as being more competent would have a lower BSFC score, showing a lower level of perceived burden. Spearman's correlation coefficient between the CCS and BSFC sum score was .43 ($p < .0001$), indicating that there is a moderate correlation between perceived caregiver competence and perceived caregiver burden (Chiu, 2003).

Sensitivity to Change

A nine-month longitudinal study (Holz, 1999) demonstrated the ability of the BSFC sum score to indicate changes in the subjective burden arising from significant changes in the care situation or from intervention measures. In this intervention study (without a control group) family caregivers (Table 4) were given a three-week period of rehabilitation aimed at stabilizing the health of the caregivers and giving them psychosocial support. Depression, mood, and physical complaints were identified at the beginning of the

¹¹ Provocateur is a care-receiver who displays irritating behaviors on the caregivers.

treatment (measuring-point T1), at the end of the treatment (T2), four weeks after the treatment (T3), and nine months after (T4). The subjective burden of caregivers was measured at T1, T3 and T4, that is, at the points at which those tested were currently caring. With regard to the sensitivity to change of the BSFC sum score, the following results are to be reported.

The analysis of variance ($N = 64$ individuals with complete data) demonstrated a statistically significant main effect in the factor time ($F = 6.2, p < .01$). This main effect can be traced to differences in mean values between T1 and T3 ($F = 9.3, p < .01$) and between T1 and T4 ($F = 8.3, p < .01$). In other words: rehabilitation of family caregivers resulted in a significant reduction in caregiver burden and this is still the case nine months later (Holz, 1999).

The change in the subjective burden (the difference between the BSFC sum scores T1 – T4) is a significant predictor for the extent of alteration in mood ($p = .016$) and physical complaints ($p = .047$) after the period of rehabilitation (difference T2 – T4) and broadly predicts the change in depression ($p = .060$) (method: multifactorial covariance analyses; (Holz, 1999).

Study 6 was an outcome study applying a pretest-posttest design. The BSFC was used to measure changes of caregiver burden following home-based occupational therapy services in Toronto (Ontario, Canada) (Chiu, 2003). Occupational therapists visit the clients' home to conduct assessment and provide intervention to both clients and their family caregivers. Practical strategies include prescribing equipment, linking to community resources, teaching proper transfer techniques, creating a safer living environment, educating caregivers about the disease process and advising them on behavior management to help caregivers to improve their caregiving situation.

The results of the 41¹² pretest-posttest BSFC observations showed a mean initial BSFC sum score of 42.2 ($SD = 15.0$), a mean reassessment sum score of 36.4 ($SD = 13.0$), and a mean change of 5.8 (Figure 4), which was statistically significant (paired t-test, $t = 3.2, df = 40, p = .002$). The results demonstrated that caregivers' perceived burden was reduced following intervention.

¹² Out of the 99 caregivers who completed the initial BSFC, only 41 BSFC reassessments were available for analysis. Some caregivers were still receiving services at time of writing this manual, and some did not complete the reassessment at discharge.

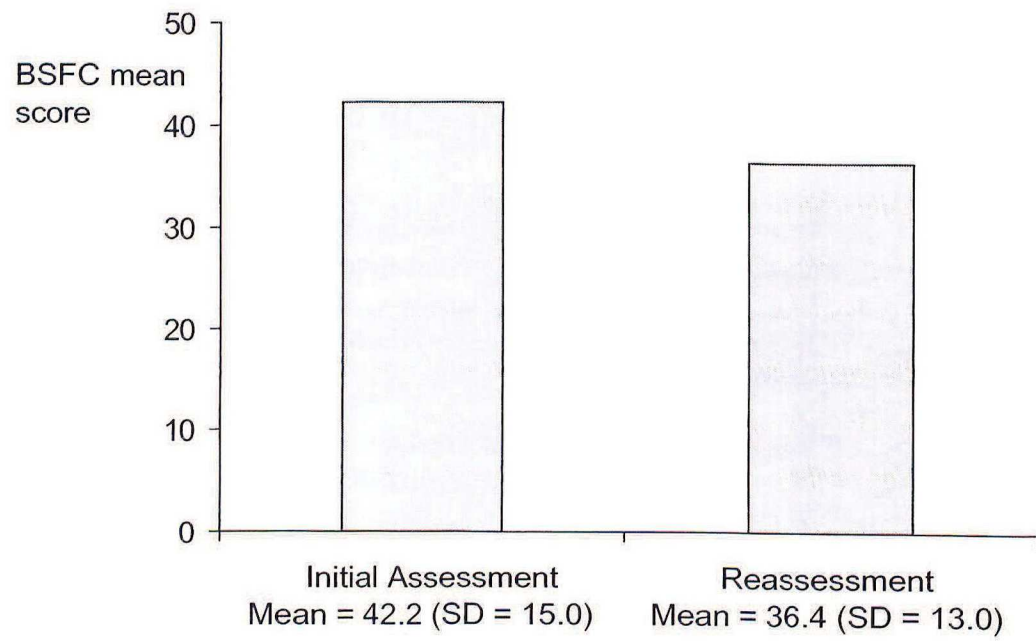


Figure 4 Mean BSFC scores before and after Occupational Therapy home-based services

Chapter 5. Conclusion

The 28-item BSFC is a scientifically developed instrument designed to measure the subjective burden of family caregivers. It is completed by family caregivers and can be used as a research or clinical tool. The assessment results provide information about the risk for negative effects on the caregiving situation and on the caregivers' health because of caregiving burden. Older adults living in the community often need their family to take care of them, and family caregivers experience more caregiving burden when the older adults begin to have health and/or functional problems. Clinicians can use the BSFC to plan appropriate interventions for family caregivers, and researchers can use it to evaluate the service outcomes of caregiver support programs. These uses of the BSFC can help to improve not only family caregivers' health and well-being but also their care-receivers' health and quality of life.

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