

Background

As treatments extend survival the potential burdens on carers increase. Measurement of the impact on caregivers is needed. Although caregiving may have positive outcomes it can impose many burdens.

A raft of instruments purport to measure caregiver impact with a focus on caregiver burden, needs and Quality of Life but some are not well validated or were developed for use with those caring in different circumstances, such as for the elderly with cognitive impairment.

A well-validated measure to assess the impact of the cancer carer's role on their life and lifestyle is crucial.

Aims

To conduct a systematic review to 1) identify instruments that measure caregiving impact 2) evaluate their psychometric performance specifically in cancer and 3) appraise the content; what is and is not captured.

Findings of the content analysis of measures and key areas of omission pertinent to cancer are highlighted here.

Methods

The review involved a two stage search:

- Stage one identified generic and cancer specific self-report instruments used to measure impact of caregiving.
- Stage two identified evidence about psychometric properties and performance of these instruments in the specific context of cancer.

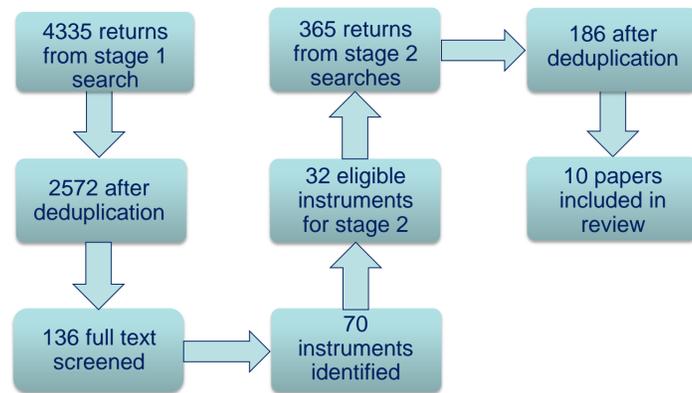
Data Extraction:

- Individual scale items from all included measures systematically categorised into conceptual domains.
- Initial domains identified from the literature and additional ones defined until all individual items had been mapped.
- Content of each domain was reviewed to ensure that the concepts were consistently applied and had face validity.

Results

- Stage 1 resulted in a list of 32 eligible candidate instruments and in stage 2, individual searches were conducted for each candidate instrument.
- 10 papers were included in the systematic review, reporting on the psychometric performance of 8 eligible measures.

Study selection:



Measures included in the review:

Name	Acronym	Papers included in review	Primary area of measurement
Appraisal of Caregiving Scale	ACS	Oberst et al, 1989; Lambert et al, 2015	Appraisal
Brief Assessment Scale for Caregivers of the Medically Ill	BASC	Glajchen et al, 2005	Distress and subjective burden
Caregiver Quality of Life Index – Cancer	CQOLC	Weitzner et al, 1999a and 1999b	Multi-dimensional quality of life
Caregiver Reaction Assessment	CRA	Given et al, 1992	Multi-dimensional measure of reaction to caring for a family member
Family Appraisal of Caregiving Questionnaire for Palliative Care	FACQ-PC	Cooper et al, 2006	Appraisal
Quality of Life in Life Threatening Illness – Family Carer Version	QOLLI-F	Cohen et al, 2006	Multi-dimensional quality of life
Quality of Life – Family Version	QOL-F	Sherman, 2006	Multi-dimensional quality of life
Zarit Burden Interview	ZBI	Higginson et al, 2010	Subjective burden

Domains measured by different instruments □ = 1 item ■ = 2-4 items ■ = 5 items or more on this domain

Overarching theme	Specific domain	ACS	BASC	CQOLC	CRA	FACQ-PC	QOL-F	QOLLI-F	ZBI
Health of caregiver	Psychological health of caregiver	4	1	6		2	7	2	
	Physical health of caregiver	2		1	4	2	5	1	1
	Sexual activity			1			1		
Lifestyle disruption	Lifestyle disruption	3	1	5	3		1		1
	Impact on paid employment					1	1		
	Financial implications	1		3	3	1	1	1	
	Time for self, social life and leisure	2	1	1	2	2	2	2	5
Relationships	Relationship with care recipient	1	2	1		1		1	2
	Communication with family and friends			1		4		1	
	Relationships with family and friends	3	2			1	1		1
	Support from family and friends			3	5	1	1		
	Impact on other family members			1			1		
Wellbeing	Confidence, self-esteem and self-efficacy	4	1		3	7	3	2	4
	Spirituality			1			3	1	
	Bringing purpose and meaning to life	2	1	2	3	2	2	1	
Managing the situation	Coping	1	1	1		1	1		
	Concerns for the future	4		1			1		
	Concerns about care recipient		3	6			6	4	
	Burden		1	1	1				2

Instrument content and categorisation into related domains:

The 8 included instruments yielded 194 individual items.

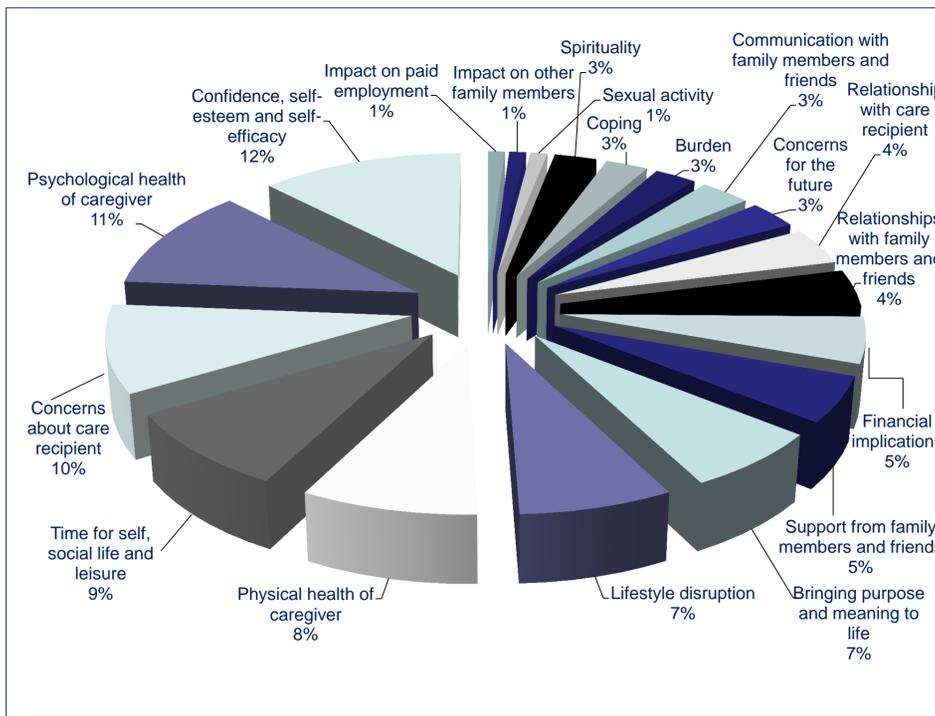
These were categorised into 16 conceptual domains under 5 overarching themes of approximately equal size:

1) lifestyle disruption (22% of items) 2) wellbeing (22%) 3) health of the caregiver (21%) 4) managing the situation (18%) and 5) relationships (18%).

Most dominant domains were 'confidence, self-esteem and self-efficacy' (24 items across 7 measures) and 'psychological health of the caregiver' (22 items across 6 measures).

Least represented were 'impact on other family members' (2 items across 2 measures) and 'impact on paid employment' (2 items across 2 measures).

Proportional representation across the item pool



Example items from included measures:

Overarching theme	Example items (measure item taken from)
Health of caregiver	As a caregiver I feel my own health has suffered (FACQ-PC)
Lifestyle disruption	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself? (ZBI)
Relationships	It is very difficult to get help from my family in taking care of X (CRA)
Wellbeing	Taking care of X makes me feel good about myself (BASC)
Managing the situation	The responsibility I have for my loved one's care at home is overwhelming (CQOLC)

Summary and Conclusions

- Many instruments assess the impact of informal caregiving but few have had psychometric performance evaluated in a cancer population.
- 24/32 identified measures, had no evidence of their psychometric performance evaluated using English-language versions with cancer caregivers.
- We identified 16 conceptual domains in the 194 item pool from the 8 included measures.
- Domains assessed by individual measures varied. Only 1/16 conceptual domains, *time for self, social life and leisure* was represented in all 8 instruments.
- 8/16 domains were assessed in at least 6/8 measures.
- The focus on psychological impacts of caregiving was evident, 2 domains *confidence, self-esteem and self-efficacy* and *psychological health of caregiver* account for 23% of the item pool.
- Several areas are not well captured by the instruments in this review e.g. only 2/194 items measured *impact on other family members* and 2 measured *impact on paid employment*. Impact on career aspiration and planning or career progression were not addressed.
- Some measures were developed ≥35years ago and their current day relevance needs to be reviewed.
- Current scales do not adequately capture changes in occupational, financial, household and family roles and responsibilities as a result of caregiving, or the broader impacts on the family unit or how these might change over time in line with different lines of treatment or transition to palliative care.
- A new measure is required that could provide data to inform clinical discussions about the way in which new and existing treatments impact these broader outcomes.
- Supportive interventions could also be developed and evaluated with newer instruments to be of benefit to informal carers and the people they support.