

Review

Tools for measuring the impact of informal caregiving of the elderly: A literature review

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ABSTRACT

Objectives: (1) Describe available tools to assess the impact of informal caregiving of home-dwelling elderly, (2) identify an acceptable and appropriate tool for a study aiming at the evaluation of the impact of innovative projects for care and support of care for elderly at home, on their main informal caregiver and (3) find a definition of 'main informal caregiver'. **Study design:** Literature review by searches of the following electronic databases: MEDLINE, CINAHL, EMBASE, using firstly keywords and exclusion criteria, then citations and reference search.

Results: This review has identified 105 scales assessing the impact of informal caregiving of the elderly. Those scales were described in terms of characteristics of the care receiver population, content and psychometric properties. Most retrieved scales are intended to measure the impact of caregiving on caregivers' health of elderly with dementia ($n = 49$), overall elderly ($n = 21$), cancer patients ($n = 7$), chronically ill patients ($n = 7$), psychiatric patients ($n = 7$) and stroke patients ($n = 3$).

Dimensions of the impact of caregiving were classified into its positive ($n = 34$), negative ($n = 55$) or neither positive nor negative ($n = 16$) consequences on the informal caregiver's health. Internal consistency varied from 0.48 to 0.99 and in half of the cases ($n = 52$), construct validity was reported. Scales comprised 1–200 questions. The Zarit Burden Interview (ZBI-12) was selected for the study and an operational definition of the concept of "main informal caregiver" was constructed.

Conclusion: This review identified a large number of scales that can be used to assess the impact of caregiving, viewed through different dimensions. The Zarit Burden Interview can be a useful tool for researchers and clinicians due to its user-friendliness, extensively validation and international use, making comparisons between groups possible. Despite the fact that only the original version of each scale was selected, this inventory should be a useful tool for intervention studies and even clinicians work.

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What is already known about the topic?

- Caring for a dependent elderly may affect negatively the physical, psychological, psychosocial, social, and financial health of her/his informal caregiver.
- Careful assessment of the caregiving's impact on the informal caregiver's health enables professional carers to

help them to shoulder the possible effects of caregiving and measure the effectiveness of interventions.

- Assessments include positive and negative aspects of caregiving, as well as aspects which are neither positive nor negative.

What this paper adds

- A summary of caregiving instruments for informal caregivers of community dwelling elderly.
- A definition of 'informal caregiver', based on a literature review and experts meeting.

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1. Introduction

In a context of rapidly growing frail elderly population, informal caregiver's role is becoming an important issue at a political, sociological and economic level. One of the reasons is that informal caregiving has a positive cost-efficacy balance. For example, a US study in 2009 (data from 2007) showed that the cost of caregiving by an informal caregiver could save \$ 257 billion yearly for government or institutions (National Alliance for Caregiving, 2009). Massachusetts' data from 2007 (Albelda et al., 2009) described that residents from this US state perform 24.9 million hours a day of unpaid care work (the equivalent of 3.1 million full-time workers, for a total population of 6.4 million (annual estimates for the population of Massachusetts; Mass.gov, 2010)).

Besides economical reasons, the health of caregivers and their elderly care-receivers is a major concern. Indeed, there is not only evidence of the positive impact of caregiving on the health of caregivers and care-receivers (i.e. quality of relationships, feelings of accomplishment and meaning of the caregivers' role; Carboneau et al., 2010; Farfan-Portet et al., 2007), but also evidence of a negative impact on their health.

Firstly, caregiving may provoke caregivers suffering and ill-health. This consequence on health has been mainly studied for caregivers of patients with dementia, stroke and cancer (Goldstein et al., 2004; Schneider et al., 2002; Visser-Meily et al., 2004). This negative impact of caregiving reflects at several levels (Powers et al., 2002): when caregivers stay without assistance and help they are more likely to show *stress symptoms* (Joling et al., 2008). Caregiving might also *alter physical health* (Rose-Rego et al., 1998; Schulz et al., 2009), *increase anxiety*, *social isolation* (Sherwood et al., 2005), *alter interpersonal relationships* (Bodnar and Kiecolt-Glaser, 1994), *provoke lesser well-being* (Rose-Rego et al., 1998; Tessler and Gamache, 1995), *lead to depressive symptoms* (Sherwood et al., 2005), and even *premature death* (Schulz et al., 2009; van Exel et al., 2004).

Secondly, the negative impact of caregiving can contribute to elder abuse (Service Public Fédéral Santé Publique, 2004), as caregivers become too stressed by the burden and the inadequacy of the help they received for themselves.

Thirdly, the negative impact that the caregiver perceives may play a determinant role in the decision to institutionalize the elderly (Bedard et al., 2000; Pearlin et al., 1990).

Since the 1980s, there has been a growing interest in documenting the caregiving experience, as shown by the variety of instruments intended to measure caregiver variables. Among those, the psychological, emotional and physical stress related to the caregiving experience, as well as caregivers' needs related to performing their caregiving tasks has been widely investigated. These instruments tend to measure the caregiver burden, needs and quality of life. An overview of validated instruments described in scientific literature can be useful for the researcher or the clinician wishing to investigate the impact of caregiving on the informal caregiver.

The main objective of this article was to identify available tools to assess the impact of home-dwelling

elderly people's care on informal caregivers. This research took place during a larger study, in which the impact of innovative interventions had to be assessed through several outcomes (i.e. delaying institutionalization, maintaining or improving the functional status and perceived quality of life of the elderly, impact on the main informal caregiver and cost evaluation). In this context, innovative interventions were interventions that were not reimbursed by the compulsory Belgian health care insurance, NIHDI (National Institute for Health and Disability Insurance). These interventions were mainly nursing night care, coordination of care, speech therapy, occupational therapy and psychosocial support at home. The aim of the innovative interventions was to maintain frail elderly at home. One of the measured outcomes was the impact of a given intervention on the main informal caregiver. To measure that impact, we aimed to identify a validated tool that is easy to use (short) and extensively studied, to allow (inter)national comparisons on effectiveness of interventions targeting informal caregivers' health. As part of that objective, we wanted also to clarify the meaning of the concept of "main informal caregiver", by analyzing the description provided by the articles found during the literature review that would be performed for identifying the scale.

2. Methods

In order to fulfill our objectives of making an inventory of validated tools, finding an appropriate one for our study purposes and, eventually, find a definition of 'main informal caregiver', we performed a literature review in spring 2010.

2.1. Database search

MEDLINE, CINAHL and EMBASE databases were used to identify the validated scales measuring the impact of caregiving on the informal caregiver of elderly. The keywords used were "caregivers/carers", "cost of illness/burden", "elderly/old" and "instrument/questionnaire/scale/assessment". The filter function limited the articles to those published after 1980, patients aged 65 years and more, and with abstract. The complete filter can be found in Table 1 and the flowchart of the articles is shown in Fig. 1. Articles describing the development, or the use of a validated scale in elderly caregivers were included, even if the original scale was not validated in such a population. To complete our inventory of scales, we searched references and citations. The language was limited to English, French, Dutch and German articles.

2.2. Inclusion criteria

Only the original scale was selected (i.e. no revised scales, translations, short-forms, scales validated in other populations or settings than the original). In doing so, we wanted to be as exhaustive as possible in identifying the published scales, even if it included the possibility of not having the latest updated version. This is because of the extensive amount of revisions of some scales, not enabling

Table 1

Search filter for scales for databases.

AND					Limits
OR	Needs assessment Risk assessment Process assessment (health care) Geriatric assessment Nursing assessment Quality assurance (health care) Observation Questionnaires Nursing process Nursing diagnoses Psychometrics Reproducibility Disability evaluation Nursing evaluation research Program evaluation	Cost of illness Burden Caregiver burden Caregiver support Social support Dependency Stress (mental) Adaptive behavior ADL disability	Caregivers Spouses Family health	Frail elderly Aged Elderly care Very elderly	> 65 years Abstract

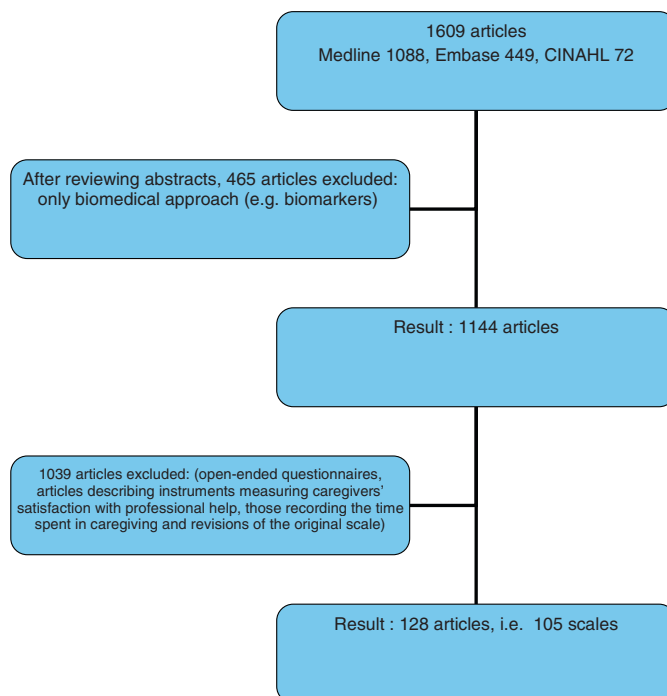
the identification of all revised versions of all scales into one single article.

The reported psychometric evaluations of the scales were, if possible, those of the original article describing the scale development. If the original article could not be found, further psychometric assessment by other authors was reported (secondary sources).

During this literature review, definitions of the terms 'informal caregiver' and 'main informal caregiver' were sought in the selected articles, in order to allow the construction of our own definition of this concept in our research. The articles were thoroughly screened to find those definitions and, when found, the definitions were repeatedly read and listed, to enable a content analysis. Salient attributes of the caregiver function were selected.

Based on the results of the content, a definition was constructed by searching a consensus between the authors and other researchers of the consortium of four Belgian universities performing the scientific evaluation of innovative projects. The aim was to find a comprehensive definition, consistent with the purpose of the study and the expected study population. Consortium members are engaged in ongoing research with community living frail elderly. In addition of their experience as researchers (PhDs or candidate PhD), they are nurses, economists, sociologists, medical doctors and occupational therapists.

While performing this review, we were confronted by the absence, in many cases, of a proper definition of 'informal caregiver'. For instance, out of the 128 selected articles (Fig. 1), 13 (10%) contained a formal definition of

**Fig. 1.** Flowchart to find articles about scales for measuring the impact of caregiving for caregivers of elderly.

the informal caregiver (Ankri et al., 2005; Bertrand et al., 2006; Clark and Diamond, 2010; Czaja et al., 2009; Gort et al., 2007; Lee et al., 2001; Losada et al., 2010; McCusker et al., 2007; McGarry and Arthur, 2001; Okamoto et al., 2009; Schoenmakers et al., 2009b; Seoud et al., 2007; Wallsten, 2000). Some articles were found using only a list of inclusion criteria for ‘informal carer’ or ‘informal caregiver’ ($n = 37$; 29%). Finally, 78 (61%) did not use any definition of the informal caregivers.

In the 50 articles (39%) where the concept of the informal caregiver was defined ($n = 13$) or described through inclusion criteria ($n = 37$), seven definition components or inclusion criteria were identified (Table 6). The components provided in this table focus merely on the function of the informal caregiver (i.e. related to the nature, duration or intensity of care, presence of payment or not, link to the patient), and are not conceptualizations as such. Of those 50 articles with either a definition or a description of the concept ‘informal caregiver’, 17 were from the USA, 8 were Canadian, 5 from the United Kingdom, 4 from the Netherlands, 4 were Swedish, 3 Spanish, 3 Japanese, 2 Taiwanese, 1 French, 1 Italian, 1 Lebanese and 1 South Korean.

Because we did not find a satisfactory description of ‘informal caregiver’, we used two main sources to build a definition. Firstly, we started with the MeSH definition of “caregivers” (PubMed) presents them as: “Persons who provide care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients, etc.”. As our study specifically addressed the impact of the intervention on the informal caregiver, we excluded professional and formal care.

After the definition for informal caregiver, we wanted to refine the concept of ‘main informal caregiver’. In order to achieve this, we sought for definitions related to this topic in the retrieved articles. Authors define ‘main’ informal caregivers as those who spent most of their time with the frail elderly and/or the frail elderly declares that he/she is his/her main informal caregiver (O’Rourke and Tuokko, 2003).

After this, the definition was built during a consortium meeting, in order to reach a consensus.

3. Results

3.1. Description of available tools to assess the impact of informal caregiving of home-dwelling elderly

As a result of the literature review, we found 105 validated scales meeting the search criteria. They are summarized in Tables 2–4.

Among the themes presented in Tables 2–4, we chose to present the number of items of the scale (which provides an idea of the duration of the interview required for the assessment). The number of questions rated from 1 (self-rated burden scale, van Exel et al., 2004) to 200 (Family

Table 2
Scales assessing the impact on caregiving: positive dimensions.

Name of the tool	Source	Description	# items	Items responses	Internal consistency (Cronbach's alpha)	Validity	Population of care receiver	N	Main dimensions assessed
Appraisal of caregiving scale	Folkman and Lazarus (1980)	Caregiving appraisal as threat, problem	7	7-Point scale	0.87	Construct	Overall population	100	Appraisal
Appraisal of caregiving scale (ACS)	Oberst et al. (1989)	Assesses the intensity of four possible appraisals of caregiving: harm/loss, threat, challenge, or benign	53	5-Point scale	0.72–0.91	Construct	Cancer patients	47	Appraisal
Bakas Caregiving Outcomes Scale (COS)	Bakas and Champion (1999)	Life changes resulting from caregiving	10	7-Point scale	0.77	Criterion and construct	Stroke and patients in revalidation process	92	Appraisal
Caregiver appraisal scale (CAS)	Lawton et al. (1989)	Appraisal of caregiving	19	5-Point scale	0.67–0.85	Construct	People in need of respite care	632	Appraisal
Caregiver competence	Kosberg and Cairl (1986)	Level of caregiver competence	21	2- and 4-point scale	Not available	Not found	Elderly with Alzheimer's disease	96	Competence
Caregiver competence scale	Pearlin et al. (1990)	Adequacy of own competences	4	4-Point scale	0.74	Construct	Elderly with Alzheimer's disease	555	Competence
Caregiver competence scale	Schumacher et al. (1998)	Perceived adequacy of their performance as caregivers	4	4-Point scale	0.74	Construct	Elderly with Alzheimer's disease	555	Competence
Caregiver experience assessment	Scholfield et al. (1997)	Different aspects of caregiving (health, social support, overload)	75	3–5-Point scales	0.59–0.78	Construct	Variety of chronic illnesses	946	Appraisal
Caregiver quality of life index	McMillan and Mahon (1994)	QoL of caregivers	4	Visual analogue scale	0.76–0.88	Construct	Cancer patients	130	QoL
Caregiver quality of life index	Weitzner et al. (1999)	QoL of caregivers	35	3–5-Point scales	0.91	Construct	Cancer patients	411	QoL

Table 2 (Continued)

Name of the tool	Source	Description	# items	Items responses	Internal consistency (Cronbach's alpha)	Validity	Population of care receiver	N	Main dimensions assessed
Caregiver satisfaction	Kramer (1993)	satisfaction with the caregiving role	12	4-Point scale	0.9	Construct	Elderly with Alzheimer's disease	72	Satisfaction
Caregiver self-Efficacy Scale (CSS)	Zeiss et al. (1999)	Caregiver self-perception of abilities	14	Rating between 0 and 100%	0.83	Construct	Frail and/or cognitively impaired elderly	217	Self-efficacy
Caregiver well-being	George and Gwyther (1986)	Well-being of caregiver	15	Various	0.79–0.89	Not found	Elderly with Alzheimer's disease	Not found	Well-being
Caregiver well-being scale	Zarit (1990)	Caregiver's well-being	21	4- or 5-point scale	0.78–0.86	Not found	Elderly with Alzheimer's disease	Not found	Well-being
Caregiver well-being scale	Tebb (1995)	Basic and non-basic needs of caregiver measured	55	7-Point scale	0.81–0.91	Construct and criterion	Elderly and chronically ill	165	Well-being
Caregiving effectiveness	Noelker (1987)	Perception of caregiver's effectiveness	3	4-Point scale	0.64	Not found	Not found	Not found	Effectiveness
Caregiving satisfaction scale	Lawton et al. (1989)	satisfaction with caregiving	15	4-Point scale	0.9	Construct	Disabled elderly	632	Satisfaction
Carer quality of life scale	Brouwer et al. (2004)	Impact of informal care on QoL of caregivers	8	Visual analogue scale + 3-point scales	Not available	Construct Convergent validity	Variety of chronic illnesses	175	QoL
Carer's Assessment Of Satisfaction Index (CASI)	Nolan et al. (1995)	Rewards of caregiving	30	4-Point scale	0.5–0.8	Construct	Not available	Not found	Satisfaction
Carers Assessment of Difficulties Index (CADI)	Nolan et al. (1995)	Assessment of caregiver's difficulties	30	4-Point scale	0.71–0.84	Not found	Not available	Not found	Appraisal
Family caregiving factors inventory	Shyu (2000)	Inventory of different possible factors influencing caregiver well-being	42	Likert-type scales	0.68–0.91	Content and construct	Frail elderly	97	Well-being
Finding Meaning Through Caregiving	Farran et al. (1999)	3 subdimensions: loss/powerlessness, provisional meaning and ultimate meaning	43	5-Point scale	0.88–0.91	Convergent and discriminant validity	Elderly with Alzheimer's disease	46	Meaning
Gain in the Caregiving Experience	Kramer (1993)	Appraisal enhancing caregiver life's space	15	4-Point scale	0.9	Not found	Elderly	74	Gain
Mastery scale	Pearlin et al. (1990)	Generalized sense of control	7	4-Point scale	0.75–0.79	Not found	Elderly with Alzheimer's disease	555	Mastery
Multidimensional scale of perceived social support	Canty-Mitchell and Zimet (2000)	Perceptions of the availability of support from significant others	12	7-Point scale	0.85–0.91	Test–retest reliability	University undergraduates	275	Social support
Perceived Self-efficacy scale	McRae et al. (2000)	Self-efficacy from the caregiver perspective	20	7-point scale	0.89	Construct	Parkinson's disease patients	Not found	Self-efficacy
Philadelphia geriatric center appraisal scale	Lawton et al. (1989)	Caregiver burden, perceived impact, satisfaction, and mastery	28	2–5-Point scales	Not available	Test-retest reliability	Elderly	632	Appraisal
Picot caregiver reward scale	Picot et al. (1997)	Rewards of caregiving	25	5-Point scale	0.83–0.88	Construct	Elderly and chronically ill	339	Reward
Positive caregiver scale	Tarlow et al. (2004)	Self Affirmation and Outlook on Life	9	5-Point scale	0.89	Convergent and discriminant validity	Elderly with Alzheimer's disease	1229	Reward
QOLTLI-F (Quality of Life in Life Threatening Illness Family Carer Version)	Cohen et al. (2006)	Quality of Life scale in Life Threatening Illness for the caregiver	16	11-Point scale	0.7–0.77	Construct	Cancer patients	149	QoL
Quality of life tool for family of cancer patients	Ferrell et al. (1999)	Physical, psychological, social and spiritual QoL	20	Visual analogue scale	0.84	Construct	Cancer patients	219	QoL
Revised scale for caregiving self-efficacy	Zeiss et al. (1999)	Caregiver's self care and obtaining respite	51	Rating between 0 and 100%	0.74–0.85	Construct	Frail and/or cognitively impaired elderly	217	Self-efficacy
Sense of competence scale	Vernooij-Dassen et al. (1996)	Caregiver's feelings of being capable of caring for the demented person	27	4-Point scale	0.79	Not found	Elderly with Alzheimer's disease	141	Competence
Social support questionnaire (SSQ)	Sarason et al. (1983)	Social support	27	Open questions	0.9–0.93	Test-retest reliability	Undergraduates and students	1164	Social support

Table 3

Scales assessing the impact on caregiving: neutral dimensions.

Name of the tool	Source	Description	# items	Items responses	Internal consistency (Cronbach's alpha)	Validity	Population of care receiver	N	Main dimensions assessed
Caregiver reaction assessment	Given et al. (1992)	Impact of caregiving on daily life	24	5-Point scale	0.62–0.83	Construct	Chronic patients with various conditions	754	Reaction
Caregiver subjective physical health	Whitlatch et al. (1999)	Subjective physical health of caregiver	4	3-Point scales	0.82	Not found	Not found	Not found	Health
Caregiving hassles and uplifts scale	Kinney and Stephens (1989)	Appraisal of hassles or uplifts	42	4-Point scale	0.71–0.90	Construct	Elderly with Alzheimer's disease	60	Hassles and uplifts
Caregiving impact scale	Cameron et al. (2002)	Impact of caregiving on health domains	14	7-Point scale	0.87	Not found	Cancer patients	44	Impact
Carers' Assessment of Managing Index (CAMI)	Nolan et al. (1990)	Statements made by carers about their coping strategies	38	4-Point scale	Not available	Not found	Elderly with Alzheimer's disease	Not found	Management assessment
Coping Inventory	Barusch (1988)	Coping response of caregiving	34	5-Point scale	Not available	Inter-rater	Spouse caregivers of elderly	89	Coping
Coping strategies inventory	Quayhagen and Quayhagen (1982)	Dimensions of coping	48	4-Point scale	0.57–0.79	Content	Elderly with Alzheimer's disease	58	Coping
Cost of care index	Kosberg and Cairl (1986)	Negative impact of care	20	4-Point scale	0.91	Not found	Impaired elderly	83	Impact
Experience of caregiving inventory	Szmukler et al. (1996)	Positive and negative experiences of caregiving	66	5-Point scale	0.79–0.91	Construct	Elderly with serious mental illnesses	626	Impact
Inventory of coping Strategies	Kiyak et al. (1985)	Difficulty and stress experienced during caregiving.	16	5-Point scale	0.61–0.73	Construct	Not found	Not found	Coping
Jalowiec coping scale	Jalowiec et al. (1984)	Burden levels and coping strategies	40	5-Point scale	0.86	Construct and content	Hypertension and emergency room patients, revised for other illnesses	141	Coping
Perceived change index	Gitlin et al. (2006)	Use of specific strategies to cope with caregiving dependency	19	5-Point scale	0.74–0.81	Construct	Elderly with Alzheimer's disease	255	Coping
Perceived health index	Deimling and Bass (1986)	Perception of health status of caregiver and care receiver	4	5-Point scale	Not available	Not found	Elderly with Alzheimer's disease	614	Health
Physical health deterioration	Deimling and Bass (1986)	Caregiver perception about impact of caregiving on his health	5	4-Point scale	0.89	Not found	Elderly with Alzheimer's disease	614	Health
Preparedness for caregiving	Archbold et al. (1990)	Preparedness of caregiver	8	5-Point scale	0.86–0.92	Construct	Elderly	78	Preparedness
Ways of coping checklist	Vitaliano et al. (1985)	5 subscales of coping	42	4-Point scale	0.76–0.88	Construct	Students	425	Coping

Table 4
Scales assessing the impact on caregiving: negative dimensions.

Name of the tool	Source	Description	# items	Items responses	Internal consistency (Cronbach's alpha)	Validity	Population of care receiver	N	Main dimensions assessed
Brief assessment scale for caregivers	Glajchen et al. (2005)	Burden	14	4-Point scale	0.70	Construct	Different chronic illnesses	102	Burden
Burden Assessment Scale (BAS)	Reinhard et al. (2007)	Objective and subjective burden	19	4-Point scale	0.91	Construct	Psychiatric patients	188	Burden
Burden Index for Caregivers (BIC)	Miyashita et al. (2006)	Subjective burden	11	5-Point scale	0.84–0.89	Correlation between BIC and ZBI	Japanese stroke and neurology patients	46	Burden
Burden questionnaire	Grafstrom et al. (1992)	Stress and difficulties for caregiver	21	Not available	Not available	Not found	Elderly with Alzheimer's disease	474	Burden
Burnout measure Caregiver Burden Inventory	Pines and Aronson (1988) Novak and Guest (1989)	Burden	21	7-Point scales	0.91–0.93	Construct	Overall population	3900	Burden
		Burden	24	5-Point scale	0.77–0.87	Construct	Elderly with Alzheimer's disease or organic brain disease	171	Burden
Caregiver Burden scale	Gerritsen and van der Ende (1994)	Relationship and consequences of caregiving	13	5-Point scale	0.84	Construct	Psychogeriatric patients	89	Burden
Caregiver Burden scale	Elmstahl et al. (1996)	Various dimensions of burden	22	4-Point scale	0.70–0.87	Construct	Stroke patients	150	Burden
Caregiver grief inventory	Meuser and Marwit (2001)	Grief experience of caregiver relative with progressive dementia	50	5-Point scale	0.90–0.96	Not found	Elderly with Alzheimer's disease	166	Grief
Caregiver guilt questionnaire	Losada et al. (2010)	Feelings of guilt	22	5-Point scale	0.88	Construct	Elderly with Alzheimer's disease	288	Guilt
Caregiver problem checklist & strain scale	Gilleard et al. (1984)	Caregiver Problems and strain	34	3-Point scales	Not available	Not found	Elderly with Alzheimer's disease	129	Strain
Caregiver Risk Screen Caregiver Strain Index	Guberman (1999)	Risk for caregiver	15	4-Point scale	0.88–0.85	Construct	Elderly	82	Risk
	Robinson (1983)	Caregiver strain	13	Yes/no questions	0.86	Construct	Elderly with arteriosclerosis or hip operations	85	Strain
Caregiver stress effects	Deimling and Bass (1986)	Impact of caregiving on family life	13	Not available	0.80–0.88	Not found	Cognitive impaired elderly	614	Stress
Caregiver stress Inventory	Pearlin et al. (1990)	Stress, role and care	89	4–5-Point scale	0.48–0.87	Not found	Elderly with Alzheimer's disease	555	Stress
Caregiver-role overload	Pearlin et al. (1990)	Evaluation of intrapsychic strain and role-related stress	20	Yes/no questions	Not available	Not found	Elderly with Alzheimer's disease	555	Role overload
Caregiving consequences inventory	Sanjo et al. (2009)	Family members' perception of caregiving consequences	24	7-Point scale	0.78–0.93	Construct	Cancer patients	298	Burden
Caregiving task difficulty	Shyu (2000)	Difficulty in performing caregiving tasks	6	5-Point scale	0.73	Content and construct	Frail elderly	97	Task difficulty
Carers' checklist	Hodgson et al. (1998)	Objective and subjective burden	Combines STAS, BMDS and Problem Checklist 20	3-Point scales	0.93	Not found	Elderly with Alzheimer's disease	Not found	Burden
Center for epidemiology studies depression scale (CES-D)	Radloff (1977)	Depression scale	20	4-Point scale	0.9	Test-retest reliability	Adult and elderly	Not found	Depression

Demand and Difficulty subscales of the Caregiving Burden scale	Carey et al. (1991)	Caregivers rate each task according to how much time it requires (demand) and how difficult it is (difficulty).	15	5-Point scale	0.83–0.89	Construct	Receiving chemotherapy	49	Burden
Ervaren Druk door informele zorg (Perceived stress scale)	Pot et al. (1995)	Self-Perceived Pressure from Informal Care	9	5-Point scale	Not available	Not found	Elderly with Alzheimer's disease	167	Burden
Family burden interview	Morycz (1985)	Stress and problems	15	4-Point scale	0.87	Not found	Elderly with Alzheimer's disease	Not found	Burden
Family burden scale	Stein and Test (1980)	Only objective measure of burden	6	Open questions	Not available	Not found	Psychiatric patients	49	Burden
Family Experiences Interview Schedule (FEIS)	Tessler and Gamache (1995)	Objective and subjective burden of family members	200	Interview	0.56–0.87	Not found	Elderly with severe mental disorders	Not found	Burden
Family Strain Scale	Morycz (1985)	Subjective burden	14	4-Point scale	0.77	Construct	Elderly suffering from Alzheimer's disease	Not found	Strain
Geriatric Depression Scale (GDS)	Brink et al. (1982)	Depression scale	30	Yes/no questions	0.99	Test-retest reliability	Elderly	Not found	Depression
Geriatric Depression Scale (GDS)-SF	Yesavage et al. (1982)	Depression scale	15	Yes/no questions	0.75	Construct	Elderly	Not found	Depression
Global strain scale	Archbold et al. (1990)	Confinement, difficulty and stress experienced during caregiving	3	5-Point scale	0.76–0.82	Construct	Elderly and Parkinson's patients	106	Strain
Involvement evaluation questionnaire	Schene et al. (1994)	Caregivers' worries, coping and emotional burden as a consequence of mental illness of patients	31	5-Point scale	0.68–0.91	Not found	patients with schizophrenia	288	Burden
Loss of self	Skaff and Pearlin (1992)	Sense of a loss of sense	2	4-Point scale	0.76	Not found	Elderly with Alzheimer's disease	Not found	Loss of self
Marwit–Meuser grief inventory (MM-CGI) long form	Marwit and Meuser (2002)	Measure grief of persons caring for others with progressive dementia	50	5-Point scale	0.8–0.83	Construct	Elderly with Alzheimer's disease	292	Grief
Measurement of burden (CSOB)	Montgomery et al. (1985)	Objective and subjective burden	22	5-Point scale	0.85–0.86	Construct	Elderly	80	Burden
Measures of strain	Bass and Bowman (1990)	caregiver as threat to family well-being	8	2–4-Point scale	0.67	Not found	Not found	Not found	Strain
Mental health effects	Pruchno et al. (1995)	Burden and consequence of caring	31	5-Point scale	0.78–0.89	Not found	Elderly	140	Burden
Modified caregiver strain index (CSI)	Thornton and Travis (2003)	Caregiver strain	13	2-Point scales	0.9	test-retest reliability	Chronically ill with complex medication needs	158	Strain
Montgomery Borgatta caregiver Burden scale	Montgomery et al. (1985)	Objective burden, subjective demand and subjective stress burden	14	5-Point scale	0.68–0.90	test-retest reliability	Impaired elderly	541	Burden
Negative perception of care situation	Brubaker (1987)	Defining of caregiving situation in a negative way	7	4-Point scale	0.77	Not found	Not available	Not found	Burden
Neuropsychiatric inventory caregiver distress scale	Kaufer et al. (1998)	Impact of neuropsychiatric symptoms in Alzheimer's disease (AD) patients on caregiver distress.	10	6-Point scale	Not available	Criterion validity and test-retest reliability	Elderly with Alzheimer's disease	85	Stress
Objective Burden Questionnaire	Provencher (1996)	Focus on objective burden	10	4-Point scale	0.70	Not found	patients with schizophrenia	70	Burden
Perceived burden measure	Macera et al. (1993)	Burden	15	Yes/no questions	0.87	Construct	Elderly with Alzheimer's disease	82	Burden

Table 4 (Continued)

Name of the tool	Source	Description	# items	Items responses	Internal consistency (Cronbach's alpha)	Validity	Population of care receiver	N	Main dimensions assessed
Perceived burden scale	Stommel et al. (1990)	Perceived burden	31	4-Point scale	0.72–0.92	Criterion Construct	Elderly	307	Burden
Perceived family burden scale	Levene et al. (1996)	Impact of schizophrenic behaviors on family	24	Yes/no questions	0.83		Adults with schizophrenia	58	Burden
Perceived Stress Scale	Cohen et al. (1983)	Perceived stress	14	5-Point scale	0.84–0.86	Concurrent and predictive	Students and participants of a smoke-cessation program	346 + 64	Stress
Rapid screen for caregiver burden	Hirschman et al. (2004)	Perceived burden	7	5-Point scale	0.86	Construct	Elderly with Alzheimer's disease	251	Burden
Relatives Stress Scale	Greene et al. (1982)	Emotional and social distress, and negative feelings of care receiver relatives	15	5-Point scale	0.7–0.86	Construct	Elderly with Alzheimer's disease	196	Stress
Risk appraisal measure	Czaja et al. (2009)	Depression, burden, self-care and health behaviors, social support, safety, and patient problem behaviors	16	4–7-Point scale	0.65	Concurrent validity	Elderly with Alzheimer's disease	642	Risk
Role captivity	Pearlin et al. (1990)	Feelings of 'being trapped' in caregiver role	3	4-Point scale	0.83	Construct	Elderly with Alzheimer's disease	555	Role captivity
Role overload	Pearlin et al. (1990)	Caregiving-related feelings of exhaustion and fatigue	3	4-Point scale	0.78	Construct	Elderly with Alzheimer's disease	555	Role overload
Screen for Caregiver Burden	Vitaliano et al. (1991)	Objective and subjective burden	25	5-Point scale	0.85–0.88	Construct and criterion	Elderly with Alzheimer's disease	191	Burden
Self-rated Burden scale	van Exel et al. (2004)	Subjective burden	1	Visual analogue scale	Not relevant	Convergent validity	Patient with stroke and rheumatoid arthritis	196 and 131	Burden
Strain scale	Gilleard et al. (1982)	Caregiver strain	13	3-Point scales	Not available	Not found	Psychogeriatric patients	129	Strain
Subjective caregiving burden	Lawton et al. (1991)	Appraisal of stress	13	5-Point scale	0.85	Construct	Disabled elderly	239	Burden
T-Care Tailored Caregiver Assessment & Referral process	Montgomery and Kwak (2008)	Assessment and referral for the caregivers: 4 burden scales	32	Not found	Not found	Not found	Not stated	900	Burden
Zarit Burden Interview-22	Zarit et al. (1980)	Caregiver burden	22	5-Point scale	0.85	Construct	Elderly with Alzheimer's disease	29	Burden

Experiences Interview Schedule, Tessler and Gamache, 1995).

Most retrieved scales are intended to measure the impact of caregiving on caregivers' health of elderly with dementia ($n = 49$), elderly without specification of illnesses ($n = 21$), cancer patients ($n = 7$), chronically ill patients (7), psychiatric patients ($n = 7$) and stroke patients ($n = 3$).

Psychometric testing included internal consistency by the means of Cronbach's alpha. Evaluation of the internal consistency is only one of the statistic tests performed to assess the validity of a scale. Even if this test is insufficient to prove psychometric validity of a scale on its own, it is the one that is consistently cited while reporting the psychometric properties in literature, allowing comparisons of this item. The results from Tables 2–4 show that internal consistency rated from 0.48 to 0.99 (respectively Caregiver Stress Inventory; Pearlin et al., 1990 and Geriatric Depression Scale; Brink et al., 1982). According to Nunnally and Bernstein (1994) a scale of minimum 0.70 shows strong internal consistency. In this study, 14 scales were below this cut-off point and showed weak internal consistency.

Of the 105 scales listed, 35 were published before 1989, 48 between 1990 and 1999 and 22 from 2000 to 2010, showing thus a slight decrease since the new millennium.

The impact of caregiving is multidimensional. It is affected at the one hand by objective elements, such as the nature and the time spent in practical tasks. At the other hand, it is impacted by subjective elements, like emotional, social and relational stressors, which are linked to the caregiving role. The scales were categorized according to their dominant construct, as expressed by their conceivers. This enabled us to make a classification of the scales in 3 tables (Tables 2–4), categorizing them into positive, neutral or rather negative impact.

The largest number of scales assessed the negative impact of caregiving ($n = 55$), exploring dimensions such as burden or determinants of burden, strain, stress, grief, loss of self. Positive impact of caregiving ($n = 34$) was explored by appraisal, competence, quality of life and well-being. Other scales were found to study more neutral dimensions, like coping, health, impact, and reaction ($n = 16$).

An overview of all dimensions, classified by positive, neutral or negative dimensions, can be found in Table 5.

3.2. Identification of an acceptable and appropriate tool

The most useful tool, according to our study design, was the Zarit Burden Interview. It measures the perceived burden of the informal caregiver in its multidimensional aspects: social, physical, financial and emotional burden, as well as the relation with the care receiver. The ZBI has been widely validated; it is easy to use and has been extensively studied (was cited 1081 times in Medline). Perceived burden is defined by its author as "One's subjective belief that current and future resources are insufficient to meet role demands" (Zarit et al., 1980). The Zarit Burden Interview (22-item version) has been translated in 18 languages (Mapi Research Trust, 2010).

A 12-item version has been validated in elderly with dementia in large populations (Bedard et al., 2000; O'Rourke and Tuokko, 2003). It has been used to allow comparison between caregivers (Zarit et al., 1980). Moreover, it has been validated in longitudinal studies with a study population whose characteristics were very close to the study population of the project evaluation study, described above (Higginson et al., 2010; Bedard et al., 2000).

Factor analysis of the ZBI-12 provided evidence for two underlying factors for the scale: role strain and personal strain (Bedard et al., 2000). According to Higginson et al. (2010) internal consistency of the ZBI-12 was found to be high (Cronbach's alpha > 0.70) for the total scale and the two subscales (role strain and personal strain) and discriminative ability was good (0.99; 95% confidence interval [CI]: 0.98–0.99) in caregivers of patients with dementia, advanced cancer and acquired brain injury. As for the initiators of the short version, Bedard et al. (2000) found a Cronbach's alpha > 0.88 for the overall scale and high values for the personal strain factor and the role strain factor (respectively 0.89 and 0.77). Psychometric testing of this scale is still in process, as is shown by the constant new studies studying this scale (e.g. Flynn Longmire and Knight, 2011).

3.3. Definition of caregiver and main caregiver

As a consequence of the search, we propose the following definition for main informal caregiver: "The person who spends most of the time with the frail elderly

Table 5
Main dimensions of assessment of the impact of caregiving.

Positive impact		Negative impact		Neutral impact	
Main dimension	No. of scales	Main dimension	No. of scales	Main dimension	No. of scales
Appraisal	7	Burden	30	Coping	6
Quality of life	5	Strain	7	Health	3
Competence	4	Stress	5	Impact	3
Well-being	4	Depression	3	Hassles and uplifts	1
Satisfaction	3	Grief	2	Management assessment	1
Self-efficacy	3	Risk	2	Preparedness	1
Social Support	2	Role overload	2	Reaction	1
Reward	2	Guilt	1		
Mastery	1	Loss of self	1		
Meaning	1	Task difficulty	1		
Effectiveness	1	Role captivity	1		
Gain	1				
Total	34	Total	55	Total	16

and/or from whom the frail elderly declares that he/she is his/her main informal caregiver, for care or support of care, and who does not take part in a formal network of organized care.”

4. Discussion

This paper aimed to (1) provide an overview of available scales measuring the impact of caregiving on elderly's caregivers and (2) identify in the literature, a validated, user-friendly and well-studied scale for assessing the impact of care for the main caregiver through an extensive literature research. By doing so, we were confronted by the need to clarify the meaning of the concept of ‘informal caregiver’ (Table 6).

The present literature review provides an extensive overview of the used scales, while describing their main psychometric properties. When internal consistency was reported (Cronbach's alpha), 14 scales were shown to be below the cut-off point of 0.7, which is considered too low to show acceptable consistency (Bowling, 1997; McDowell, 2006). Moreover, eight scales reported Cronbach's alpha over the threshold of 0.9, increasing

the risk of inter-item redundancy and weakening the conceptual field (Nunnally and Bernstein, 1994).

Of the 105 selected scales, 26 had 1–10 questions, 35 had 11–20 questions, 20 had 21–30 questions, nine had 31–40 questions and 15 scales had more than 40 questions. The length of the questionnaire raises the question about the risk of overburdening the caregiver with long questionnaires. If possible and when psychometric testing is at minimum good, short questionnaires must be preferred (Gagné and Godin, 1999).

In more than half of the articles (78/128), no definition of the term ‘informal caregiver’ was given at all and only 13 out of 128 articles provided a definition of the terms ‘informal caregiver’. Even if the articles provided a definition, the term was not very well defined, as issues of cohabitation and intensity of care were not addressed. This raises concerns about the external validity of studies (i.e. using results in other settings). When interpreting the results, the reader cannot infer them to other populations, especially in relation to studies about the impact of caregiving, because issues about the intensity of care (number of interventions) and the fact that the care receiver is cohabiting or not with the caregiver can affect

Table 6
Definitions or descriptions of the ‘informal caregiver’ concept.

Definition components or inclusion criteria	Description (values given to the criteria)	Number of articles	Authors
Function of the informal caregiver	Functions are defined by the care receiver	3	Chen and Hu (2002), Higginson and Gao (2008), O'Rourke and Tuokko (2003)
	Functions are defined by caregiver him/herself	6	Ford et al. (1997), Goode et al. (1998), Lee et al. (2001), Losada et al. (2010), Montgomery et al. (1985), Wallsten (2000)
Link to the patient	Family or friend	23	Almberg et al. (1997), Almberg et al. (1998), Andren and Elmstahl (2005), Ankri et al. (2005), Baker et al. (2010), Clark and Diamond (2010), Ducharme et al. (2005), Ford et al. (1997), Goode et al. (1998), Gort et al. (2007), Kramer (1993), Larson et al. (2005), Levesque et al. (2008), Losada et al. (2010), McCusker et al. (2007), Post et al. (2007), Schoenmakers et al. (2009b), Schulz and Beach (1999), Schulz et al. (2009), van den Heuvel et al. (2002), Wallsten (2000), Lingler et al. (2008)
Living together with the patient	Cohabitant	5	Crespo et al. (2005), Czaja et al. (2009), Gitlin et al. (2006), Larson et al. (2005), Okamoto et al. (2009)
Duration of care	Cohabitant or not	1	Schoenmakers et al. (2009b)
	Expressed in months	6	Crespo et al. (2005), Czaja et al. (2009), Gitlin et al. (2006), Lee et al. (2001), Losada et al. (2010), Seoud et al. (2007), Bilotta and Vergani (2008)
Intensity of care	Expressed in number of hours/day or week	8	Clark and Diamond (2010), Czaja et al. (2009), Gitlin et al. (2002), Gitlin et al. (2009), Lee et al. (2001), Losada et al. (2010), Seoud et al. (2007), Siegert et al. (2010)
Nature of care	‘regular’ care	1	Chiou et al. (2009)
	Provides care	12	Almberg et al. (1997), Almberg et al. (1998), Chiou et al. (2009), Cohen et al. (2006), Crespo et al. (2005), Ducharme et al. (2005), Ford et al. (1997), Goode et al. (1998), Gort et al. (2007), Levesque et al. (2008), Miyashita et al. (2006), Sherwood et al. (2005)
	Brings the patient to the hospital	2	Hirschman et al. (2004), Lingler et al. (2008)
	Conducts or coordinates the majority of CG needs	1	Cameron et al. (2002)
	Help for ADL/IADL	12	Bertrand et al. (2006), Clark and Diamond (2010), Lee et al. (2001), McGarry and Arthur (2001), Nguyen et al. (2008), Okamoto et al. (2009), Pound et al. (1993), Schulz and Beach (1999), Seoud et al. (2007), van den Heuvel et al. (2002), van den Berg et al. (2005), Wallsten (2000)
	Help for socialization	2	van den Berg et al. (2005), Wallsten (2000)
Payment	Responsible for day-to-day decisions	1	O'Rourke and Tuokko (2003)
	Unpaid	7	Bertrand et al. (2006), Cameron et al. (2002), Clark and Diamond (2010), Cohen et al. (2006), Lee et al. (2001), McCusker et al. (2007), Siegert et al. (2010)
	Paid or not	1	van den Berg et al. (2005)

strongly the measured outcome (i.e. as described in the scale).

We did not study the international variation of the definitions of the 'informal caregiver' in this paper, at the one hand because we believe that our sample of selected articles is not representative enough of all the published papers in this topic (42/50 articles where a definition or a description of the terms was found were North American or European) and secondly, because this was not the scope of the present article.

In her doctoral thesis about interventions aiming at caregivers health and well-being, Schoenmakers (2009a) suggested following definition for the concept of 'informal caregiver', both based on international literature, guidelines and focus groups: *"A person who, for evident reasons and on a regular basis, provides care for a care demanding person, in his/her immediate environment and who is not part of a formal or professional organization."* In agreement with Ducharme et al. (2009), Schoenmakers insists on not introducing the term 'natural' or 'volunteer' in the definition, since social pressure limits freedom of choice of this 'natural' caregiver (i.e. automatic). Moreover, professional or formal caregivers are excluded from this definition.

There are many tools to assess the impact of caregiving on the informal caregiver. As shown in our results, researchers and clinicians have a broad choice when it comes to choosing a scale for measuring the impact of interventions aimed at main informal caregivers of elderly individuals. Understanding of the dimension impacted by the care is of importance and interventions aiming at alleviating the potentially negative impact of caregiving on a given dimension need to be carefully assessed. Even so, one can be overwhelmed by the number of scales assessing the same dimension (e.g. 30 scales assessing burden). Even if the majority of the scales depict the negative impact of burden ($n=55$), positive ($n=34$) and neutral ($n=16$) dimensions were also addressed. The choice of the tool relies on the question and the population group.

Our choice to select the Zarit Burden Interview (12-item) relied principally on its extensive validation, conciseness and user-friendliness. Moreover, its ability to detect changes over time (O'Rourke and Tuokko, 2003) was of importance, as the tool will be used in our ongoing study to evaluate the impact of services to both care receivers and caregivers.

5. Study limits

As described in Section 2, only originally designed scales were included in this article. The references included in Tables 2–4 described only the original scale and the population in which it was validated, omitting the further validation processes the scale underwent in different populations, settings, or the sometimes more concise forms ('short-forms') and more in-depth validations, according to most recent validation standards. In our view, this can be easily addressed because, once the original author, the name of the scale and measured dimension(s) of the scale are identified, it should not be too time-consuming for the researcher or the clinician to

perform a database search, in order to find if revised versions were published after the publication of the original version.

In order to be as extensive as possible, the review included secondary sources as well as original articles, which are supposed to describe the validation process of the scale. In doing so, one cannot exclude transcription errors in those secondary sources. This might be addressed by referring to the original article, of which references were provided in the list of Tables 2–4.

6. Conclusion and implication for future research

Our literature review identified a large number of scales that can be used to assess the impact of interventions aiming at improving elderly people's caregivers' health. Despite a lack of accurate definitions of concepts and study population, this inventory of scales should be a useful tool for intervention studies and even clinicians work.

Researchers might be helped by the availability of updated databases, listing validated scales according to their outcome measures. In addition, research reports should contain clear definitions of concepts used to describe the population, in order to avoid any confusion in this regard.

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