Outcome measures for informal carers of individuals with neurodegenerative conditions

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The impact of a disease on a patient has become an important outcome measure in medicine and health care. More recently, increasing attention has also been paid to the impact on informal caregivers of someone with a long-term disease. Carers or caregivers play an important role in the care of chronically ill patients, particularly because there is an increase in the number of people with a long-term condition. Vitaliano et al. (1) define informal carers as "caregivers who are not financially compensated for their services." Informal carers tend to be family members, often the patient's spouse, or friends, and provide significant amounts of support to the patient who may have difficulties because of physical, cognitive, or emotional impairments (1). Caring for someone with ill health poses challenges, including psychological, physical, financial, and social factors (2). It is increasingly recognized that caring for someone can be stressful and difficult and that it can lead to adverse physical and psychological outcomes for the carer.

Two types of outcome measures have been used to assess carer burden: generic and carer-specific outcome measures. Using generic instruments is an indirect approach to assessing carer outcomes, whereas using a carer-specific instrument is a direct approach to the assessment of carer outcomes (3). Generic instruments provide broad insight into health, but they do not provide information on the burden resulting from

being a carer. Generic outcome measures tend to have been tested extensively, but mostly not in a carer population. On the other hand, carer-specific instruments provide a more direct measure of carer burden by focusing specifically on carers' experiences.

Carer-specific instruments can be generic in that they have been developed for carers generally, or they can be disease-specific in that they have been developed for the carers of patients with a specific condition. Generic carer instruments (e.g., the Carer Strain Index (4)) provide a more specific measure of carer burden than generic instruments, but these may not capture disease-specific burden. Thus some instruments have been developed to assess disease-specific carer burden, such as the Coping with Multiple Sclerosis Caregiving Inventory (5). Disease-specific measures are sometimes used for conditions other than the condition the instrument was developed for because the items on disease-specific carer instruments mostly do not refer to the specific condition. For example, the Carer Strain Index (CSI) was developed for carers of patients who have recently been discharged from hospital after surgery, but the CSI has been used in dementia (6). However, frequently these instruments will not have been tested for that particular population of carers, and the usefulness of using instruments in this way has been questioned by Vitaliano and colleagues (6).

Outcome measures can also vary in the number of dimensions that they measure. Dimension-specific instruments may measure fatigue or depression (often these are generic rather than carer-specific), whereas other instruments measure several dimensions, including, for example, physical health, psychological health, and social functioning. Many studies use a combination of several outcome measures to assess carer burden. This can be a combination of one or several generic, carer-specific, dimension-specific instruments, or all three. For example, a Japanese study used a generic quality of life questionnaire (WHOQoL), a carer-specific questionnaire (Zarit Burden Interview [ZBI]), and a dimension-specific questionnaire (Beck Depression Inventory) (7).

It is challenging to provide an overview of psychometric properties of outcome measures used in carers for several reasons. First, different types of instruments (generic, disease-specific, and dimension-specific) have been used in carers of a person with a neurodegenerative condition; however, few generic instruments have been formally tested in this population. The psychometric information presented in this chapter on generic instruments is largely extrapolated from surveys rather than being information from formal psychometric evaluations of the instrument. Second, many different instruments have been used, of which the majority have not undergone thorough psychometric testing. Third, different versions of the same instrument have been used, making it difficult to draw overall conclusions on the psychometric properties of any instrument. Fourth, some disease-specific instruments have been used, but have not necessarily been tested, in neurodegenerative conditions other than the condition the instrument was developed for. Finally, some instruments that have been developed and tested in a condition other than a neurodegenerative condition have been used in studies on carers of someone with a neurodegenerative condition. Given all these challenges, this chapter reviews psychometric information on multidimensional generic and carer-specific instruments that have been developed or tested for informal carers of an individual with a neurodegenerative con-

dition. It is beyond the scope of this chapter to discuss dimension-specific carer outcome measures; however, they are widely used, as will be evident from the information given on the validity of some of the generic or carer-specific instruments. This chapter differs from other chapters in this book in that, because of these challenges, the psychometric information had to be largely extrapolated from surveys rather than presented as a review of psychometric evaluation studies. This applies to both the generic instruments and the carer-specific instruments, including the Zarit Burden Interview, which is reviewed more extensively. The various studies used in this chapter are outlined in several tables in the various sections to give information on the study population and on the version of the instrument that was used.

Generic instruments

A wide range of generic outcome measures are available, some of which have been used to assess carer burden. However, few studies have evaluated the psychometric properties for carers of someone with a neurodegenerative condition. The four instruments for which psychometric information is available are the SF-36 (or SF-12), the General Health Questionnaire (GHQ), the World Health Organization Quality of Life (WHOQoL and WHOQoL-bref), the EQ-5D, and the schedule for evaluation of individual quality of life (SEIQoL). The WHOQoL (7, 8) and the EQ-5D (9, 10) were evaluated in only two studies, and the SEIQoL in one study (8). Because of limited information on these three instruments, their psychometric properties will not be discussed in greater detail in this chapter. The SF-36 (including the SF-12) and the GHQ have been evaluated more frequently, and their respective psychometric properties will be outlined in this section.

SF-36 and SF-12

The SF-36 is a generic self-administered health measure that can be used within different

Table 10.1 Evaluative studies related to the SF-36 or the SF-12 when completed by carers of someone with a neurodegenerative condition

Author, date	Disease	Sample	Country	Version
Bell et al. (2001) (12)	Alzheimer's disease	679 carers	Canada	SF-36
Berg-Weger et al. (2003) (13)	Alzheimer's disease	102 former carers whose family member died at least 1 year prior to the study	USA	SF-36
Lyons et al. (2004) (14)	Parkinson's	311 spouse carers	USA	Physical Subscale of SF-36
Argimon et al. (2005) (15)	Dementia	181 carers	Spain	SF-36
McConaghy and Caltabiano (2005) (16)	Dementia	42 carers	Australia	SF-12
Van Den Berg et al. (2005) (17)	Amyotrophic lateral sclerosis (ALS)	208 patients and carers	The Netherlands	SF-36
Patti et al. (2007) (18)	Multiple sclerosis	445 patients and their carers	Italy	SF-36
Martinez-Martin et al. (2007) (19)	Parkinson's	80 patients and 79 carers	Spain	SF-36
Argimon et al. (2004) (20)	Dementia	181 carers	Spain	SF-36
Jenkinson et al. (2000) (21)	Amyotrophic lateral sclerosis (ALS)	451 patients and 415 carers	15 European countries	SF-36

populations (11). It mostly uses Likert-style response scales, but some questions are dichotomous (yes/no). The SF-36 has eight dimensions, including physical function, social function, role physical, role mental, pain, mental health, energy, and health perception. It has been suggested that two summary scales can be derived, namely, a physical component summary score (PCS) and a mental component summary score (MCS). The SF-12 is a shorter, 12-item version of the SF-36, from which the two summary scales (PCS and MCS) can also be derived.

Table 10.1 provides a summary of different evaluative studies on the SF-36 and the SF-12. Half of these studies were carried out in a sample of carers of someone with dementia. Psychometric information mainly relates to issues of validity, and few studies give information on reliability, responsiveness, or precision. No information on feasibility, interpretability, or acceptability is available.

Reliability

Only four studies have evaluated the internal consistency of the SF-36 or SF-12. Good internal consistency for the SF-36 was found in carers of patients with amyotrophic lateral sclerosis (ALS) (21) and for Alzheimer's disease (13). Good internal consistency was also found for the physical subscale of the SF-36, with Chronbach's alpha being 0.89 for the baseline and after 2 years, and 0.91 after 10 years (14).

However, weak internal consistency was found for both the physical and mental component scales of the SF-12 (version 2) in a sample of dementia carers (16).

Validity

Convergent and discriminant validity

The PCS and MCS scores of the SF-36 have been found to be lower in ALS carers than in the general

population in a Europe-wide study (21). A total of 49.7% of carers scored below the mean on PCS and 71.6% below the mean for MCS in comparison with the general population (21). Significant differences in the SF-36 scores of carers and the scores of the Italian normative sample were found on all dimensions of the SF-36, expect for physical functioning (18). In this study, all dimension scores, apart from physical functioning and bodily pain, were significantly lower in carers than in normal subjects. Mental health was the dimension that was most affected in carers, especially among men, followed by vitality and general health. Bodily pain was slightly higher in carers than in normal subjects, especially among women.

Carers with higher pessimism had significantly lower scores on physical health than carers with lower levels of pessimism (14).

Carer instruments

Significant correlations of the dimensions of the SF-36 have been found with the Zarit Burden Interview (ZBI) (19). The correlations were strong for the mental health, mental component, and social functioning dimensions of the SF-36, whereas for the other SF-36 dimensions, the correlations were weak to moderate.

Predictive validity

The MCS scale of the SF-36 has been found to predict the results of the Health Utilities Index Mark 2 (HUI2) in carers of a person with Alzheimer's disease (12).

Sociodemographic variables

Older PD caregivers had significantly poorer physical health at baseline and faster rates of decline (14). Age and sex, in a regression model, were found to be the strongest predictors of a carer's quality of life (18).

Female carers scored lower than male carers on seven of the eight dimensions of the SF-36 in two studies (18, 20). The dimension for which the men scored higher than the women differed between the two studies, with men scoring higher on physical functioning (20) or male spousal carers scoring higher on mental health in comparison with female spousal carers (18). Male spousal carers have also been found to have higher scores than parent carers on physical functioning, role physical, social functioning, bodily pain, mental health, vitality, and general health (18).

Patient variables

Carers of patients who had been placed in a nursing home had significantly lower scores on the two subscales (physical functioning and physical role) and five dimensions (bodily pain, general health, vitality, emotional role, and mental health) of the SF-36, after controlling for confounding variables (15). The type of care received has not been found to lead to a significant difference in quality of life in carers of ALS patients who had received multi-disciplinary care versus patients receiving general care (17).

Precision

Floor and ceiling effects were investigated in only one study for ALS carers, and floor effects were found in 19.3% of carers for role physical and in 23.4% for role mental (21). Ceiling effects were found in 32.7% for physical function, 50.6% for role physical, 49.0% for role mental, and 38.2% for pain.

Responsiveness

Only one study gives information about responsiveness, finding that SF-36 scores for the physical health subscale declined by approximately 13 points over a period of 10 years (14).

General Health Questionnaire

The General Health Questionnaire, or GHQ, is a self-administered questionnaire that focuses on two

Table 10.2 Evaluative studies related to the GHQ when completed by carers of someone with a neurodegenerative condition

Author, date	Disease	Sample	Country	Version
Jackson et al. (1991) (24)	Dementia	24 carers	Ireland	GHQ-30
Draper et al. (1992) (25)	Stroke and dementia	99 co-resident carers (stroke 48 and dementia 51)	Australia	GHQ-30
O'Reilly et al. (1996) (26)	Parkinson's	154 carer spouses and 124 noncarer spouses	Ireland	GHQ-12
Donaldson et al. (1998) (27)	Alzheimer's	100 community dwelling patients and their carers	UK	GHQ-28
Rosenvinge et al. (1998) (28)	Dementia and chronic depression	57 carers (32 dementia and 25 depression)	UK	GHQ-30
Matsuda (1999) (29)	Dementia	Carers of elderly relatives	Japan	GHQ-60
Nagatomo et al. (1999) (30)	Dementia	62 relative carers	Japan	GHQ-30
Groom et al. (2003) (31)	Multiple sclerosis	49 carers (27 of community-dwelling patients and 22 of patients at rehabilitation unit)	UK	GHQ-12
Woods et al. (2003) (32)	Dementia	104 carers	UK	GHQ-28
Prince (2004) (33)	Dementia	706 carers	India, China, South East Asia, Latin America and the Caribbean, and Africa	GHQ-22
Secker and Brown (2005) (34)	Parkinson's	30 carers, 15 treatment and 15 control	UK	GHQ-28
Love et al. (2005) (35)	Motor neuron disease	75 carers	Australia	GHQ-12
Roud et al. (2006) (36)	Dementia	45 carers	New Zealand	GHQ-30

major areas – the inability to carry out normal functions and the appearance of new and distressing psychological phenomena (22, 23). The GHQ is available in several different versions: GHQ-60 (the fully detailed 60-item questionnaire), GHQ-30 (a short form without items related to physical illness), GHQ-28 (a scaled version that assesses somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression), and GHQ-12 (a quick, reliable, and sensitive short form).

No formal evaluation studies of the GHQ in carers of someone with a neurodegenerative condition have been conducted, thus psychometric information is limited and needs to be extrapolated from research studies. Mainly, it is only information on

validity that is available, although one study also gives information on responsiveness. Table 10.2 outlines studies that give psychometric information on the GHQ in carers, highlighting that most of the studies have been conducted with carers of dementia patients.

Validity

Convergent and discriminant validity

Parkinson's carer spouses did not show significant increase in the risk of psychiatric morbidity, as measured by the GHQ-12, in comparison with

controls, but those providing extensive care had an almost five-fold increased risk (26). In a sample of carers of a hospitalized MS patient and carers of a community-dwelling person with MS, the GHQ-12 score was significantly correlated the SODS (Signs of Depression Scale), which was developed to assess mood in stroke patients with communication difficulties (31).

The GHQ-30 was positively correlated with carer burden (30). The GHQ-30 score has also been found to be significantly higher in a group of carers of someone with dementia than in controls (24), and in carers of someone with dementia in comparison with carers of someone with depression (28). However, no significant differences in the score of the GHQ-28 were found between carers of someone with dementia versus someone who had a stroke (25). The GHQ-30 was found to be significantly and positively correlated with carer burden assessed by the Relatives Stress Scale for both dementia and stroke (25). Strong negative correlations were found between the GHQ-30 and the Life Satisfaction Questionnaire (25). The depression and anxiety subscales of the GHQ-30 were found to be moderately related to the negative impact subscale of the COPE (Carers of Older People in Europe) Index, but the positive value subscale of COPE was not significantly related to either of the GHQ-30 subscales (36). The COPE index assesses the role perceptions of older carers.

In a study comparing conventional nurse services versus Admiral Nurse (AN) services (treatment group), a nonsignificant trend for higher GHQ total scores and depression subscales was found for carers who had used AN teams at baseline (32). On follow-up after 8 months, carers who had used AN services had a significantly higher score on the anxiety and insomnia subscale in comparison with carers who had used conventional services.

Carer instruments

The Japanese version of the GHQ-60 was used to validate the subjective burden scale for family carers of elderly with dementia (29). A significant, medium,

and positive correlation was found between the two instruments.

Sociodemographic variables

Differences in the GHQ-12 score have been found between different developing countries and regions, including India, China and South East Asia, Latin America and the Caribbean, and Africa (33). However, it is not clear if these differences were statistically significant.

GHQ-12 scores were found to be related to time as a carer, with those who reported having been a carer for less than 2 years having lower average scores than those who reported caring for longer than 2 years (35).

Household income has been found to be significantly (26) or not significantly (35) related to GHQ-12. The significant difference found by O'Reilly et al. (26) was no longer significant after adjusting for variables such as age, gender, and social class.

Living arrangements have been found to not influence the GHQ score (27, 35); however, another study reported better outcomes for carers who were not co-residents of the patient (32). No significant correlations were found between the GHQ score and the length of time the carer and the patient had lived together (30) or whether dependent or adult children were living at home (35).

Two studies found that the relationship of the carer to the person he or she cared for did not influence the GHQ score (27, 35). However, another study found that the GHQ score was significantly worse for spouses than for offspring carers (30).

One study found no significant correlation between the GHQ and the carer's gender (28), whereas another found that distress as measured by the GHQ-28 was significantly higher in women than in men (27). No significant correlation was found for the carer's age.

Patient variables

A number of patient variables have been found to be significantly related to the carer's GHQ

score, including patient depression, some aspects of behavior disturbance, and psychotic symptoms (27). The GHQ is negatively correlated with the age of the patient with dementia and was positively correlated with the Dementia Behaviour Disturbance Scale (30).

However, a number of patient variables have been found not to be significantly related to the carer's GHQ score, including the dependent's behavioral and mood disturbance (24), patient severity ratings (measured by the MMSE [Mini-Mental State Examination] and the Brief Psychiatric Rating Scale), the behavior rating schedule of the COPE or the Montgomery–Asberg Depression Rating Scale (28), cognitive impairment, and any category of the Activities of Daily Living (ADL) scale, expect for self-expression (30).

Responsiveness

Both conventional and Admiral Nurse services led to lower scores on one of the GHQ subscales (the anxiety and insomnia) over an 8-months period (32). In a randomized controlled trial, it was found that the GHQ-28 score was reduced in both the cognitive behavioral therapy (CBT) group and the control group after 3 months, but the improvement in the CBT group was significantly greater (34).

Carer-specific instruments

Carer-specific instruments could potentially be of two different types: those developed for carers but not for a specific disease, and those developed for carers of someone with a specific disease. In reality, many carer-specific instruments have been developed in one disease, but they are used across conditions. They are suitable for use in that they do not contain any reference in the items to the disease they were developed for. However, they often have not been extensively validated in other diseases, and it could therefore be argued that they may not be suitable for use.

This section will give an overview of carer outcome measures developed in neurodegenerative

conditions, including instruments evaluated in single studies and instruments evaluated in multiple studies. The most commonly evaluated carer outcome measure is the ZBI, and its psychometric properties will be described in greater detail.

The overall picture for carer outcome measures (from both single and multiple studies) is that most have been developed for dementia (including Alzheimer's disease). The second most common condition for single-study instruments is Parkinson's disease. Some carer-specific instruments that have been developed in multiple diseases, such as the Caregiver Burden Scale in stroke and dementia (37) and the Burden of Caregiver Index in Japan, included carers of people with a variety of neurological conditions (38). Most instruments were developed in English-speaking countries, predominantly the United States. A handful of instruments were developed in Asia, but there do not seem to be any from Africa or South America. The sample sizes are mostly small, with approximately two-thirds of the single-study instruments having sample sizes below 100 (range 10–946). For the ZBI, it is "only" about half of the studies that had a sample size below 100 (range 29–770).

As far as the content of carer outcome measures is concerned, some concepts are similar to those of generic outcome measures, such as physical function, mental health, and social health. Symptoms and social support, which are concepts of interest in generic outcome measures, are rarely, if at all, assessed. Additional questions, making the instrument more carer-specific, are questions about existential issues (including personal issues, financial security, or personal costs), time-dependence burden, and demands on the carer. Most instruments assess several of these aspects, and some studies have conducted factor analysis to identify the underlying structure of the instrument (e.g., the Burden Index of Caregivers (38)). The number of items or questions is predominantly between 20 and 30, although a large number of studies do not report how many items their instrument contains. Furthermore, there also is a lack of clarity in a minority of studies on the content of the questionnaire, beyond

the authors' describing that the instrument measures carer burden.

A majority of carer outcome measures have been used in one study only, and usually little information is available on the development and psychometric evaluation. Instruments that have been evaluated and used in multiple studies are the ZBI (developed in the United States), the PIXEL instrument (France) (39, 40), the Elmstahl questionnaire (Sweden) (37, 41, 42, 43, 44), and the Glozman (Russia and Spain) (10, 45). The ZBI will be described in greater detail below because this is the instrument that has been more widely evaluated than any other carer-specific outcome measure. It is important to note that, even with the more extensively evaluated outcome measures, psychometric information is limited, usually to reliability (mostly internal consistency) and validity. Frequently, the validity of carer instruments is not formally assessed, but information on an instrument's validity can be extrapolated from studies where the instrument is used in conjunction with other instruments.

Zarit Burden Interview

The Zarit Burden Interview was first developed in the United States with carers of a person with senile dementia living in the community (46). The Zarit Burden Interview is mostly referred to as the ZBI but also sometimes as the BI (burden interview) (47), CBI (Carer Burden Inventory) (48), BIS (Burden Interview Scale) (49), ZS (Zarit Scale) (50), or ZBS (Zarit Burden Scale) (51). For the purposes of this chapter, it will be referred to as the ZBI.

The ZBI is reported to be the most widely used instrument in carers of a person with dementia (2, 52), including senile dementia, cognitive impairment, and Alzheimer's disease. However, the ZBI has also been used in conditions other than dementia, such as Parkinson's disease (53) and multiple sclerosis (54); elderly in need of care (55); muscular dystrophy (56); and stroke, chronic obstructive pulmonary disease, and general disability (57).

The ZBI, as originally described, consists of 29 questions that measure the degree of burden experienced by a carer (46). Items were developed on the basis of the authors' clinical experience and prior studies. The items refer to the spouse, despite the original study sample also including daughters who were carers. None of the items refer to dementia. From the item scores, a total score was calculated, with four items scored negatively (and hence subtracted from the total score). The items were scored on a scale from "not at all" to "extremely," but it is not clear how many points were on the scale, nor what score was given to "not at all" or "extremely." No formal testing of the ZBI was reported at this point in time.

The original ZBI included 29 questions (46), but was later modified to a 22-item version (93). The ZBI was developed to evaluate subjective impact of caregiving and contains questions on the carer's health, psychological well-being, finances, and social life, and on the carer's relationship with the patient (46, 93). The authors report that the instrument has primarily been used in research but may also be useful for health care practitioners as a way of estimating how much stress the carer is experiencing. The ZBI is scored on a 5-point Likert-type scale (0 = never and 4 = nearly always), with a higher score meaning a higher burden (58). If the extent of the burden on the carer has been assessed before an intervention, then administering the interview again after the intervention will indicate the degree of burden of success or improvement in the caregiver's situation.

The original ZBI was interviewer-administered, and mostly, this has been the method of administration of the questionnaire. Despite this, it has been reported that the ZBI is a self-administered questionnaire (56), and a number of studies (as shown in Table 10.3) have used the ZBI as a self-administered questionnaire.

Versions

As already indicated above, there are a number of different versions of the ZBI, in terms of the number

Table 10.3 Evaluative studies related to the Zarit Burden Interview (ZBI) when completed by carers of someone with a neurodegenerative condition

Author, date	Disease	Sample	Country	Version	Administration
Zarit et al. (1980) (46)	Senile dementia	29 patients in the community and their carers (18 spouses and 11 daughters)	USA	29-item	Interview
Zarit et al. (1986) (58)	Dementia	64 spouse carers (community)	USA	20-item	Interview
Zarit et al. (1987) (59)	Dementia	119 family carers (community)	USA	22-item	Interview
Anthony-Bergstone et al. (1988) (60)	Dementia	184 caregivers (community)	USA	22-item	Not specified
Whitlatch et al. (1991) (47)	Dementia	113 primary carers of a non-institutionalized patient	USA	22-item	Interview
Hébert et al. (1993) (61)	Dementia	40 carers of patients living in the community	France	22-item	Not specified
Magone et al. (1993) (62)	Dementia	25 patient-carer dyads	Argentina	21-item	Self-administered
Hadjistavropoulos et al. (1994) (63)	Dementia	136 patients and their carer (community)	Canada	22-item	Interview
Rankin et al. (1994) (64)	Cognitive impairment	140 patients and their carers (community)	USA	22-item	Not specified
Majerovitz (1995) (65)	Dementia	54 spouse carers currently residing with patient and who are primary carer	USA	22-item	Interview
Molloy et al. (1996) (66)	Cognitive impairment	108 adult- carer dyads	Canada	22-item	Not specified
Arai et al. (1997) (55)	Elderly in need of care	66 carers	Japan	22-item	Self-administered
Coen et al. (1997) (67)	Alzheimer's	50 patients and their primary carers	Ireland	22-item	Not specified
Coen et al. (1999) (68)	Alzheimer's	50 patients and their primary carers	Ireland	25-item	Not specified
Schneider et al. (1999) (48)	Alzheimer's	20 carers for preliminary study, 280 carers for main study	14 European countries	29-item	Semistructured interview for preliminary study Not specified for main study
Hébert et al. (2000) (69)	Dementia	312 carers of an elderly person with dementia	Canada	22-item	Interview
Knight et al. (2000) (70)	Dementia	Sample 1: 220 carers of demented elderly; sample 2: 108 carers	USA	22-item	Interviews
Bedard et al. (2001) (71)	Cognitive impairment	413 carers	Canada	22-item and 4-item	Not specified

Table 10.3 (*cont.*)

Author, date	Disease	Sample	Country	Version	Administration
Colvez et al. (2002) (72)	Alzheimer's disease	322 informal carers	European (Denmark, Germany, Belgium, Spain, Sweden, and France)	29-item	Interview
Edwards and Ruettiger (2002) (73); Edwards and Scheetz (2002) (74)	Parkinson's disease	41 couples in which one spouse or partner had Parkinson's disease	USA	22-item	Self-report
Gallicchio et al. (2002) (75)	Dementia	327 carers of patients living in the community	USA	22-item	Interview
Miyamoto et al. (2002) (76)	Dementia	379 primary caregivers of people with dementia living at home	Japan	21-item	Not specified
O'Rourke and Tuokko (2003) (77)	Dementia	770 carers of community-dwelling patients	Canada	12-item	Interview
Rivera-Navarro et al. (2003) (54)	Multiple sclerosis	91 patients and their carers	Spain	22-item	Interview
Dooley and Hinojosa (2004) (78)	Alzheimer's	40 patients and their carers	USA	29-item	
Taub et al. (2004) (79)	Dementia	50 carers	Brazil	22-item	Interview
Ankri et al. (2005) (80)	Dementia	152 community-dwelling patients and their caregivers	France	22-item	Not specified
Mc Conaghy and Caltabiano (2005) (16)	Dementia	42 carers	Australia	22 -item	Mixture of mailed questionnaire and face-to-face interviews
Spurlock (2005) (49)	Alzheimer's	150 African American or Caucasian caregivers related to the community-dwelling patient	USA	29-item	Self-administered
Boyer et al. (2006) (56)	Muscular dystrophy	56 patients and their family carers	France	22-item	Self-administered
Cifu et al. (2006) (53)	Parkinsonism	49 patients and their carers	USA	22-item	Not specified
Serrano-Aguilar et al. (2006) (81)	Alzheimer's disease	237 carers	Spain	25-item	Self-administered
Arai et al. (2007) (82)	Early-onset dementia (EOD) and late-onset dementia (LOD)	68 patient-carer dyads (14 EOD and 54 LOD)	Japan	22-item	Self-administered

(*cont.*)

Table 10.3 (*cont.*)

Author, date	Disease	Sample	Country	Version	Administration
Bridges-Webb et al. (2007) (83)	Dementia	107 carers of patients living in the community	Australia	Modified ZBI	Not specified
Boutoleau-Bretonniere et al. (2008) (84)	Alzheimer's (AD) and frontotemporal dementia (FTD)	26 FTD and 28 AD patients and their carers	France	22-item	Interview
Bruce et al. (2008) (85)	Mild cognitive impairment	51 patients and their carers	USA	22-item	Interview
Dias et al. (2008) (51)	Dementia	81 patients and their principal carers (41 for intervention and 40 as control)	India	29-item	Interview
Gaugler et al. (2008) (86)	Alzheimer's	406 spouse carers of community-dwelling patients	USA	15-item	Interview
Ko et al. (2008) (87)	Dementia	181 patient-carer dyads	China	22-item	Self-report
Choo et al. (2003) (88)	Dementia	70 carers of a family member with dementia	Malaysia	22-item	Interview
Prince (2004) (33)	Dementia	706 people with dementia living in their own home with their principal caregivers; 179 from India, 91 China and South East Asia, 416 Latin America and the Caribbean, and 20 Nigeria	Multi-country	22-item	Interview
Takahashi et al. (2005) (7)	Dementia	23 informal home-based carers, 24 professional carers, and 31 controls	Japan	22-item	Self-report
Onishi et al. (2005) (89)	Elderly people some with dementia	116 carers of elderly patients, some with dementia, but not clear how many had dementia	Japan	21-item	Self-report
Goldstein et al. (2006) (90)	Amyotrophic lateral sclerosis	50 spouse carers	UK	22-item	Interview
Kim et al. (2006) (91)	Elderly in need of care including some with cognitive impairment	484 carers of the elderly, of which 61 (13%) had dementia	Korea	22-item	Interview
Roud et al. (2006) (36)	Dementia	45 primary carers	New Zealand	18-item, 12-item personal strain subscale and 6-item role strain subscale	Interview
Gort et al. (2007) (50)	Dementia	66 carers of dementia patients who were not in residential care	Spain	22-item	Self-report
Martinez-Martin et al. (2007) (19)	Parkinson's	88 carers of hospital outpatients	Spain	22-item	Self-report

of items or the language used. The original version of the ZBI had 29 items, but a subsequent 22-item version, a short 12-item version, and a 4-item screening version have followed. However, other versions (i.e., with different numbers of items) have also been used (see Table 10.3), and these modifications to the ZBI have been carried out by the authors of specific studies to suit the needs of that particular study, for example, Roud et al. (36).

Reviewing and comparing psychometric properties of the ZBI are challenging because of the number of different versions and because not all studies make it clear which version was used (e.g., (49)), and some such as Cifu et al. (53) report using the 22-item version but reference the 29-item version. In their meta-analysis on the ZBI, Bachner and O'Rourke (52) found that the range of ZBI total items was 7 to 33 (only studies with ZBI items over 6 were included) with almost half of studies (49.3% or 68 out of 138 studies) using the "standard" 22-item scale; 10% used the 29-item version. In four articles, authors had added items to either the 22- or the 29-item scale, and the remaining studies (n = 138) used various abridged versions of the ZBI (52). In Australia, a "modified ZBI" was used (83), but it was not clear what these modifications were, or how many questions this version had.

The ZBI has been used in a number of different countries (Table 10.3); therefore, different language versions exist. Often studies that describe the translation and validation of the translated version are not published in English. Not all translations and evaluations have been carried out in carers of someone with a neurodegenerative condition; the 22-item Japanese version was developed in a sample of carers of the elderly (55), or an 8-item Japanese version of the ZBI was developed in carers of the elderly (93). The 22-item Japanese ZBI was later used in a study with carers of someone with dementia (82).

Psychometrics

The ZBI was originally developed by Zarit et al. (46), but formal evaluation studies were not carried out until later. Mostly, psychometric information remains limited to internal consistency reliability, and validity information can be extrapolated from studies that have used other instruments (carer, patient, or proxy reported). Some more formal evaluation studies were carried out at a later date. The reliability and validity of the ZBI were studied by Hébert and colleagues nearly 20 years after initial development of the instrument (69). The various versions of the ZBI make it challenging to establish, summarize, and compare the psychometric properties of the ZBI from different studies.

Reliability

Mostly, reliability information remains limited to internal consistency (Cronbach's alpha). Overall, internal consistency is the most frequently given psychometric information on the ZBI. For their meta-analysis on the reliability of the ZBI, Bachner and O'Rourke (52) included articles that had used a range of different versions of the ZBI (studies using 6 or fewer ZBI items were excluded). Of the 258 studies found, 149 (57.8%) did not report reliability information in relation to their respective samples, and the remaining 138 articles were included in the study. For internal consistency, the average was Chronbach's alpha = 0.86 (SD = 0.006, median 0.88, range 0.62 to 0.95). Five studies (each using an abridged ZBI version) reported an alpha below the acceptable level of 0.69. Using regression analysis, a large number of variables (such as sample size, mean age of carers) failed to significantly predict the ZBI's internal consistency. Only three variables contributed significantly and uniquely to the regression equation, including the number of ZBI items (with fewer item versions being found to be less reliable), residence of the care recipient (ZBI completed by community-dwelling carers had higher reliability), and language format (Hebrew version statistically lower reliability estimates relative to the English language version). The Hebrew version was the 29-item version, which generally has lower reliability.

Even though it is not clear whether the ZBI is a multi-dimensional outcome measure (see below), internal consistency has been assessed on the dimensions of the ZBI that have been identified in a study by Whitlatch et al. (47), with personal strain having an alpha coefficient of 0.80 and role strain an alpha of 0.81 (47).

Although the meta-analysis by Bachner and O'Rourke (52) shows good internal consistency for the ZBI, it is not clear from the article which studies were included and what information relates to which article. Presumably, studies using the ZBI that were not carried out in dementia were also included in the sample. From the studies included in this chapter (Table 10.3), internal consistency (Cronbach's alpha) ranged from 0.79 to 0.93. Differences in internal consistency have been found between men (alpha 0.82) and women (0.85) for the 12-item version (77), but both these alphas are within the acceptable range.

The meta-analysis also provided information on test-retest reliability. Of the 102 studies included (52), only 11 studies reported test-retest reliability, with the mean correlation coefficient being r = 0.59 (SD = 0.22) (range r = 0.24–0.89) over an interval of 31.56 (SD 27.72) months on average (ranging from a few days to 5 years). Bachner and O'Rourke (52) believed that the variability in the correlation coefficient may have been due to the large range of time and may therefore reflect sensitivity to change as opposed to suspect reliability. The test-retest coefficient was 0.89 in a French study (69) and 0.88 in a Chinese study (87). The time span between testing was 2 weeks in the Chinese study in a small sample of 36 carers (87).

Construct validity

The factor structure of the ZBI was analyzed in eight studies (47, 63, 64, 69, 70, 71, 77, 80). The first of these studies was carried out more than 10 years after the development of the original 29-item ZBI. The samples in these studies were carers of non-institutionalized dementia patients (47, 80), carers of dementia patients (63, 69, 77), and carers of cog-

nitively impaired elderly (71). The ZBI's structure was examined by factor analysis in four studies and by principal component analysis in three studies. The ZBI structure was mostly studied for the 22-item questionnaire apart from the two studies on the 12-item version (69, 77). When the structure of the 22-item ZBI was analyzed, item 22, an overall general burden factor, was generally omitted.

An initial study found two factors: personal strain (12 items) and role strain (6 items) (47). Thus, four items were not contained in either of the two factors. A second study analyzed the ZBI's structure by creating subscales based on the findings by Whitlatch et al. (47) and then calculating Pearson's correlation coefficient between the scores of the subscales. It was found that the two factors were significantly correlated, which led the authors to suggest a unifactorial solution (63). The unifactorial solution found accounted for 40% of the variance (63).

A small study found a two-factor solution, based on factor analysis, with the first factor being "uncertainty and inability for caring," and the second "a familial and social life impact" factor (62). The authors list seven items included for each factor, but it is not clear if these are examples or all the items in that particular factor.

A further study found a five-factor solution accounting for 64% of the variance of the ZBI (64). No further information on this is given, but this finding, together with findings from the factor analysis of the Impact of Caregiving Scale, was used to reduce the total number of items for a burden screen (containing items and factors of both the ZBI and the Impact of Caregiving Scale).

The factor model by Whitlatch (47), as well as two other models (a one-factor and a three-factor solution), was tested by Knight and colleagues (70). Item 22, a global measure of burden, was omitted from the three confirmatory factor analyses. With two different samples, neither the first nor the second model fitted the data. Exploratory analysis revealed a five-factor solution, but two factors had only one item loading on them. Therefore the authors proposed a three-factor solution on 14 of the 22 items, with the factors being embarrassment/anger (nine

items), patient's dependency (two items), and self-criticism (three items). The three-factor solution was confirmed in a second sample, and shifting one item from factor 1 to factor 2 resulted in an improved fit of the model (70). These findings led the authors to conclude that the ZBI does not have a clear factor structure.

A further study used principal component analysis on 21 items (again, item 22 was omitted) of the ZBI and found support for a two-factor solution (personal strain and role strain) (71). From this, the 12-item version was determined by selecting the six items for each factor with the highest factor loading and the highest item-total correlation. Four items were selected according to the highest ranking item-total correlations while respecting factor weighting of the 12-item version (3:1 ratio) to create a screening version of the ZBI. When the short version was used with a two-way ANOVA, the results obtained were identical to those produced with the full version (71).

The viability of the two-factor solution of the 12-item version was further tested by O'Rourke and Tuokko (77) with an initial factor analysis with 200 carers and a second confirmatory factor analysis with 895 carers. Initial factor analysis revealed three factors, but one factor explained less than 10% of the variance and thus was omitted from further analysis. Further analysis of the two remaining factors produced results similar to those of Bedard et al. (71), with each of the 12 items loading on its respective factors. However, four items loaded significantly across factors, and one factor loading in this sample was greater on "personal strain" than on "role strain," which was not in agreement with the findings of Bedard et al. (71). The second confirmatory factor analysis showed good fit of the data for the two-factor solution, and the authors concluded that their findings show that the two-factor solution was viable (77).

Ankri et al. (80) found a five-factor solution for the 22-item ZBI through principal component analysis. Three of the factors were retained because they were clinically relevant, and two factors were discarded (one because it contained only one item, and the second because there was overlap with another factor). The factors for the 22 items represented "consequences on the carer's daily social and personal life" (factor 1 accounted for 41.5% of variance), "psychological burden and emotional reactions" (factor 2, 8.6% of variance), and "guilt" (factor 3, 6.2% of variance).

Another five-factor solution was found for the Chinese version of the ZBI, including the factors of "caregiver's feelings of oversacrifice" (eight items), "patient's dependence on the caregiver" (four items), "negative emotions due to caring" (four items), "caregiver's feelings of inadequacy" (two items), and "uncertainty about the patient's future" (three items) (87). Item 22, a general item often not included in the factor analysis, was included in this factor analysis and loaded on the first factor.

The factor structure of the ZBI was not part of the development process of the ZBI. To date, there is no agreement as to the dimensionality of the ZBI, with some studies having shown that it is multifactorial and other studies having found that it is unidimensional. Studies that have found multiple factors do not necessarily agree on the number of factors, and to date, the factor structure of the ZBI remains unclear.

Validity

Few studies have directly investigated the validity of the ZBI, but some information can be extrapolated from the findings of studies that have used multiple instruments. Predictive validity can be extrapolated from data on the patient or the carer. These data were gained from generic, disease-specific, or dimension-specific outcome measures, and in some cases, carer-specific outcome measures. Associations between the ZBI and personal characteristics of the patient or carer, or with the patient's disease characteristics, have also been studied. Associations between the ZBI and other instruments have mostly been studied through correlations, although some studies have carried out regression analysis or multi-factorial analysis.

Carer variables

Carer characteristics

The type of carer (e.g., formal vs. informal, male vs. female) has in some, but not all, studies been found to have an effect on burden. The ZBI score is statistically significant higher for informal versus professional carers, and this difference remains for the two factors by Whitlatch: "personal strain" and "role strain" (47). No statistically significant relationship was found between ZBI score and the gender of the carer (50, 91), but another study found that female spouses reported almost twice the mean burden of male spouses (74). When the cutoff score was 33 or above as high burden, and below 33 as low to normal burden, it was found that a significantly higher percentage of women reported a high burden score in comparison with male carers (75). Other studies found no significant difference in ZBI score, depending on the carer's gender (47, 88, 89).

With respect to the carer's age, it has been found that there is no significant difference in the burden measured by the ZBI according to the carer's age (50, 88, 89, 94) and that there is a higher burden with increasing age of the carer (81, 91). Using logistic regression, with the ZBI score above 21 as a cutoff score, significant relationships were found between the ZBI and the age of the carer (younger than 48 years of age, or 48 years of age or older) (56). However, another study found that when dichotomizing carers into low or high burden (as determined by the median), no difference in ZBI according to carer's age was noted (94).

Higher burden was significantly associated with lower levels of education (81).

Significant associations of the ZBI score were found with financial dissatisfaction (48), but not with household income (88). Spouse carers in the lowest financial category (<\$25,000/year) reported more than twice the burden of spouse carers in other financial categories (74).

No significant difference in ZBI was found for work outside the house (dichotomized yes or no) (50) or location of residence (rural vs. urban) (74). However, in a later study, the ZBI score was found to be related to location of residence, with carers living in rural areas having a higher burden than carers living in urban areas (91).

After 2 years, patients whose carers had reported higher burden at baseline were more likely to have been placed in a nursing home (58). A variation of ZBI scores was found, depending on whether patients lived in an institution or in the community (86). However, it is questionable whether this information is useful to assess the ZBI, as this study used a modified 15-item version of the ZBI, and it was not clear whether these are all ZBI items, or whether some items are from the original ZBI; some items are newly generated for this study. Another study found that living in an institution was significantly associated with lower ZBI (72).

Four studies report on the effect of ethnicity or country in relation to the ZBI. Differences in burden were found between Korean and American carers of elderly parents with dementia, with Koreans reporting significantly more developmental, social, and emotional burden (95). The authors reported an overall higher burden for Americans, but this difference was small and not significant. Differences in ZBI scores have been found between the countries of India and South Asia; China and South East Asia; Taiwan and Hong Kong; Latin America and the Caribbean; and Nigeria (range, 25.9–50.3) (33), but the authors do not report whether these differences are statistically significant. A significant difference in burden was found between Malays, Chinese, and Indians in Malaysia, with the Malays having a lower score than the Chinese or Indian respondents (88), and between African Americans and Caucasians, with African Americans reporting lower burden (49).

Family relationship

The findings on associations between the ZBI score and the relationships of carers to the persons they care for are conflicting. Some studies found no significant differences in total burden score for child versus spouse carers (46, 91), between a variety of family carers (89), or between different (unspecified) carers (7, 50, 76, 88). However, other studies

have found a significant relationship between ZBI score and the relationship between the caregiver and the care recipient. A European study found that spouses (both husbands and wives) expressed significantly more burden than the other types of informal carers (72), and another study found that higher burden was significantly associated with family relationships (81).

The association between ZBI score and family relationships has been found to change over time, with husbands who were carers reporting less burden than wives who were carers at baseline, but after 2 years, average scores for husbands and wives were about the same (58). In a study that has found that the ZBI is multi-factorial, the scores of two of the three ZBI factors were related to the carer's family status (80). For factor 1 ("consequences on the carer's daily social and personal life"), spouses had higher scores than children. For factor 3 ("guilt"), children had higher scores than spouses. Scores on factor 2 ("psychological burden and emotional reactions") were independent of the carer's family status.

However, associations have been examined not only for the type of relationship between the carer and the person being cared for but for the quality of the relationship or the carer's perception of social support. Carers' subjective social support and quality of relationship before the onset of dementia were both significantly and negatively correlated with carer burden (58). The significant correlation between the ZBI and the quality of the premorbid relationship between the carer and the person who is cared for was not found in another study (89). Marital satisfaction significantly predicted ZBI scores (74).

Social support

Full-time carers have been found to have higher ZBI scores than carers who share the caring responsibility with a sibling (88), but no correlation was found between the ZBI scores and paying for caring services by a nurse or a maid (88). A significant relationship between the ZBI and having no alternative carer has also been found (91). However, there is

also evidence that having an alternative carer does not make a significant difference to the carer's burden (7, 89). Furthermore, no significant difference in ZBI was found according to the help provided to the carer (50).

Social support assessed with the Social Support Appraisals Scale significantly predicted carer burden (68), as did perceived social support (measured by the Perceived Social Support-Family Scale) (74).

Caring variables

Significant correlations were found between the ZBI score and a number of caring variables, including years of caring (80, 89, 96); hours spent caring (19, 80, 88), including number of hours helping the patient with ADLs; number of hours helping with instrumental tasks; the carer's hours of sleep (19); the carer's ability to cope (36, 53, 65); and the number of hours invested in care. The ZBI subscales of "personal strain" and "role strain" have also been found to be weakly to moderately and significantly correlated with the "negative impact" and "positive value" subscales of the COPE Index (36).

Health status and quality of life

It has mostly been found that there is a significant association between carer burden and quality of life. The carer's quality of life has been assessed by a number of different outcome measures. Burden was found to be significantly and inversely correlated with the carer's well-being, as measured by the Satisfaction with Life Scale (65). Individual quality of life (measured by the SEIQoL) was significantly and negatively correlated with burden measured by the ZBI (68). When health status was assessed by the EQ-5D, it was found that carers who reported higher burden had significantly lower quality of life (81).

The ZBI showed low to moderate correlations with the different dimensions of the SF-36 (10). The Chinese ZBI has been found to be significantly related to the Chinese Health Questionnaire and the Caregiver Activity Survey (87).

When the cutoff score was 33 or above as high burden, and below 33 as low to normal burden, carers with worse perceived health had higher odds of reporting a high burden score than carers with good perceived health, although the levels were not statistically significant (p = 0.07) (75). For this study, a single question was used to assess health status with 5- point Likert-style response options. Another study which also found no significant correlation with the ZBI had used a single question rated on a 6-point Likert-style scale on which carers reported their health status (53).

Dimension-specific

A significant correlation has been found between the ZBI score and the carer's distress (53), the carer's anxiety (10, 82), depression (10), spiritual well-being (49), and insomnia (82). Furthermore, for a late onset of dementia group (but not an early onset of dementia group), the ZBI was significantly correlated with the carer's somatic symptoms and perceived difficulties due to the patient's behavioral disturbances (82). The role strain factor of the ZBI has been found to be significantly correlated with the Beck Depression Inventory (7).

Patient variables

Patient characteristics

When carers were dichotomized into low or high burden, it was found that the high-burden group tended to be caring for older patients and for a longer duration (94). Using logistic regression (cutoff score above 21), significant relationships were found between the ZBI and the age of the patient (<or> = 26 years of age) (56). One study found significant but weak correlations between the ZBI and the Parkinson's disease patient's age and age of onset of PD (19). No significant correlation was found between the ZBI and the patient's education, age, gender, or estimated premorbid intelligence, or living situation (living independently vs. living with the carer) (85). One study did not find any sig-

nificant relationships between patient demographic variables and the ZBI (76).

Type of condition

Only information on dementia and Parkinson's in relation to the ZBI score is available. ZBI scores have been found to be significantly higher in carers of elderly with dementia in comparison with carers of elderly without dementia (91). For both the early-onset dementia group and the late-onset group (i.e., age of onset of 65 years and older), the ZBI score was significantly correlated with the Neuropsychiatric Inventory (NPI), but no significant difference in total burden score was found between the early-onset and late-onset groups (82). However, when frontotemporal dementia was compared with Alzheimer's, the ZBI score was found to be significantly higher when the person cared for had frontotemporal dementia (84). Also, the ZBI score significantly increases with the severity of dementia (80). Parallel to an increase in burden with dementia severity, the progression of Parkinson's disease has been found to be significantly related to carer burden (19).

Illness severity

The relationship with the ZBI has been assessed in a number of studies that have used a range of different instruments to assess the patient's illness severity. For some instruments (the Barthel Index and the Hoehn and Yahr Scale), both significant and non-significant correlations have been found.

Significant correlations of total burden have been found between various measures of the patient's impairments (46), including decreasing patient function (66). Significant correlations have been found between all the subscales of the Brief Symptoms Inventory and the ZBI, with the anxiety and hostility subscale being the most strongly correlated with the ZBI (60). Significant correlations were also found between the Direct Assessment of Functional Status Scale (to measure abilities in different functional domains) (62) and some domains of the

Functional Assessment of Multiple Sclerosis questionnaire (including mobility, general contentment, thinking and fatigue, family/social well-being, and the total score) (54), and with the severity of dementia (89), the degree of dependency of the patient (KATZ questionnaire) (56), the "motor examination" of the Unified Parkinson's Disease Scale (53), the Barthel Index (19), the Hoehn and Yahr Scale (19), and the clinical global impression-severity scale (19), as well as the Mattis Dementia Rating Scale for Alzheimer's disease but not for frontotemporal dementia (84).

However, the ZBI score did not differ according to the Barthel Index in another study (55). Other variables that were not significantly related to the ZBI were duration of illness (46), pain measured by a visual analogue scale (53), the Hoehn and Yahr Staging Scale (53), the dementia rating scale (53), disability (measured by the Functional Disability Scale) (84), and the patients' neuropsychological test performance (85).

Patient behavior

Patient behavior or activity has been found to be mostly significantly related to carer burden as measured by the ZBI. Significant associations have been found between the ZBI and behavioral disturbance of the person cared for (48, 50, 55, 58, 69). Carers of patients with behavioral disturbances had significantly higher ZBI scores than those who cared for patients without behavioral disturbances (as measured by the Behavioral Disturbances Scale) (55). Furthermore, patient behavior disturbance, as measured by the Baumgarten Behavior Disturbance questionnaire, significantly predicted carer burden (68).

A significant positive linear relationship has been found between the total score of the Dysfunctional Behaviour Rating Instrument (DBRI) and the ZBI score (66), and three of the seven domains ("acting out," "disruptive behavior," and "frustration") of the DBRI and the ZBI were strongly significantly associated. Other domains of the DBRI were significantly, but weakly, related to the ZBI, including "hallucinations" and "other behaviors," but no significant association was found with the domains of "delusions" and "repeating."

The ZBI has been found to be significantly related to ADL (Activities of Daily Living) (62, 66, 80), IADL (Instrumental Activities of Daily Living) performance (66, 80), IADL involvement (80), and SMS-ADL (Activities of Daily Living Subscale of the SCOPA-Motor scale) (19). The ZBI is also significantly correlated with some other (specific) items of ADL, including incontinence, grooming, toileting, and feeding (62). The relationship between IADL (instrumental ADL) and burden has been found to be stronger than that between basic ADL and burden (66). The amount of assistance needed with ADLs was found to be the single strongest predictor of burden, with the burden increasing with the greater need for assistance of the person with Parkinson's (74). When patient behavior was assessed by proxy, it was also found to be significantly related to carer burden (85). Only one study did not find a significant difference in ZBI score between carers of patients with no IADL impairment and those with any IADL impairment (91).

One study examined how ZBI factors are related to patient behavior (80) and found that the ZBI has five factors; investigators examined how the scores of the factors are related to patient behavior. The scores of factor 1 were found to be related to degree of difficulty on ADL and IADL performance or involvement. The scores of factor 1 were also related to the patient's aggressiveness, verbal aggressiveness, wandering, and communication problems (80). Scores on factor 2 were related to the patient's verbal aggressiveness, sadness, and depression, with lack of IADL involvement and with progression of dementia (80).

Correlations between carer burden and patient behavior have been found to be related to the severity of illness. For mobile patients, there was a significant correlation for the degree of care needed in dressing and the ZBI but not for any other ADLs (76). There was no significant correlation for any ADLs and the ZBI for nonmobile patients (76). For the two groups together (mobile and nonmobile), two ADL

items (feeding and ambulating) were significantly related to the ZBI score (76). In the mobile group, there was a significant relationship between the ZBI and frequency of 13 out of 14 individual behaviors, and in the nonmobile group, there was a significant relationship only for six individual behaviors (such as "interfering with family conversations" or "physical and/or verbal aggression") (76). In the mobile group, "wandering" was the strongest predictor of carer burden, accounting for 16% of the variance. Other predictors of carer burden for the mobile group were "interfering with family conversation," "physical and/or verbal aggression," and "repetition and/or clinging." In the nonmobile group, "repetition and/or clinging" was the only predictor of carer burden (76).

Patient mental state

The relationship between carer burden and the patient's mental state has been frequently investigated. It has been found that the patient's mental state after 2 years was significantly related to carer burden (58). Various aspects of mental state have been assessed, including cognition, depression, and memory of the patient. Frequently, the Mini-Mental State Examination (MMSE) has been used to assess the patient's mental state. The ZBI has been found to be significantly correlated with cognitive decline (as assessed by the Blessed Dementia Scale) (48, 62), the patient's cognitive impairment (48), the patient's mental state as assessed by the MMSE (80) and the Folstein MMSE (53), and cognitive difficulties (as measured by the Cognitive Difficulties Scale) (85). Furthermore, ZBI scores were significantly higher in carers of patients with moderate to severe cognitive impairment (according to MMSE) than in carers of individuals with mild cognitive impairment (91). A significant negative correlation was found between the MMSE and the ZBI for mobile patients, but not for the nonmobile group (76).

However, some studies failed to find significant correlations with the patient's mental state; for example, no significant correlations were found for the ZBI with the Global Deterioration Scale, which measures cognitive decline (62), the MMSE (62), and the standardized MMSE (66). One study has examined how ZBI factors are related to the patient's mental status (80), and the scores of factor 1 were found not to be related to severity of dementia as measured by MMSE or the Clinical Dementia Rating scale.

The patient's mental state in terms of depression has been assessed in a number of studies, all of which have found significant associations between the patient's depression and the carer's burden, despite the fact that a variety of different outcome measures were used to assess the patient's depression. Significant relationships between burden and depression were found with the Geriatric Depression Scale (66), the Hospital Anxiety and Depression Scale (19), and the Beck Depression Inventory (85). Scores on factor 2 of the ZBI were related to the patient's sadness and depression, irrespective of MMSE score or CDR (clinical dementia rating) measurement (80). Significant relationships between burden and patient depression were also found when the carer reported that the patient was depressed or unhappy (89), or when the carer completed the Beck Depression Inventory by proxy (85).

As far as the patient's memory was concerned, it has been found to be significantly related to carer burden (both at baseline and at 2-year follow-up) (58). Furthermore, the ZBI was significantly correlated with the subscales of the revised memory and behavior problems checklist, as well as the total score (69).

Longitudinal

Variation in ZBI scores was found, depending on whether patients were in the treatment versus the nontreatment group and whether they lived in an institution or in the community (86). Again, this information is based on a modified 15-item version of the ZBI, and it was not clear whether these are all ZBI items or whether some items were from the original ZBI or were newly generated for this study.

Responsiveness to change

The association between ZBI score and family relationship has also been found to change over time, with husbands who were carers reporting less burden than wives who were carers at baseline, but after 2 years, the average scores for husbands and wives were about the same (58).

At baseline, there was a difference in burden between husband and wife carers, but this difference did not exist after 2 years (59).

No changes in ZBI score were found as a result of an intervention, which was a community-based program focusing on supporting the carer by providing information on dementia, guidance on behavior management, a psychiatric assessment and psychotropic medication if needed (51).

Cut-off scores

The first study that aimed to establish clinical cut-offs for carer burden was conducted by Rankin et al. (64). The authors concluded that they did not find a definite cutoff, but even if they had, it probably would not have been useful in terms of providing information on a cut-off score for the ZBI because the instrument used to establish the cut-off score was based on items from two carer burden outcome measures: the ZBI and the Impact of Caregiving inventory.

Bedard et al. (71) suggest a cutoff score of 17 for the 12-item ZBI, and of 8 on the 4-item ZBI. This cutoff represents the top quartile of the burden score; however, the authors point out that their data cannot be assumed as normative. In their study, O'Rourke and Tuokko (77) further tested the cutoff score first suggested by Bedard et al. They found that a score of above 16 on the ZBI identified less than half of the carers presenting with clinically significant depression, as measured by the Center for Epidemiologic Studies Depression Scale (CED-S). A cut-off score of above 10 increased sensitivity to 75% relative to the CED-S but reduced specificity to 68%.

This led the authors to conclude that it is premature to propose a definite clinical cutoff.

Two further studies use cut-off scores for their analysis. The first study used a cut-off score of 33 or higher to signify "high burden" and a score below 33 as "low to normal burden" (75). Boyer et al. (56), for the purposes of their study, classed a ZBI score of below 21 as absent to slight burden, and a ZBI of 21 and above as moderate to severe burden. For both studies, no information is available on how this cut-off score was derived.

Feasibility

One study (12-item version) found a significantly higher response rate from female carers in comparison with male carers (77).

Floor and ceiling effects

One study described having 90% of computable scores with 1.3% of ceiling and floor effects (19).

Conclusion

To summarize, carer burden in long-term conditions is being increasingly assessed, including in neurodegenerative conditions. A wide range of instruments have been used, but little formal psychometric testing has been undertaken, and psychometric information mostly needs to be extrapolated from studies using the instruments. This means that little, if any, psychometric information is available for generic instruments, and for most generic instruments, the information is derived from a single study. The largest number of studies for generic instruments giving some psychometric information are related to the SF-36 (and SF-12) and the GHQ. Mostly, only information on validity is available, although information on responsiveness is available from one study for each measure. Additionally, some reliability and precision information

is available for the SF-36. Because generic outcome measures have been assessed and validated widely, it is likely that these instruments are useful in the assessment of carer health-related quality of life. However, more formal and extensive psychometric testing would need to be carried out to confirm this.

As far as carer-specific instruments are concerned, many different instruments have been used, but few have been formally developed and tested. The instruments have mostly been developed for dementia, including the ZBI, which has been reviewed more extensively in this chapter. The ZBI is thought to be the most commonly used carer burden instrument for dementia (2). Available psychometric information is predominantly validity information, which is similar to the evaluation information available for generic instruments. Some evaluation studies, such as those evaluating the dimensionality of the ZBI, were carried out many years after the first development of the ZBI. Additionally, some evidence is conflicting, such as the evidence on whether the ZBI is unidimensional or multi-dimensional. However, evidence from a wide range of studies indicates that the ZBI is a valid instrument. The ZBI also fared favorably in a review by Moniz-Cook et al. (97), who rated the ZBI well, despite the paucity of intervention outcome data, and concluded that the ZBI will probably stand the test of time. Similarly, because generic instruments are increasingly used in carer populations for which they have not been validated, the ZBI is commonly used for populations for whom it has neither been intended nor validated (52). The conclusion regarding the value of using ZBI in carers of someone with a neurodegenerative condition other than dementia has to be the same as for generic instruments. Given evidence of the psychometric properties of the ZBI, it is likely that it is useful for assessing carer burden in neurodegenerative conditions generally, and not only in dementia, for which it was originally developed. As for generic instruments, more formal and extensive testing of the ZBI is required to confirm this.

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