

Chapter 10: Patient-reported Health Instruments: Carer Impact

The impact of a disease on a patient is an increasingly important outcome measure in medicine and healthcare. Issues such as quality of life are now widely used in clinical trials and in patient management for assessing morbidity and the impact of treatment. For a long time, studies focused almost exclusively on changes in the impact of ill health on patients, but increasing attention is now being paid to the impact on carers of patients with chronic diseases.

Carers (or caregivers) play an important role in the care of chronically ill patients, as the number of people with chronic illnesses is increasing and informal and community care outside of acute services is increasingly encouraged. Carers tend to be family members (often the spouse) or friends, who are called upon to provide significant and continuous support to the person with ill health. It is being increasingly recognized that caring for someone with ill health poses challenges and can represent a stressful and difficult situation to the carer with adverse physical and psychological outcomes for the caregiver.

Two different approaches have been used to study carer burden. The first approach, which is an indirect approach, uses generic instruments as proxy measures such as the SF-36. Generic instruments have usually been extensively tested, although not necessarily in the carer population. They provide a broad perspective of health, but they do not give an insight into carers' specific problems. The second approach, which is direct, investigates the carers' experience, focusing specifically on the content of carers' experiences. It uses either instruments that have been developed for carers generally (hereafter referred to as general carer instrument) or instruments that have been developed for people caring for a person with a specific condition (hereafter referred to as disease-specific carer instrument). An example of a general carer instrument is the Carer Strain Index. These instruments provide a more specific measure of the carer-specific burden. However, these instruments are not specific to a particular disease group, and as such may not capture all the relevant issues for a person caring for a patient with a particular condition. Thus, a number of disease-specific carer instruments have also been developed, for example, the Parkinson's Impact Scale (PIS).

Instruments that have been used to assess carer burden also vary in terms of their dimensions, with some instruments investigating multiple dimensions (including for instance, physical health, psychological health, social roles), and other instruments being dimension-specific (e.g. fatigue, depression). Caregiver well-being has traditionally been considered from a deficit perspective and little attention has been paid to positive aspects of caregiving (Berg-Weger and Tebb 1998) and increasingly some instruments also focus on positive aspects of caregiving.

This review reports the psychometric properties of generic and carer-specific instruments that have been used in people who care for people with ill health. This review does not discuss dimension-specific or disease-specific instruments. Furthermore, the focus of this review is on caregiving for adults with ill health, not for children (either healthy or with ill health) or healthy elderly. The review only includes articles published in English with data from English speaking populations (UK, USA, Canada, Australia and New Zealand).

RESULTS: Patient-reported Health Instruments: Carer impact

Search terms and results: identification of articles

At the time of the review, the PHI database contained 12,000+ records (up to June 2005). Search results are detailed in table 10.1. When assessed against the review inclusion criteria, 44 articles were retrieved and reviewed in full. Of these, 26 articles were included in the review.

Table 10.1

Source	Results of search	No. of articles considered eligible	Number of articles included in review
<i>PHI database: original search (up to June 2005)</i> <i>Total number= 12.562</i>	129	44	26
<i>Supplementary search</i>	-	-	49
TOTAL	-	-	75

Supplementary searches included hand-searching of titles from 2004 to 2006 of the following key journals:

- Health and Quality of Life Outcomes
- Medical Care
- Quality of Life Research

Further searches were conducted within the bibliography and using Pub Med per instrument up to September 2006.

Identification of instruments

Five indirect measures in the form of generic health instruments were included in the review, together with 26 general carer instruments. The developmental and evaluative studies relating to the generic health instruments reviewed are listed in Tables 10.2 to 10.6. Those relating to general carer instruments are shown in Tables 10.7 to 10.17. Table 10.18 includes examples of carer disease-specific instruments.

RESULTS: GENERIC INSTRUMENTS (INDIRECT APPROACH)

Five generic instruments were identified which were evaluated for use to assess carer impact. Full details of the development, domains and scoring methods are detailed in Chapter 3.

The following instruments measurement properties are reported:

- a) SF-36 and SF-12
- b) Health Utilities Index Mark 2
- c) Reintegration to Normal Living Index
- d) Ferrans and Power Quality of Life Index
- e) General Health Questionnaire

a) SF-36 and SF-12

Reliability

Good internal consistency for the SF-36 overall was reported in studies by Jenkinson et al., (2000); Berg-Weger et al., (2003) and for the Physical Component Subscale (PCS) and Mental Component Subscale (MCS) in a study by Clark et al., (2004). One study found adequate internal consistency for the other subscales (Berg-Weger et al., 2003), whereas another found good internal consistency for the different SF-36 subscales (Cameron et al., 2006b).

The SF-12v2 has been found to have weak internal consistency for a sample of carers of dementia patients (McConaghy and Caltabiano 2005).

Validity

Convergent and discriminant validity

Depression, measured by the Centre for Epidemiologic Studies-Depressed Mood Scale, was found to be significantly related to the Physical Health and Mental Health domains of the SF-36 (Berg-Weger et al., 2003). In the same study, anxiety (assessed by the Self-rating Anxiety Scale) was also significantly negatively related to Physical Health and Mental Health, and physician's visits. Visits to mental health professionals were only significantly and negatively related to The Mental Health summary score. There was also moderate discriminative validity, as alternative mental health measures correlated more strongly with the Mental Health subscale than with the Physical Health subscale. On the other hand, alternative measures of physical health correlated more strongly with the Physical Health subscale.

Internal validity

Factorial analysis supported the original structure of the SF-36 in a study by Berg-Weger et al., (2003).

Predictive validity

One study found support for the predictive validity of the SF-36, with particularly the Vitality Scale being a predictor of stroke carer stress (Smith et al., 2004).

Socio-demographic variables

The scores on the SF-36 for carers have been found to be below those for the general population in studies by Jenkinson et al., (2000) and Cameron et al., (2006b). The scores on the SF-12 have also been found to be slightly below the general norms (Clark et al., 2004). In a further study, carer scores were reported to be lower than population norms on the Energy and Vitality scales (Smith et al., 2004).

Generic carer instruments

The PCS and MCS has strong correlations with the Caregiver Strain Index (CSI), supporting construct validity in a study by Jenkinson et al., (2000).

Responsiveness

No data available.

Precision

Some floor effects have been found for the SF-36 for carers for the Role Physical (19.3%) and Role Mental (23.4%), as well as some ceiling effects (50.6% and 49.0% respectively) (Jenkinson et al., 2000).

Acceptability

No data available.

Feasibility

The survey was administered by telephone interviews in a study by Berg-Weger et al., (2003), reporting 30 minutes completion time.

Table 10.2: Evaluative studies relating to the SF-36 when completed by carers of people with ill health

Study/ Country	Population (N) Age (years) Method of administration Setting	Measurement and Practical properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
SF-36							
Berg-Weger et al., 2003 USA	Adult daughters who had been primary caregivers to a parent with Alzheimer Disease or a related disorder, who had died at least 12 months before the study (102) Age 57 years Telephone interview Alzheimer Association members	√	√ Factorial validity Convergent and discriminant validity				
Clark et al., 2004 USA	Family caregivers of stroke survivors (132) SF-36v2 mental and psychical scales Age 56.7 Sampled from a sample of a national, multi-site clinical trial Interviewer administered	√					
Smith et al., 2004 UK	Carers of stroke patients (90) and stroke patients Age 57.8 Patients identified from 2 hospital stroke registers		√ Predictive				
Jenkinson et al., 2000 Multi-national including the UK	Carers of patients with amyotrophic lateral sclerosis (415) Age 55.1 years Carers of patients recruited through 74 clinical sites throughout Europe Self-administered	√	√			√	
Cameron et al., 2006b Canada	Caregivers of patients with acute respiratory distress syndrome	√					
SF-12v2							
McConaghy and Caltabiano 2005 Australia	Carers of people with dementia (42) Age 62.0 years Self-completion questionnaire Self-administered or face to face interviews	√					

b) HUI 2

Reliability

No data available.

Validity

One study evaluated criterion validity of HUI 2 in carers of patients with Alzheimer Disease (Bell et al., 2001) by comparing HUI 2 to a caregiver time questionnaire, a caregiver burden instrument and the SF-36. It was found that the HUI 2 may not adequately capture differences in the burden of caregivers for patients with Alzheimer Disease.

Responsiveness/ Precision/ Acceptability/Feasibility

No data available.

Table 10.3: Evaluative studies relating to the HUI 2 when completed by carers

Study/ Country	Population (N) Age (years) Method of administration Setting	Measurement and Practical properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Bell et al., 2001 Canada	679 caregivers of individuals with Alzheimer Disease 63 years Interviewer administered questionnaire		√				

c) RNLI

Reliability

Good internal consistency has been found for the RNLI in a study by Bluvol and Ford-Gilboe (2004).

Validity/ Responsiveness / Precision/ Acceptability

No data available.

Feasibility

The questionnaires (the RNLI, which has 11 items, plus 2 more questionnaires) took 30-40 minutes to complete in a study by Bluvol and Ford-Gilboe (2004).

Table 10.4: Evaluative studies relating to the RLNI when completed by carers

Study/ Country	Population (N) Age (years) Method of administration Setting	Measurement and Practical properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Bluvol and Ford- Gilboe 2004 Canada	Carers (40) and stroke patients (40) Age carers 66.2 Self-completion questionnaire	√					√

d) FPQLI

Reliability

High internal consistency was found for the Total instrument and moderate to high alphas for the Life domains (Weitzner et al., 1997).

Validity

Socio-demographic variables

Caregiver age was significantly correlated with the Health/functioning and Psychological/spiritual domains, as well as the Total score in a study by Weitzner et al., (1997).

Responsiveness/ Precision/ Acceptability/ Feasibility

No data available.

Table 10.5: Evaluative studies relating to the FPQLI when completed by carers

Study/ Country	Population (N) Age (years) Method of administration Setting	Measurement and Practical properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Weitzner et al., 1997 USA	Caregiver of cancer patient (22) Age 51.7 Interviewer administered	√					√

e) GHQ

Reliability

No data available

Validity

Discriminative validity

There was a non-significant trend in GHQ Total scores and Depression subscales scores to be higher for carers using Admiral Nurse (AN) teams vs. carers who did not (Woods et al., 2003). On follow-up, a significant difference was found on the Anxiety and Insomnia subscale, where outcome was better for the AN group. Another study showed that carers of dementia patients showed higher levels of distress as measured by GHQ than carers for patients with depression (Rosenvinge et al., 1998).

Furthermore, significant differences in GHQ scores have been found between carers of people with anorexia and psychosis (Treasure et al., 2001). GHQ scores have also been found to differ in carers of people with a head injury according to different time intervals post-injury. The GHQ scores were higher for carers of people with a recent head injury, which indicates greater burden in this group (Sander et al., 1997).

Predictive validity

Coping style has been found to contribute significantly to GHQ score variance, with emotion-focused coping being related to GHQ scores in a study by Sander et al., (1997). Furthermore, coping accounted for more of the GHQ variance than disability scores.

Socio-demographic variables

Gender has been found to have a significant effect on GHQ scores, but neither race nor relationship to the injured person had a significant effect (Sander et al., 1997).

Dimension-specific variables

Strong positive correlations were found between the GHQ and the Relatives Stress Scale (Draper et al., 1992).

Responsiveness

The GHQ-28 has been shown to be responsive to change in a study using cognitive behavioural therapy in carers of Parkinson's disease patients. Both the Total score and the scores for 3 of the sub-scales decreased in response to the intervention (Secker and Brown 2005). Both conventional and AN services led to lower GHQ scores overall and 2 of the 4 subscales over an 8-month period (Woods et al., 2003).

Precision/ Acceptability/ Feasibility

No data available.

Table 10.6: Evaluative studies relating to the GHQ when completed by carers

Study/ Country	Population (N) Age (years) Method of administration Setting	Measurement and Practical properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Draper et al., 1992 Australia	Co-resident carers of dementia (51) and stroke patients (48) Age stroke 72.0 and dementia 76.0 Self-completion		√				
Sander et al., 1997 USA	Carers of patients with head injury (60) 3 groups corresponding to 3 post-injury intervals: early (26), intermediate (21) and long-term (22) Age 'early' 39.1, 'intermediate' 45.8 and 'late' 45.1 Self-completion		√				
Rosenvinge et al., 1998 UK	Carers of patients with dementia (32) or depression (25) Age 67.8 for dementia carers 66.8 for depression carers Interviewer administered		√				
Treasure et al., 2001 UK	Carers of patients with anorexia (71) or psychosis (68) Interviewer administered		√				
Woods et al., 2003 UK	Carers of people with dementia (128, of which 55 used an admiral nurse (AN) service and 73 did not (comparison group)) Age 62.4 for AN group and 58.8 for comparison group Interviewer administered		√	√			
Secker and Brown 2005 UK	Carers of patients with Parkinson's (30) Age 59.1 for treatment group (n=15) and 58.8 for control group (n=15)			√			

RESULTS: DIRECT MEASURES OF CARER IMPACT

Eight instruments that investigate the carers' general burden have been identified. Full details of the development, domains and scoring methods are detailed in Tables 10.7 and 10.8.

The following instruments measurement properties are reported:

- a) Appraisal of Caregiving Scale
- b) Bakas Caregiver Outcomes Scale
- c) Caregiver Burden Inventory
- d) Caregiveing Burden Scale
- e) Caregiver Impact Scale
- f) Caregiver Strain Index
- g) Caregiver Well-Being Scale
- h) Zarit Burden Interview

a) Appraisal of Caregiving Scale (ACS)

The ACS has been developed in the USA with carers of cancer patients receiving radiotherapy. The ACS is a 53-item instrument that measures the meaning of illness-caregiving situation in terms of the intensity of four dimensions (Harm/loss, Threat, Challenge and Benign).

b) Bakas Caregiver Outcomes Scale (BCOS)

The BCOS was developed to measure changes in caregiving outcomes. The BCOS is a unidimensional scale based on 10 items and addresses changes in caregiving social functioning, subjective well-being and physical health. It was first developed and evaluated in carers of stroke survivors in the USA.

c) Cargiver Burden Inventory (CBI)

The CBI is a 25 item instrument with 5 subscales that was developed in carers of confused or disoriented older people in Canada. The CBI aims to give a reading of caregivers' feelings and a picture of the carers' responses to the demands of caregiving.

d) Caregiver Appraisal Scale (CAS)

The CAS was designed as a 47-item interview questionnaire for caregivers of disabled elderly. The CAS has five domains of caregiving appraisal: Caregiving satisfaction, Perceived caregiving impact, Caregiving mastery, Caregiving ideology and Subjective caregiving burden.

e) Caregiver Impact Scale (CIS)

The CIS was developed in Canada in carers of cancer patients and is based on the Illness Intrusiveness Rating Scale by (Devins et al., 1983). The CIS assesses the extent to which providing care interfered with the caregiver's participation in 14 domains of lifestyle (such as health, employment, recreation).

f) Caregiver Strain Index (CSI)

The CSI was developed in the USA to measure caregiver reactions, including perception and emotional feeling with regards to caregiving. It includes 13 items and was developed in caregivers of patients, aged 65 or over, who had recently been hospitalized for hip surgery or heart problems. At a later stage it was modified, to include a 'sometimes' response category, rather than just the 'yes/no' response options and some items were rephrased.

g) Caregiver Well-Being Scale

The Caregiver Well-Being Scale was developed in the USA in a sample of caregivers of older adults with dementia, caregivers of children with developmental problems and caregivers of healthy children who were younger than 12 years of age. The scale has also been evaluated in a sample of caregivers of chronically ill patients. It includes 45 items, with 2 subscales: Basic Human Needs and Activities of Daily Living. The scale identifies the caregivers' strengths in meeting their basic needs and daily activities.

h) Zarit Burden Interview (ZBI)

The Zarit Burden Interview assess the degree to which a caregiver perceives their caregiving responsibilities to have a negative effect on their health, personal and social life, finances and emotional well-being. Different versions of the ZBI are available, the 22-item full version and the 12-item short version. The ZBI was developed and tested in carers of patients with dementia in the USA.

Table 10.7: General carer instruments

<i>Instrument (no. items)</i>	<i>Domains (no. items)</i>	<i>Response options</i>	<i>Score</i>	<i>Administration/ Completion (time)</i>
Appraisal of Caregiving Scale (53)	4 domains harm/loss (15 items) threat (15 items) challenge (15 items) benign (8 items)	5 point Likert Scale 1= very untrue, 5= very true	Higher scores on each subscale represent greater intensity of the appraisal dimension	Self-completion 20 minutes
Bakas Caregiving Outcomes Scale (10)	Unidimensional	7-point Likert scale 1=changed for the worst, 7=changed for the best		Self-completion or interviewer administered
Caregiver Burden Inventory (24)	5 domains: developmental, physical, social, emotional burden and time dependence	5 point Likert scale 0=strongly disagree, 4=strongly agree	Items for each domain are summed. Domain scores range from 0-20, except for physical burden (0-16). For physical burden the summed score is multiplied by 1.25 to give an equivalent score out of 25	Self-completion or interviewer administered
Caregiving Impact Scale	14 domains of caregivers' lifestyle	7-point Likert scale 1=not very much, 6=a lot	Summation of items with higher scores indicating higher interference	Self-completion or interviewer administered
Caregiving Appraisal Scale (original 47, later 35)	5 domains (47 items): caregiving satisfaction, perceived caregiving impact, caregiving mastery, caregiving ideology and subjective caregiving burden. 4 domains (35 items): perceived burden (15), caregiver relationship (11) satisfaction, caregiver ideology (5) and caregiving mastery (4)	Self-completion questionnaire uses 5 point scale 1= strongly disagree and 5=strongly agree	For 35 item instrument: Scores calculated by summing individual domain scores, using reversed scoring for certain items.	Interview or self-completion
Carer Strain Index (CSI) (13 items)	Unidimensional		0-100 (lowest to highest level of strain)	Self-completion or interviewer administered 15-45 minutes
Caregiver Well-Being Scale (45 items)	Basic human needs (4 factors and 22 items) Activities of daily living (5 factors and 23 items)			Self-completion
Zarit Burden Interview (Original 29, full version 22 items, short version 12 items)	For 12 item short version Personal strain (9) Role strain (3)	5-point Likert style 0=never and 4=nearly always	0-88 with higher scores a greater burden	Interviewer administered

Table 10.8 summarizes the domains included in the different instruments. However, some general carer instruments do not include these domains as such, but include items that reflect these domains. For example, the CSI is unidimensional. Another example is the CAS which does not include a ‘social well-being’ domain, but within the ‘perceived burden’ domain several items relate to social well-being such as ‘my social life has suffered’ or ‘I feel isolated and alone’. Other domains found in general caregiving instruments are not reflected in the health status domains by Fitzpatrick et al. (1998), such as the domain of ‘caregiving mastery’ of the CAS, which includes items on how well the carer copes with caring or ‘time-dependence burden of the Caregiving Impact Scale, which describes burden due to restrictions of caregivers time. Also, some domains (symptoms, cognitive function and treatment satisfaction) from Fitzpatrick et al. (1998) are of less relevance for carer instruments.

Table 10.8: Summary of carer-specific instruments: health status domains (*after Fitzpatrick et al., 1998*)

<i>Instrument</i>	<i>Instrument domains</i>								
	Physical function	Symptoms	Global judgement	Psychol. well-being	Social well-being	Cognitive functioning	Role activities	Personal construct	Treatment satisfaction
Appraisal of Caregiving Scale	x			x	x		x		
Bakas Caregiving Outcomes Scale (10)			x	x	x				
Caregiving Appraisal Scale (47/35)				x	x			x	
Caregiver Burden Inventory (24)	x			x	x				
Caregiving Impact Scale (14)			x		x		x		
Carer Strain Index (13)	x			x	x		x		
Caregiver wellbeing scale (45)	x			x	x		x	x	
Zarit Burden Interview (29, 22, 12 or 4)			x	x	x		x		

RESULTS: CARER IMPACT

a) Appraisal of Caregiving Scale (ACS)

Reliability

Two studies have found the ACS sub-scales to be internally consistent (Oberst et al., 1989; Carey et al., 1991).

Validity

Strong correlations were found between the Harm/loss and Threat subscales, indicating that they may represent the same construct (Oberst et al., 1989). Also, the high correlation between the challenge and benign subscales represent a problem.

Socio-demographic variables

Each of the four sub-scales was related to at least one other caregiver variable (Oberst et al., 1989). Harm/loss scores were correlated with the carer's level of education, social status and health status. Threat scores were correlated with the carer's level of education and social status. Challenge and benign scores were correlated with caregiver age. Benign scores were related to the carer's perception of the illness (as more or less serious).

Patient variables

Correlations were also found with various patient variables (Oberst et al., 1989). Harm/loss scores for carers were related to the length of time patients received radiation. The carer's relationship to the patient was also related to the benign subscale, with those caring for a parent perceiving the situation as less benign than those caring for a spouse or others.

Table 10.9: Developmental and evaluation studies relating to the Appraisal of Caregiving Scale:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Oberst et al., 1989	Family members of cancer patients receiving radiotherapy.(47) Age 53.3 USA Self-completion	√	√				
Carey et al., 1991	Family caregivers of patients receiving outpatient chemotherapy (49) USA Self-completion	√					

b) Bakas Caregiver Outcomes Scale

Reliability

Good internal consistency was found for both the 10 and 12 item BCOS in a study by Bakas and Champion (1999). High internal consistency for the 10-item BCOS was also found in two further studies (Bakas et al., 2004; Bakas et al., 2006). One study reported finding good test-retest reliability (0.66 for the 15-item BCOS and 0.68 for the 10-item BCOS) (Bakas et al., 2006). It was not clear whether the findings of test-retest reliability refer to group or individual comparisons.

Validity

Internal validity

Two studies report evidence on construct validity, by using factor analysis that supported unidimensionality of the BCOS (Bakas and Champion 1999; Bakas et al., 2006).

Generic health status

Significant weak to moderate correlations with LIFE-3 and with the SF-36 subscales were found in a study by Bakas and Champion (1999) and a significant weak correlation was found with the SF-36 General Health Subscale by Bakas et al., (2006).

Responsiveness/ Precision/ Acceptability/ Feasibility

No data available.

Table 10.10: Developmental and evaluation studies relating to the Bakas Caregiving Outcomes Scale:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Bakas and Champion, 1999 USA	Caregivers of stroke survivors (sample 1= 92, sample 2= 104) Age sample 1 60.5 and sample 2 62.2 Self-completion questionnaire	√	√				
Bakas et al., 2004 USA	Caregivers of stroke survivors (114) Age 60.5 Self-completion questionnaire	√					
Bakas et al., 2006 USA	Family caregivers of stroke survivors (147) (USA) Age 51.7 years Interviewer administered (face to face or telephone) or self-completed	√ Internal consistency Test-retest	√ Construct				

c) Caregiver Burden Inventory (CBI)

Reliability

The total CBI score (Foster and Chaboyer 2003) and the five subscales of the CBI have been found to be internally consistent in studies by Novak et al., (2001); and Foster and Chaboyer (2003).

Validity

Internal validity

The five factor structure was supported empirically in a study by Novak and Guest (1989).

Dimension-specific variables

The total CBI score, as well as 4 of the 5 subscales (with the exception of emotional burden), have been found to be significantly correlated to filial (family) obligation (Foster and Chaboyer 2003).

Responsiveness

The Total CBI score was responsive to change in carers of patients with Parkinson's disease receiving cognitive behavioural therapy after 3 months of therapy, compared to controls in a study by Secker and Brown (2005).

Precision/ Acceptability/ Feasibility

No data available.

Table 10.11: Developmental and evaluation studies relating to the Caregiving Burden Inventory:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Novak and Guest, 1989 Canada	Carers of confused or disoriented older people (107) Age 60.1 Interviewer administered	√	√				
Foster and Chaboyer, 2003 Australia	Carers of a family member who had been critically ill & admitted to intensive care (71) Age 50.3 Self-completion	√	√				
Secker and Brown, 2005 UK	Carers of patients with Parkinson's (30) Age 59.1 for treatment group (n=15) and 58.8 for control group (n=15)			√			

d) Caregiving Appraisal Scale

Reliability

Internal consistency was good for the three factors of the ACS for 2 different samples of carers (Lawton et al., 1989). However, it has to be noted that the 3 factors were different for the 2 samples. Internal consistency was good for three of the four factors (Struchen et al., 2002). Caregiving mastery showed poor internal consistency, but since the factor emerged from the analysis of 2 different cohorts, Struchen et al. (2002) believed that it was a significant construct of caregiver appraisal. Using two of the original subscales (perceived burden and impact of caregiving role), Dracup et al. (2004) found good internal consistency of these subscales.

Test-retest reliability was found to be reasonable in one of the samples investigated by Lawton et al (1989).

Validity

Construct Validity

Factor analysis has provided conflicting evidence of the structure of the CAS. Three factors found in a sample of carers of disabled elderly people in respite were not confirmed in a sample of carers of disabled elderly people in institutions (Lawton et al., 1989). Another study found a five-factor solution, but two factors (caregiving mastery and caregiving burden) were found to be less robust (Lawton et al., 1991). Another study concluded that factor analysis showed that the CAS has four subscales: perceived burden and caregiver satisfaction with their relationship to the patient, caregivers' ideology and caregiving mastery (Struchen et al., 2002). The four

factor solution was also found with 35 items (rather than the initial 47) and in different samples (carers of the traumatic brain injury model system and carers of the residential treatment programme cohort) (Struchen et al., 2002).

Generic health status

One of the factors (perceived burden) was significantly correlated to the GHQ, Subjective Burden Scale and Objective Burden Scale (Struchen et al., 2002). A negative significant correlation was found between caregiver relationship satisfaction and the Objective Burden Scale. However, this was a weak correlation.

Dimension-specific variables

The caregiving satisfaction subscale of the ACS was found to be significantly related to caregiving burden and caregiving burden was related to depression (Lawton et al., 1991).

Validity/ Responsiveness/ Precision/ / Feasibility

No data available.

Acceptability

Of 241 participants, 11 cases had more than one response missing (Struchen et al., 2002).

Table 10.12: Developmental and evaluation studies relating to the Caregiving Appraisal Scale:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Lawton et al., 1989 USA	Carers of disabled older people in respite care or in institutions (632) Age 59.7 respite care, 76.2 institutionalized care Interviewer administered	√	√				
Lawton et al., 1991 USA	Spouse (285) and adult child (244) carers of elderly people with Alzheimer's Disease Age 76.3 Interviewer administered		√				
Struchen et al., 2002 USA	Carers of person with traumatic brain injury (241) Age 47.0 Self-completion	√	√			√	
Dracup et al., 2004 USA	Spouses of patients with heart failure (75) Age 54.0 Self-completion	√					

e) Caregiving Impact Scale

Reliability

The CIS has been found to be internally consistent in two studies (Cameron et al., 2002; Cameron et al., 2006a).

Validity/ Responsiveness/ Precision/ Acceptability/ Feasibility

No data available.

Table 10.13: Developmental and evaluation studies relating to the Caregiving Impact Scale:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties						
		Caregiving Impact Scale	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Cameron et al., 2002	Family caregivers of cancer patients (44) Age 55.8 Interviewer administered	√						
Canada								
Cameron et al., 2006a	Informal carers of stroke survivors (94) Age 60.8 Interviewer administered or self-completion	√						
Canada								

f) Caregiver Strain Index

Reliability

Internal consistency

Four studies found the CSI Total score to be internally consistent (Robinson 1983; Berg-Weger et al., 2000; Jenkinson et al., 2000; Diwan et al., 2004). However, one study found internal consistency for 2 of the 3 subscales below 0.7 (Diwan et al., 2004). The modified CSI has also been found to be internally consistent (Thornton and Travis 2003).

Test-retest reliability

Test-retest reliability had not been investigated in the original CSI studies. However, in the modified CSI study, it was found that test-retest reliability was better for the modified CSI than the parent CSI (Thornton and Travis 2003).

Validity

Construct validity

Principle component analysis identified 3 factors of the CSI, which were comparable but not identical to findings reported by others (Diwan et al., 2004). Exploratory factor analysis and structural equation modelling found three factors that the authors reported to be similar, but not identical, to those proposed originally by Robinson in 1984 (Rubio et al., 1999). However, it is unclear what the authors are referring to, as Robinson (1984) does not report any factors or sub-scales of the CSI in the original development.

Socio-demographic variables

No significant difference was found in the level of strain as measured by the CSI at three or six months after a stroke between men and women in a study by Blake et al., (2003). Adult children were significantly more likely to report role strain compared to spouses and other carers. Higher income of the caregiver was predictive of greater role strain, and perceived lack of support from health care services was associated with greater personal strain (Diwan et al., 2004). For the modified CSI, age was found to be inversely related to carer strain (Thornton and Travis 2003).

Generic health status

The CSI has been found to be significantly moderately to strongly correlated with the General Health Questionnaire-12 (Blake and Lincoln 2000; Blake et al., 2003), patient Extended Activities of Daily Living Scale (EADL), and Negative Affectivity (Blake et al., 2003). In one study, the best predictor of the CSI was the carer's mood and other factors were the perceived patient EADL and negative affectivity (Blake and Lincoln 2000). In a second study, strain was accurately predicted by a model based on the General Health Questionnaire-12, Positive and Negative Affectivity Schedule (Blake et al., 2003). Also, CSI scores correlated moderately with PCS and weakly with MCS scores of the SF-36 in a study by Jenkinson et al., (2000).

Patient variables

Significant correlations were found between the CSI and a variety of patient variables (Robinson 1983). Positive correlations were found for CSI score and the patient's age, re-hospitalization within to months and mental status. Negative correlations were found with the patients' ability to perform activities of daily living and satisfaction with progress during convalescence. Another study however, found no significant correlation was found for CSI score with age of the patient or time since the stroke of the patient (Blake and Lincoln 2000). The modified CSI was found to be significantly correlated to the patient's mental capacity and physical functioning and the patient's age (Thornton and Travis 2003).

Caregiver variables

CSI scores were correlated with a number of variables of caregivers' perceptions (for example carer's perception that they were very involved with caregiving or emotional strain of the caregiver) (Robinson 1983).

Responsiveness

CSI scores have been shown to significantly reduce in a study examining effectiveness of cognitive behavioural therapy for the carer (Secker and Brown 2005).

Feasibility

Interviews took 15-40 minutes in a study by Diwan et al., (2004), but this included the completion of several other questionnaires. For the modified CSI, interview time was between 10 and 20 minutes (Thornton and Travis 2003).

Precision/ Acceptability

No data available.

Table 10.14: Developmental and evaluation studies relating to the Carer Strain Index:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Carer Strain Index							
Robinson, 1983 USA	Carers of recently hospitalized hip surgery or heart patients (81) Age 22-83 Interviewer administered	√	√				
Rubio et al., 1999 USA	Caregivers of adults with dementia (27) and children with developmental problems (8) or 'healthy' children younger than 12 years of age (53); and non-caregivers (77) Self-report questionnaire		√				
Blake and Lincoln, 2000 UK	Co-resident spouses of stroke patients (222) Age 69.0 Self completion questionnaire		√				
Berg-Weger et al., 2000 USA	Caregivers of chronically ill family members (142) Self-report Recruited through six caregiver-support organizations	√					
Jenkinson et al., 2000 Europe incl. UK	Carers of patients with amyotrophic lateral sclerosis (415) Age 55.1 years Set in 74 clinical Self-completion questionnaire	√	√				
Blake et al., 2003 UK	Spouses of stroke patients (130 at 3 months and 116 at 6 months) Age 66.4		√				
Thornton and Travis (2003) USA Modified CSI	Caregivers of family members or friends aged 53+ taking medication regularly and receiving formal or informal assistance (158) Interviewer administered	√	√				√
Diwan et al., 2004 USA	Caregivers of community-dwelling dementia patients (150) Age 61.9 Interviewer-administered	√	√				√
Secker and Brown, 2005 UK	Carers of patients with Parkinson's (30) Age 59.1 for treatment group (n=15) and 58.8 for control group (n=15)			√			

g) Caregiver Well-Being Scale

Reliability

Internal consistency was high for the scale overall, for the two subscales, and for the four factors of the first subscale (Basic Human Need) and for three out of the five factors of the second subscale (Activities of Daily Living) (2 factors had low internal consistency) (Tebb 1995). The Caregiver Well-Being Scale had good reliability (Berg-Weger et al., 2000).

Validity

Face validity

Face validity was examined by four people familiar with the caregiving literature (Tebb 1995)

Construct validity

For construct validity, moderate to high correlations were found to the Computerized Stress Inventory (Tebb 1995). Lifestyle satisfaction scores were moderately to highly correlated to the two sub-scales of the Caregiver Well-Being Scale (Tebb 1995).

Factor analysis suggested that some items could be deleted from the questionnaire, as these items did not load highly on any factor (Berg-Weger et al., 2000). Furthermore, structural equation modelling showed that the original models did not fit the data, and consequently the models were revised to fit the data (Rubio et al., 1999). For example, only three of the original four constructs measured the sub-scale of 'basic needs'.

Criterion validity

Criterion validity was assessed by comparing the scores of caregivers to non-caregivers. Not all the expected significant differences were found, but the differences were in the expected direction (Tebb 1995).

Responsiveness/Precision/Acceptability/Feasibility

No data available.

Table 10.15: Developmental and evaluation studies relating to the Caregiver Well-Being Scale:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Caregiver Well-Being Scale	Reliability	Validity	Responsiveness	Precision	Acceptability
Tebb, 1995 USA	Caregivers of adults with dementia (27) and children with developmental problems (8) or 'healthy' children younger than 12 years of age (53); and non-caregivers (77) Self-report questionnaire	√ Internal consistency	√ Face Criterion and construct				
Rubio et al., 1999 USA	Re-analysis of the sample from the study by Tebb (1995)		√				
Berg-Weger et al., 2000 USA	Caregivers of chronically ill family members (142) Self-report Recruited through six caregiver-support organizations	√	√				

h) Zarit Burden Interview

Reliability

Good internal consistency was found for the 29-item ZBI (Williams 1993), the 22-item ZBI (Zarit et al., 1987; Whitlatch et al., 1991; Majerovitz 1995; Hebert et al., 2000; Bedard et al., 2001; McConaghy and Caltabiano 2005), for a short (12-item) ZBI (Hebert et al., 2000; Bedard et al., 2001; O'Rourke and Tuokko 2003) and for a 4-item screening ZBI (Bedard et al., 2001). Good internal consistency has also been found for the 2 sub-scales (Personal Strain and Role Strain), as well as individual items of the ZBI (Whitlatch et al., 1991).

Validity

Internal validity

Factor analysis supported a two factor solution for the short ZBI (Hebert et al., 2000; Bedard et al., 2001; O'Rourke and Tuokko 2003), but the short ZBI showed a better adjustment than the original ZBI (Hebert et al., 2000). Strong significant correlations were found between the original ZBI and the short ZBI (Bedard et al., 2001), making the short version of the ZBI comparable to the full version.

Socio-demographic variables

For the 29-item ZBI, no difference was found in the total score between daughters and spouses as caregivers (Zarit et al., 1980). However, in a later study, daughters and wives were found to score significantly higher on the ZBI than other caregivers (Zarit et al., 1987). Significant differences in ZBI score (20-item) were found between husband and wife carers (Zarit et al., 1986). No significant effect was found for education and income (Zarit et al., 1987). Scores for the short ZBI (12-item) were significantly higher for women than for men (Bedard et al., 2001). However, another study did not find any correlation between ZBI score and the gender of the caregiver (Hebert et al., 2000). Furthermore, the same study did not find any correlation of the ZBI score and marital status and employment status. It has also been found that more women than men have a higher ZBI score (Gallicchio et al., 2002). Younger carer age has also been found to be significantly associated with a higher ZBI score (Schneider et al., 1999)

Patient variables

Contrary to expectations, none of the variable on the patient's impaired behaviours were correlated with the carer's burden (Zarit et al., 1980). Significant associations were found between ZBI scores and behavioural disturbance (behavioural deficits) and cognitive impairment of the patient (Schneider et al., 1999). No correlation was found between carer burden and duration of illness (Zarit et al., 1980).

General health status

A lack of association between the GHQ-12 and carer burden, measured by the ZBI, was found in a European study (Schneider et al., 1999).

Dimension-specific outcomes

In the original development of the ZBI, only social support, in terms of frequency of family visits, was significantly (negatively) correlated with carer burden (Zarit et al., 1980). For the 29-item ZBI, the sense of burden was moderately to strongly associated with psychological well-being, but not significantly correlated with most variables of physical well-being (Williams 1993). One study found that high levels of burden were negatively correlated to psychological health (measured by SF-36v2) (McConaghy and Caltabiano 2005). Caregiver burden, as measured by the 22-item ZBI was not correlated with caregiver adaptability, but was correlated moderately to caregiving stress variables and memory and behaviour problems (Majerovitz 1995). Correlations for the 22-item ZBI with other measures were statistically significant, but weak, apart for depression for which a moderate correlation was found and correlations for the short ZBI were also weak to moderate (Hebert et al., 2000). Evidence of predictive validity of the short ZBI for depressive symptoms has also been found (O'Rourke and Tuokko 2003).

Responsiveness

A significant decrease over time in carer burden was found in wives, but not husbands, especially for wives who had placed their spouses into a nursing home (Zarit et al., 1986). ZBI scores have been shown to decrease over time, however the

decrease was greater in the waiting list group than in the intervention groups (support or counseling groups) (Zarit et al., 1987).

Interpretability

According to (Bedard et al., 2001), a score of 17 or above on the short ZBI (representing the top quartiles) may be used as cut off point to identify high burden. However, O'Rourke and Tuokko (2003) found this not optimal, upon comparison of the short ZBI scores to scores of the Centre for Epidemiologic Studies-Depression Scale. Their suggested cut off of 10 was not optimal either, and thus it is too early to propose a definite cut off point.

Acceptability

Only one study reported on missing variables, with data missing only on 10 individual items (3.2%) (Hebert et al., 2000).

Feasibility

Both the long and the short ZBI have a low number of items. The ZBI has mostly been interviewer administered.

Table 10.16: Developmental and evaluation studies relating to the Zarit Burden Interview:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Zarit Burden Interview							
Zarit et al., 1980 USA 29 items	Caregivers or people with senile dementia (29) Age 65.0 Interviewer administered		√				
Zarit et al., 1986 USA 20-item	Husbands (31) and wives (33) who were caring for their spouse with Alzheimer's Disease Age husbands 72.3, wives 63.4 Interviewer administered		√				
Zarit et al., 1987 USA 22 items	Care givers of patients with dementia living in the community (119) Age 62.0 Interviewer administered	√		√			
Whitlatch et al., 1991 USA 2-item	Carers of non-institutionalized dementia patients (113) Age 62.0	√					
Williams, 1993 USA 29-item	Caregivers of stroke patients (29) USA Age 56.4	√	√				
Majerovitz 1995 USA 22-item	Spouses of patients with dementia (54) Age 70.5 Interviewer administered	√	√				

Table 10.16 (contd.): Developmental and evaluation studies relating to the Zarit Burden Interview:

Study/ Country	Population (N) Age Method of administration Setting	Measurement properties					
		Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility
Zarit Burden Interview							
Schneider et al., 1999 Europe including the UK 29-item	Co-resident spouses of people with probable dementia (20) Age 71.0 Interviewer administered		√				
Hebert et al., 2000 Canada 22-item	Caregivers of people with dementia in the community (327) 61.7 years Face to face interview in the caregiver's home	√	√				
Bedard et al., 2001 22-, 12- and 4-item versions Canada	Caregivers of cognitively impaired adults referred to a memory clinic (413) Age 61.0 Interviewer administered	√	√				
Gallicchio et al., 2002 USA 22-item	Carers of community-dwelling dementia patients (327) Age 61.6 Interviewer administered		√				
O'Rourke and Tuokko, 2003 Canada 12-item version	Carers of institutionalized and community-dwelling patients with dementia (770) Age 58.6 Interviewer administered	√	√	√			
McConaghy and Caltabiano, 2005 Australia 22-item	Carers of people with dementia (42) Age 62.0 years Self-completion questionnaire	√	√				

Other carer-specific instruments identified from the review

The following table provides an overview of other records of carer-specific instruments identified. They have in common the fact that only one record of a study was found evaluating the instrument; insufficient evidence to justify assessing the instrument in more detail. .

Nineteen single study evaluations of instruments are included. Most of the instruments were evaluated in the USA, only 2 in the UK. The majority of evaluations only gave information on internal consistency and validity. The Caregiver Quality of Life Instrument (CQLI) (Mohide et al., 1988) was tested more extensively, but only in a small sample.

Table 10.17 General carer instruments evaluated in a single study

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Brief Assessment Scale for Caregivers (BASC) and Negative Personal Impact (NPI) subscale; Glajchen et al., 2005	Caregivers of patients with chronic illness (102) (USA) Age 49.0 Interviewer administered (face to face or telephone)	√ Internal consistency	√ Construct					Internal consistency was acceptable for the BASC and the NPI. Construct validity was confirmed by significant correlations to other measures of caregiver burden. (such as Objective Caregiver Burden).
Burden Scale; Pruchno, 1990	Carers of spouses with Alzheimer's Disease (315) USA Age 70.2 Interviewer-administered	√	√					The burden scale was found to be internally consistent. The Burden Scale was correlated to the CES-D scale.
Caregiver Activity Survey; Davis et al., 1997	Caregivers of Alzheimer patients (42) (USA) Self-completion questionnaire	√ Test-retest	√					The Caregiver Activity Survey total score had high test-retest reliability. Convergent validity was supported by comparing the Caregiver Activity Survey to other Alzheimer's disease measures and an independent measure of caregiver burden.

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Caregiver Appraisal Scale (CAS) (primary instrument) Subjective Burden Scale, Objective Burden Scale, General Health Questionnaire; Struchen et al., 2002	Caregivers of persons with traumatic brain injury (241) Age 47.0 USA Self-completion questionnaire	√	√					Factor analysis yielded 4 factors for the CAS. Three of the 4 factors showed good internal consistency. The perceived burden sub-scale had moderate correlations with the 3 other instruments, but correlations were weak for the other sub-scales (caregiver relationship satisfaction, caregiving ideology and caregiving mastery).
Caregiver Change Interview; Zarit et al., 1987	Caregivers of dementia patients living in the community (119) Age 62.0 USA Interviewer administered	√						Good internal consistency was found for the 4 sub-scales
Caregiving Burden Scale; Knight et al., 1998	Caregivers of persons with traumatic brain injury (52) Age 47.1 Self-completion	√	√					Five of the seven CBS subscales showed good internal consistency (family impact and physical burden did not have good internal consistency) For validity, Parents scored significantly higher on the pessimism and physical burden subscales of the CBS than spouses when caring for a person with traumatic brain injury. The CBS total score was significantly correlated to symptom distress, coping, social support and depression

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Caregiver Distress Scale (CDS); Cousins et al., 2002	Parkinson's caregivers (80) UK Age 69.3 years Administered by clinician or self-report	√					√	Subscales of CDS were internally consistent. Hierarchical cluster analysis and factor analysis led to a 17 item questionnaire with 5 subscales. Can be answered quickly as only 17 items and is quick to score by adding up responses to the different items.
Caregiver Experience Scale; Lemoine et al., 2005	Caregivers of people with mental health problems (405) Canada Age 41.3 Self-completion questionnaire	√	√					Construct validity was assessed by factor analysis, which led to a reduction of the items in the scale and a grouping of the IEQ into 8 subscales. Each subscale (apart from Stigma) showed good internal consistency.
Caregiver Perceived Burden; Macera et al., 1993	Caregivers of family members with dementia (82) Age 61.0 USA Interviewer administered	√	√					Good internal consistency was found. The burden score was significantly correlated with the Center for Epidemiologic Studies Depression scale.
Caregiver Quality of Life Index (CQLI) Hospice Quality of Life Index (HQLI) to evaluate patients' QOL; McMillan and Mahon 1994	Carers of cancer patients on admission to hospice care (68) USA 57.7 years Self-completion questionnaire	√	√ Content Construct					Reliability for the CQLI was acceptable. Content validity was established through careful review of the literature and by experts evaluating the CQLI. Construct validity testing showed that the instrument and individual items can discriminate differentiate QOL on adults who are caregivers and adults who are not.

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Caregiver Quality of Life Instrument (CQLI); Mohide et al., 1988	Family caregivers of patients with chronic degenerative disorders (30) and carers of well elderly (10) Canada Interviewer administered	√ Test-retest	√ Construct	√		√	√	Good test-retest reliability was established. Construct validity was shown by the instrument discriminating among different degrees of caregiver wellbeing, discriminated among caregivers caring for elderly with different levels of health, and by the CQLI correlating with the general stress measure. For feasibility, one participant felt too tired to finish the questionnaire. The average time to complete the CQLI was 20 minutes (range 7-35 minutes). Responsiveness to with-subject change over time was shown when caregivers received respite.
Caregiver Stress Scale Feldman et al., 2003	Carers of patients with Alzheimer's disease (141 treatment group, 146 in placebo group) Age 65.5 treatment group, 66.8 in placebo group Canada, Australia, France			√				CSS scores at week 24 for the treatment group improved or remained the same from baseline, whereas the CSS scores declined for the placebo group. However it was only the difference for cognitive status that was statistically significant.

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC) (primary instrument) Measures of family functioning, positive and negative affect and subjective burden; Cooper et al., 2006	Family caregivers of a relative with cancer (160) Australia Age 60.0 Self-completion questionnaire	√	√ Content Convergent and discriminant					High internal consistency was found for the 4 sub-scales of the FACQ-PC. Content validity was assessed by a panel of five experts in palliative care. Based on the assessment 26 of 28 items were retained for the questionnaire. Convergent and discriminant validity was assessed and demonstrated by comparing the FACQ-PC subscales to other measures.
Generic Caregiver Instrument; Schofield et al., 1997	Carers of people with a variety of long term conditions (976 at 1 st interview, 802 at 2 nd interview). Non-carers (200 at 1 st interview, 181 at 2 nd interview) Australia Telephone interview	√	√					Good internal consistency for the different sub-scales at the 2 times of data collection. The carers' reported levels of disability and dependency were independently validated in a sub-sample of carers through clinician assessment. Factor analysis was used to establish construct validity and to reveal sub-scales.

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Measure on positive aspects of caring (primary instrument) General Health Questionnaire, Memory and Behaviour Problem Checklist, Burden Interview, Past Social Interaction Scale and the Social Support Questionnaire; Cohen et al., 1994	Caregivers of people with dementia (196) Canada Standardized interview at carer's home	√ Test-retest	√					Test-retest reliability was assessed by correlations, which although were statistically significant were of moderate strength at best. Also the sample size reduced considerably at the 4 times of data collection. For validity of the measure, the number of positive aspects correlated with a number of different aspects from the other questionnaires used in the study. Again, although statistically significant, the correlations were at best moderate, and the majority were weak. The authors conclude that there may be need for further development of the measure.
Modified Caregiving Appraisal Scale Modified Katz Index of Independence in Activities of Daily Living; Sevick et al., 1994	Caregivers of home-based ventilator-dependent patients at home (29) 47.2 years USA Self-completion questionnaire	√	√ Face validity			√	√	Good internal consistency was found for the modified Katz Index and most of the sub-scales of the modified Caregiving Appraisal Scale (except ideology sub-scale). Final (modified) instrument was reviewed by home ventilation experts. Responses to the modified Katz Index had a moderate amount of missing data (20 pages of questions), with significant relationships found to 3 items.
Oberst Caregiving Burden Scale (OCBS) (primary instrument) Bakas Caregiving Outcomes Scale; Bakas et al., 2004	Caregivers of stroke survivors (114) Age 60.5 USA Self-completion questionnaire	√	√					High internal consistency was found for the OCBS Factor analysis showed that both OCBS subscales were uni-dimensional, thus providing evidence for construct validity. Female caregivers perceived the management of behavioural problems, provision of emotional support and carrying out household tasks as significantly more difficult than male carers .

Instrument/ reference	Population (N) Age Method of administration Setting	Reliability	Validity	Responsiveness	Precision	Acceptability	Feasibility	Comments No other records identified unless stated
Quality of Life Scale (Family Version) (QLS); Sherman et al., 2006	Caregivers for patients with AIDS (43) and cancer (38) USA Age AIDS caregivers Either interviewer administered or self-completion	√	√					QLS found to be reliable. Moderate to strong correlations were found between the different QLS subscales.
Scale for Caregiving Efficacy; Steffen et al., 2002	Two samples of family caregivers of a patient with Alzheimer Disease or another dementing disorder Study 1 n=169, 77.9 years Study 2 n=145, 77.3 years USA Both face to face administration and self-completion	√	√					The 2 subscales show strong internal consistency and adequate test-retest reliability. Support for construct validity was given in both studies, even though different measures were used to assess some of the constructs.

Examples of disease-specific instruments

Additionally, there are disease-specific carer instruments, i.e. instruments that capture the carer's experience in relation to a particular condition. Table 10.18 provides a list of instruments that have been tested for use in the population groups included in this review. This list may not be exhaustive.

The Experience of Caregiving Inventory (ECI), developed for mental health problems, may be of particular interest. The ECI has been developed in the UK and has been used in multiple mental health conditions, for example to compare the experience of caregiving for someone with anorexia or psychosis (Treasure et al., 2001). The ECI could easily be adapted to a general carer instrument.

Table 10.18: Disease-specific carer instruments

Disease	Instrument	Reference (Country)
Neuropsychiatry	Neuropsychiatry Inventory Caregiver Distress Scale (NPI-D)	Kaufert et al., 1998 USA
Cardiac Disease	Quality of Life Questionnaire for Cardiac Spouses (QL-SP)	Ebbesen et al., 1990 USA
Cancer	Caregiver Quality of Life Index- Cancer (CQOLC)	Weitzner et al., 1999; Weitzner and McMillan, 1999 USA
Multiple Sclerosis	Coping with Multiple Sclerosis Caregiving Inventory (CMSCI)	Pakenham 2002 Australia
Mental Health	Involvement Evaluation Questionnaire (IEQ)	Van Wijngaarden et al., 2003 5 European Countries, including the UK
Mental Health	Experience of Caregiving Inventory (ECI)	Szmukler et al., 1996; Joyce et al., 2000 UK

SUMMARY AND RECOMMENDATIONS - GENERIC INSTRUMENTS

Fifteen articles were included in this review of evaluation studies of generic health status instruments used to assess carer impact. Five generic instruments have been used in this way as what we consider indirect assessment of carer burden. The SF-36 and GHQ have had the most evaluations, with 4 studies identified for the SF-36 and 6 studies for the GHQ. The SF-12, a shorter version of the SF-36, has been evaluated once. Furthermore, the GHQ has been used in other studies as a reference measure for construct validity with general carer instruments. Other generic questionnaires that have been evaluated in single studies are the Health Utilities Index Mark 2 (HUI 2), Reintegration to Normal Living Index and the Ferrans and Power Quality of Life Index.

Generally, the sample sizes of the studies were relatively small (approximately 100 carers or less) and ranged from as little as 22 participants to as many as 679. The carers included cared for people with a range of illnesses, with Alzheimer's disease or dementia being the most commonly evaluated (n=6) and carers of stroke patients the second most commonly evaluated (n=3). Both the GHQ and SF-36 have been evaluated in different samples, in terms of the disease of the person that is being cared for. Mostly, the instruments were interviewer administered (n=7). Two studies to evaluate the SF-36 and all but one study to evaluate the GHQ were carried out in the UK.

For the SF-36, the psychometric properties evaluated were reliability (4 studies), validity (3 studies) and acceptability (1 study). For the GHQ, evaluations were restricted to validity (4 studies) and responsiveness (2 studies). The SF-36 is found to be internally consistent in the carer population, although the SF-12 was found to be only weakly internally consistent. No information of internal consistency has been reported for the GHQ.

Validity for the SF-36 was supported by comparing the scores of the SF-36 of carers to population norms, as well as by factor analysis which confirmed the original subscale structure of the SF-36 and by strong correlations with other relevant variables and dimensions such as depression or general carer instruments such as the Carer Strain Index. Validity of the GHQ was shown by comparing GHQ scores of people caring for patients with a different disease or by investigating the relationship of the GHQ with other variables. For the GHQ there is evidence from 2 studies that it is responsive to change, but no studies on the responsiveness of the SF-36 are reported. No or very limited data was available on precision, acceptability and feasibility for either of these instruments.

Disappointingly, there are few evaluations of the instruments reported in this review in the carer population. Thus, a lot of information on the psychometrics on the use of these instruments in the carer population is not available. The range of psychometric properties assessed is very limited, meaning that there is a lack of evidence of the performance of these generic instruments with the carer population.

Given the scarcity of evaluations for generic instruments in this population group, it is not possible to recommend a generic instrument to measure carer burden based on evaluative studies in carers. However, generic instruments such as the SF-36 and

GHQ have been widely evaluated in other population groups. It is therefore likely that these instruments are also useful in the carer population, but further studies need to be carried out to confirm this.

SUMMARY AND RECOMMENDATIONS- GENERAL CARER INSTRUMENTS

A total number of 57 studies were included for general carer instruments. Seven general carer instruments have evidence of measurement properties from multiple evaluations with carers: the Appraisal of Caregiving Scale (ACS) (2 evaluations), Bakas Caregiver Outcomes Scale (BCOS) (3), Caregiver Burden Inventory (CBI) (3), Caregiving Appraisal Scale (CAS) (4), Caregiving Impact Scale (CIS) (2), Caregiver Strain Index CSI (9), Caregiver Well-Being Scale (3) and Zarit Burden Interview (ZBI) (12). A further nineteen general carer instruments were identified which have been evaluated in only a single study each.

The instruments were developed with a range of carers, in terms of the type of patient they were caring for, such as stroke, cancer, Parkinson's disease. The majority of studies have been conducted with carers of patients suffering from Alzheimer's disease or dementia (n=21). The evaluative studies of some instruments remained limited to carers of patients with one type of condition, e.g. the ACS was evaluated in carers of cancer patients or the BCOS in carers of patients with stroke, whereas other instruments, such as the CSI, were evaluated in a range of conditions.

The method of administration was by interview in twenty-one studies, by self-completion in twenty-five studies and by both interview or self-administration in five studies. Five studies did not report the method of administration. Also, the majority of interview studies did not report if the instrument was administered by telephone or face to face (n=17). A large range of sample sizes has been used to evaluate instruments, with samples as small as 20 and as large as 770. The majority of evaluations were conducted in samples with fewer than 100 participants (n=25). Only 11 studies used samples larger than 200 people.

The majority of studies (both for multiple and single evaluations) report only on reliability (internal consistency) and validity. Responsiveness, precision, acceptability and feasibility are neglected issues when evaluating general carer instruments. In terms of the quality of reporting the development and evaluation of general carer instruments, there is often missing information regarding method of administration, population demographic information (e.g. age) or details of scoring of the instrument. Furthermore, the majority of evaluations have been carried out in the USA, with only 7 evaluative studies having been conducted in the UK.

However, given these limitations, the number of instruments identified demonstrates that there is increasing interest in studying the burden of persons caring for someone with ill health. The development of these instruments has helped to identify the important domains in the study of carer burden with the most widely used domains being psychological wellbeing, social well-being and role activities. All of the instruments that having undergone multiple evaluations comprise domains or items reflecting Social well-being, all but one instrument investigate Psychological well-being and 5 of 8 investigate Role activities.

Currently the ZBI and the CSI have been evaluated more extensively. Differences and similarities in the psychometric properties of the two instruments have been found. Both the ZBI (long and short versions) and the CSI have been found to be internally consistent. Test-retest reliability information is only available for the modified CSI.

In terms of validity, the evidence for the ZBI is contradictory. Different studies report conflicting findings on validity, for example one study found that ZBI scores are no different between different types of carers, whereas another study found a difference in ZBI scores between different types of carers. The conflicting evidence about the ZBI validity may be related to the multitude of different versions of the ZBI having been tested. More consistent evidence for the validity of the ZBI has been found by its moderate to strong correlation with dimension-specific variables, such as psychological well-being. There is also controversy for the construct validity of the CSI and it is not clear whether the CSI is uni- or multi-dimensional.

Both the ZBI and CSI have been shown to be responsive to change, but this is based on the information of only one study for each instrument. Disappointingly, the information on precision, feasibility and acceptability is limited.

However, both instruments do have attractive features. They are short, the ZBI is the longest with 29 items, although shorter versions (22, 20, 12 and 4 item versions) exist. The CSI has 13 items. It has been suggested that the short 4-item version of the ZBI may be useful for clinical practice, however no definite cut off points of when a carer experiences a heavy care burden have been established, which limits the usefulness of the instrument. Both have been evaluated in UK carer populations but the ZBI evaluation was part of a multi-national European study. One advantage of the CSI is that it is a self-completion questionnaire, whereas the the ZBI is an interviewer administered instrument (although it was used in one study as a self-completion questionnaire). Although there no evidence was found that the ZBI is disease-specific, the ZBI has been evaluated solely in carers of dementia patients.

A range of carer instruments that are disease-specific have also been developed, examples of which are given in table 10.18. Discussing the measurement properties of these instruments was beyond the scope of this review. However, these instruments may represent an appropriate and valid method to investigate carer burden by making the instrument more specific to the type of care that a carer provides given a specific illness.

Overall, due to the limited information of the psychometric properties of general carer instruments, the majority of instruments cannot be recommended for widespread use., Furthermore, given the scarcity of psychometric information of general carer instruments that have been evaluated in multiple studies, it is not possible to recommend any particular instrument at this point in time. Currently, the ZBI and CSI appear to be the most promising general carer instruments, but further evaluations are necessary before definite recommendation can be made. A small but important advantage of CSI over ZBI is the more substantial evidence of use in the more feasible format of self complete questionnaire.

Because of extensive evidence of their use in a wide range of contexts, two broad measures of health status, SF-36 and GHQ, can be used to provide indirect evidence of carer impact. The CSI and ZBI provide more direct evidence of carer impact, with

the CSI being somewhat more supported for use in the format of self completion questionnaire. Despite it not being possible currently to make definite recommendations for either a generic or general carer instrument to be used to investigate the burden of carers for a person with ill health, the combined use of generic and general carer instruments can be recommended as a strategy. The generic instrument would capture broader health impact and allow comparison of the quality of life of carers with the general population or even with persons with ill health. The use of a general carer instrument would allow capturing information that is more specific to the caregiving experience.

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