Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures

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Objective: The array of demanding tasks carried out by caregivers of people with dementia have significant negative impacts on their physical, mental and social well-being. Needs assessment allows individuals to indicate the extent to which their needs across different areas have or have not been met, allowing for estimations of the prevalence of needs and the extent to which help is required. This approach is extremely valuable in a clinical context, as it enables identification of the areas with which caregivers report a particular desire for help and allows targeting of support and resources to those who identify high levels of unmet needs. This systematic review aimed to critically examine the psychometric properties of measures that assess unmet needs of caregivers of people with dementia.

Methods: Medline, Embase, PsycINFO and Cochrane electronic databases were searched between January 1990 and August 2015 for English-language publications describing the development or validation of measures assessing the unmet needs of adult caregivers of people with dementia. The psychometric properties of included measures were assessed against standard criteria for psychometric quality.

Results: Four measures met the inclusion criteria. Only half of the indices of psychometric quality were tested across measures. Three measures had adequate internal consistency reliability, of which one also showed adequate test–retest reliability. Two measures reported adequate construct validity, while criterion validity was not assessed for any measure.

Conclusions: There is a clear need to develop a psychometrically rigorous instrument to identify the unmet needs of caregivers of people with dementia. Copyright © 2016 John Wiley & Sons, Ltd.

Introduction

Caregivers of people with dementia experience substantial burden

The number of people with dementia worldwide is projected to increase to 106.8 million by 2050 (Brookmeyer *et al.*, 2007). The increased incidence of dementia is expected to place added strain on finite health resources, leading to a greater reliance on informal caregivers providing care to people with dementia in the community. Caregivers of people with dementia commit significant amounts of time across a range of tasks, including assistance with self-care, mobility, communication, cognitive tasks, household chores and organising healthcare (Brodaty and Donkin, 2009). They also provide critical emotional support to the person with dementia. This multitude of demands, which often stretches over a number of years, can have an adverse impact on the physical, psychological and social well-being of the caregiver. Caregivers of people with dementia are more likely to develop medical and psychological comorbidities and experience social isolation and financial burdens than those who are not caregivers (Alzheimer's Association, 2013; Alzheimer's Association, 2012).

The burden on caregivers of people with dementia is among the highest of all caregiving groups (Kim and Schulz, 2008; Australian Institute of Health and Welfare, 2012), with a higher proportion of these caregivers reporting at least one adverse physical or emotional effect of caregiving relative to caregivers in general (57% vs 48%, respectively; Australian Institute of Health and Welfare, 2012). The burden experienced by the caregiver increases as the disease progresses (Warchol-Biedermann et al., 2014), and the extent of burden is associated with the likelihood of the person with dementia being placed in full-time care (Schulz et al., 2004; Tsuji et al., 1995).

Approaches to assessing burden among caregivers of people with dementia

Current approaches to identifying the burden experienced by caregivers of people with dementia have primarily focused on determining the exact types of burden experienced (e.g. Zarit Burden Interview and Caregiver Burden Inventory), or psychological outcomes such as anxiety or depression (e.g. Geriatric Depression Scale and Hospital Anxiety and Depression Scale). These approaches allow identification of the issues and problems experienced and their magnitude. However, these measures do not assess the extent to which caregivers perceive that they require help with these issues. Research has consistently shown poor agreement between healthcare providers and individuals regarding the issues that individuals report needing help with (Pollock et al., 2007; Osse et al., 2000). Therefore, it is important to ask caregivers directly about the issues with which they need assistance to achieve optimal well-being. Needs assessment is an approach that allows individuals to indicate the extent to which their need for help with different issues has or has not been met, allowing for estimations of the prevalence of needs and the magnitude of help required (Meaney et al., 2005). This approach is extremely valuable in a clinical context, as it enables healthcare providers to focus on the issues that caregivers themselves have identified as the ones they most need help with. It can also assist in identifying caregivers who experience higher levels of unmet needs and therefore require greater support. In a research setting, these measures may be used to develop targeted interventions that are responsive to the needs of caregivers and to provide reliable outcome measures to assess the effectiveness of interventions. The extent of self-reported unmet needs has been shown to be related to quality of life in other chronic disease populations (Hansen et al., 2013), suggesting that interventions to reduce unmet needs have significant potential to improve well-being.

Some measures used to assess unmet needs of people with dementia, such as the Camberwell Assessment of Need for the Elderly (Reynolds et al., 2000) and the Tayside Profile for Dementia Planning (Gordon et al., 1997) also include several items that assess caregiver unmet needs. However, these items do not comprehensively characterise the unmet needs of caregivers by focusing on the caregiver experience, or assess caregiver needs across a comprehensive range of domains. For example, the Camberwell Assessment of Need for the Elderly includes two items assessing the caregiver's need for information and the caregiver's level of psychological distress. Unmet needs measures that are developed specifically to assess the needs of caregivers of people with dementia are necessary to allow assessment of the unique concerns of this group. These measures may be more sensitive to the detection and quantification of clinically meaningful changes in need than generic measures.

Assessing the quality of unmet needs measures for caregivers of people with dementia

To ensure that measures assessing the unmet needs of caregivers of people with dementia produce data that is accurate, comprehensive and useful in clinical and research contexts, their psychometric properties should be investigated. Standardised measures should be valid, reliable and acceptable to respondents (Keszei et al., 2010). The feasibility of measures within their intended setting (either research or clinical) should also be considered. For example, measures intended for clinical use should be briefer than those intended for research, given the time-limited nature of consultations. Assessment of the quality and feasibility of unmet needs measures will determine whether data obtained from these measures is useful in informing the development of appropriate interventions and allocation of resources to benefit caregivers of people with dementia.

Aim

To critically examine the psychometric properties of measures that assess unmet needs of caregivers of people with dementia.

Methods

Literature search

Medline, Embase, PsycINFO and Cochrane databases were searched using Medical Subject Headings and keywords (Supporting Information). Searches were limited to English-language studies published from January 1990 to August 2015. The start date of 1990 was selected because of seminal work on informal caregiving that occurred in this decade (Pearlin *et al.*, 1990; Aneshensel *et al.*, 1995). After coding according to inclusion/exclusion criteria was performed (see succeeding section), a second database search using the names of identified measures was performed across all databases to ensure that all publications describing the development or testing of these measures were captured. The reference lists of all included articles were also manually searched.

Inclusion/exclusion of studies

Inclusion criteria. Qualitative, quantitative and mixed methods studies were included if they described the development, psychometric properties or acceptability of a measure of unmet needs of caregivers of people with dementia. Caregivers were defined as 'any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problem' (Martínez-Martín *et al.*, 2007). Unmet needs were defined as 'issues of concern for which the individual perceives they require assistance' (Lipscomb *et al.*, 2004). Studies were included if they described measures that (i) were developed specifically for caregivers of people with dementia, or the sample included caregivers of people with dementia whose data were reported separately from other caregivers, or caregivers of people with dementia comprised at least 80% of the sample; (ii) produced quantitative data; (iii) assessed unmet needs from the caregiver's perspective (i.e. caregivers were directly asked about their need for help with problems); (iv) assessed more than one dimension of unmet needs; (v) were developed with caregivers aged at least 18 years; and (vi) were published in English.

Exclusion criteria. Conference abstracts, commentaries, reviews or editorials were excluded.

One reviewer (A. G.) conducted an initial screen of titles and abstracts of retrieved articles according to the inclusion/exclusion criteria. The remaining full-text articles were assessed by another reviewer (E. M.) to identify measurement tools that met the inclusion criteria. A random 20% of these articles were screened according to the inclusion/exclusion criteria by a second reviewer (J. B.), with the degree of agreement between reviewers assessed using Cohen's Kappa. Discrepancies between reviewers were resolved through discussion.

Data extraction and coding of measures

Coding of included measures was performed independently by two reviewers (E. M. and A. B.), with discrepancies resolved through discussion. The following characteristics were extracted and coded:

(1) *Measure characteristics.* These included mode of administration, purpose (clinical or research), number of items, number and type of domains assessed, time frame over which needs were assessed and response scale. The characteristics of the sample used to test the psychometric properties of the measure were also extracted, including the sample size and response rate, age and gender of caregivers and care recipients, relationship between caregiver and care recipients and proportion of caregivers and care recipients cohabitating.

(2) *Psychometric properties.* These included reliability, validity, responsiveness, feasibility and acceptability. These properties were rated according to predefined criteria, summarised in Table 1. The authors of included measures were contacted to check if there were any additional psychometric properties reported in any further publications or in the grey literature. Properties were recorded as 'not reported' if the paper described this property as being assessed in the Methods section, but the corresponding data were not reported in the Results section. Properties which the authors indicated had been assessed but not yet published at the time of the review, were also recorded as 'not reported'. Properties with no evidence of having been assessed were recorded as 'not assessed'.

Results

Number of studies reporting the development or psychometric properties of measures

A summary of the study selection process following the Preferred Reporting Items for Systematic Reviews and

Table 1 Summary of the criteria used to define whether each psychometric property had been met

Psychometric property	Criteria
Reliability	
Internal consistency	
Degree of consistency between items on a measure (Devellis, 2012).	Cronbach's $\alpha > 0.70$ (Lohr et al., 1996; Mcdowell, 2006). Item-total correlations between 0.20 and 0.80 (Streiner et al., 2014).
Test–retest	
Consistency of scores across repeated instances of administration (Lohr et al., 1996).	Repeated administration after 6–14 days (Marx et al., 2003). Cohen's $\kappa > 0.60$ (Lohr et al., 1996). Pearson correlation coefficient or intraclass correlation coefficient >0.70 (Lohr et al., 1996; Mcdowell, 2006).
Validity	
Face/content	
Subjective assessment by respondents or administrators as to whether a measure appears to assess what it is intended to measure (Anastasi and Urbina, 1997).	Developed in consultation with intended users (Terwee et al., 2007). Assessed as adequately representing the construct of interest by administrators/respondents (Anastasi and Urbina, 1997).
Criterion	
Concurrent: How well a measure agrees with a 'gold standard' measure of the same construct (Mcdowell, 2006). Predictive: The extent to which a measure predicts future outcomes (Mcdowell, 2006).	Choice of 'criterion' measure justified; correlation with 'criterion' measure >0.70 (Terwee et al., 2007). Reports relationship between scores obtained on measure and a future outcome (Mcdowell, 2006).
Construct	
Way in which the structure of the measure (grouping of items) relate to conceptual constructs.	
Convergent: Positive correlation with scores on a different measure which assesses the same construct (Mcdowell, 2006).	Pearson correlation >0.40 (Cohen, 1977)
Divergent: No relationship with scores on a measure which assesses a different construct (Mcdowell, 2006).	Pearson correlation <0.30 (Cohen, 1977)
Known-groups: Ability of the measure to distinguish between different groups of individuals (Devellis, 2012).	Statistically significant differences between groups (Lohr et al., 1996).
Factor analysis: Analysis to identify underlying theoretical constructs.	Eigenvalues >1 (Kaiser, 1960) or factor loadings of >0.4 (Stevens, 1992).
Cross-cultural adaptation	
Degree to which a translated or adapted version of the measure shows similar psychometric properties to the originally developed measure (Mokkink et al., 2010).	Similar reliability and validity indices between the original and translated/adapted measures (Lohr et al., 1996).
Responsiveness	
Ability of the measure to identify clinically relevant changes over time (Lohr et al., 1996).	Reported statistically significant change over time, effect size >0.50 (Lohr et al., 1996; Mcdowell, 2006).
Acceptability	
Extent to which the measure is acceptable to respondents.	Acceptable completion time, reading age. Reported response rate, number of missing items (Lohr et al., 1996).
Feasibility	
Extent of burden placed on those administering the measure.	Time to administer, score and interpret reported (Lohr et al., 1996).

Meta-Analysis diagram is provided in Figure 1. The search retrieved 2763 articles. After removal of duplicates, 1416 unique abstracts were assessed against the eligibility criteria. Following the initial screening of titles and abstracts, the full text of 85 articles was reviewed against the eligibility criteria. Four measures were identified, which met the inclusion/exclusion criteria (Table 2). Agreement between raters who assessed the full-text articles was excellent ($\kappa = 1$). No additional articles were retrieved from the second database search utilising the names of included measures.

Characteristics of included measures

Four measures meeting inclusion criteria were included: Primary Subjective Stressor (PSS; Bass et al., 2012), Gaugler et al., unmet needs measure (Gaugler et al., 2004), Caregiver Needs Checklist for Dementia (CNCD), (Vaingankar et al., 2013) and Caregiver Needs Assessment for Dementia (CNA-D; Wancata et al., 2005). A summary of the characteristics and validation sample for each measure is given in Table 2.
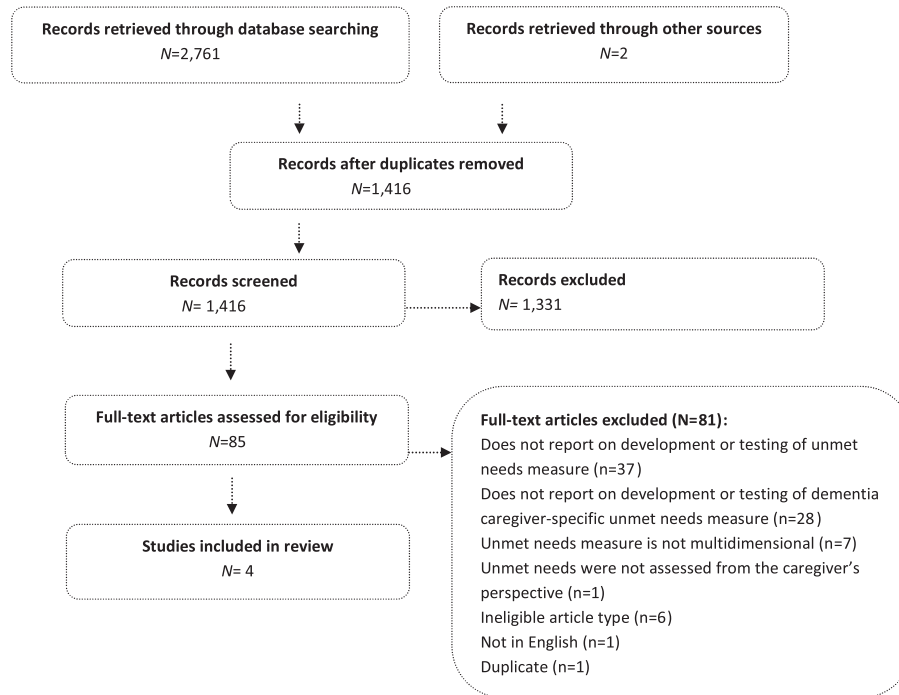
Figure 1 Flow chart showing the number of records retrieved and number of measures included in the final synthesis.

Purpose. All measures were intended for use in research, rather than clinical, settings.

Administration mode and structure. Of the four measures identified, three (Bass *et al.*, 2012; Gaugler *et al.*, 2004; Vaingankar *et al.*, 2013) included only self-reported ratings of need by the caregiver. Two of these measures used a questionnaire format (Gaugler *et al.*, 2004; Vaingankar *et al.*, 2013), and one was a structured interview (Bass *et al.*, 2012). These three measures contained 26–34 items covering four to eight domains. The other measure (Wancata *et al.*, 2005) was a semi-structured interview conducted by a trained interviewer, with ratings made by both a caregiver and the interviewer. The caregiver and interviewer first rate the severity of problems experienced within 18 problem areas. Then, a number of different intervention options are provided for each problem area. Caregivers and interviewers then provide separate ratings of whether the intervention is needed and whether the caregiver has received the intervention.

Domains. Some domains were consistently included across measures. All of the measures included the domains: informational, for example, 'Lack of information about dementia' (Wancata *et al.*, 2005); emotional, for example, 'The emotional support that

I receive from my family while taking care of my relative/friend' (Vaingankar *et al.*, 2013) accessing services or formal support, for example, 'Professional services (either hospital or community based) that I have sought for my relative/friend with dementia are geographically accessible' (Vaingankar *et al.*, 2013). A legal and/or financial domain, for example, 'Legal advice' (Gaugler *et al.*, 2004), and a care tasks and/or assistance with activities of daily living domain, for example, 'Helping your loved one bathe' (Gaugler *et al.*, 2004) was included in three measures.

Time frame. The time frame over which caregivers were asked about their needs was reported for two of the four measures. The CNA-D (Wancata *et al.*, 2005) assessed caregivers' needs over the previous 3 months, while the Gaugler *et al.*, (2004) unmet needs measure assessed unmet needs at present.

Response scale. Two measures used a Likert-style response scale, allowing caregivers to rate the extent to which their needs had been met (Vaingankar *et al.*, 2013; Wancata *et al.*, 2005). The remaining two measures used a dichotomous response scale, only allowing caregivers to indicate whether they perceived each need to be met or unmet (Bass *et al.*, 2012; Gaugler *et al.*, 2004).

Table 2 Summary of measure and validation sample characteristics

	Domains included (number of items)	Time frame over which needs assessed	Response scale	Sample characteristics
Measure name: PSS (Bass et al., 2012) *Country:* USA *Purpose (research vs clinical):* research use *Administration method:* structured interview *Number of items:* 30 *Sample size (response rate):* n = 486 (29.4%)	1. Understanding dementia and its symptoms 2. Care tasks 3. Veteran's affairs and other services 4. Legal and financial issues 5. Organising family care 6. Living arrangements 7. Emotional support 8. Medications and medical follow-up Note: Number of items was not reported	Not reported	Caregiver indicates whether they or the person with dementia needed more help or information for each item by responding 'yes' or 'no'.	*Caregiver:* M = 69 years, 94.9% female. *Care recipient:* M = 80.07 years (SD = 7.47); 2.5% female. *Caregiver relationship to care recipient:* 71.4% were wives of care recipient. *Proportion cohabitating:* 85%
Measure name: Gaugler et al., (2004) unmet needs measure *Country:* USA *Purpose (research vs clinical):* research use *Administration method:* caregiver-completed questionnaire *Number of items:* 34 *Sample size (response rate):* n = 694 (55%)	1. Activities of daily living help (5) 2. Instrumental activities of daily living help (6) 3. Dementia symptoms (2) 4. Timing of care (3) 5. Formal support (8) 6. Information (4) 7. Confidante (6)	Now	Caregivers indicate whether they need more help with an item by responding 'yes' or 'no'.	**Community-dwelling** *Caregiver:* M = 62.23 years (SD = 13.48) 69.7% female *Care recipient:* M = 76.36 years (SD = 9.09) 63.6% female *Caregiver relationship to care recipient:* 48.3% spouse of care recipient *Proportion cohabitating:* not reported. **Institutional care** *Caregiver:* M = 57.64 years (SD = 11.82) 70.7% female *Care recipient:* M = 78.00 years (SD = 9.79) 76.1% female *Caregiver relationship to care recipient:* 23.1% spouse of care recipient *Proportion cohabitating:* not applicable. **Deceased** *Caregiver:* M = 61.67 years (SD = 13.38) 72.7% female *Care recipient:* M = 80.46 years (SD = 7.11) 64.6% female *Caregiver relationship to care recipient:* 28.7% spouse of care recipient *Proportion cohabitating:* not applicable.

(Continues)

Table 2. (Continued)

	Domains included (number of items)	Time frame over which needs assessed	Response scale	Sample characteristics
Measure name: CNCD (Vaingankar et al., 2013) *Country:* Singapore *Purpose (research vs clinical):* research use *Administration method:* caregiver-completed questionnaire *Number of items:* 26 *Sample size (response rate):* n = 63 (response rate not reported)	1. Information (7) 2. Emotional and social support (7) 3. Financial support (4) 4. Accessible and appropriate facilities (8)	Not reported	6-point response scale ('strongly agree', 'agree', 'disagree', 'strongly disagree', 'I did not want [need specified]/these services', 'This does not apply to me')	*Caregivers:* M = 52.9 years 60% female *Care recipients:* Age range 54–93 years Gender not reported *Caregiver relationship to care recipient:* 60% were children, 20% were spouses, 20% were siblings, grandchildren or daughters/sisters-in-law. *Proportion cohabitating:* not reported.
Measure name: CNA-D (Wancata et al., 2005) *Country:* Austria *Purpose (research vs clinical):* research use *Administration method:* Interview with ratings made by caregiver and trained interviewer *Number of items:* 18 problem areas *Sample size (response rate):* *Content validity sample:* n = 40 caregivers, 40 providers (response rate not reported) *Concurrent validity/reliability sample:* n = 45 (100%)	Problem areas: 1. Lack of information about dementia 2. Lack of information about treatment 3. Lack of information about services 4. Financial burden 5. Legal issues 6. Disappointment caused by the illness, concerns for the patient's future 7. Communication problems and conflicts with the patient 8. Burdened by behavioural problems of the patient 9. Problems caused by crises 10. Not enough time for oneself 11. Social isolation, conflicts with the family. 12. Burden caused by dangerous situations 13. Fear of stigmatisation and discrimination 14. Feelings of guilt, being blamed 15. Missing nursing skills 16. Difficulties concerning household tasks 17. Burned out or overstrained by care 18. Physical or psychiatric illness of the carer	3 months	The severity of each problem area is rated on a 3-point scale, including 'no or mild problem', 'moderate problem' or 'severe problem'. Between 2 and 6 different intervention options are then provided for each of these problem areas. Ratings of whether each intervention is needed are made according to the following 5-point scale: 'no need', 'overprovision', 'unmet need', 'partially met need' and 'met need'. Separate ratings of need are completed by the caregiver and a professional rater.	**Sample to test content validity** *Caregivers:* M = 51.1 (SD = 13.4) 62.5% female *Care recipients:* Age not reported Gender not reported *Caregiver relationship to care recipient:* 59.5% were children of the care recipient *Proportion cohabitating:* not reported **Sample to test concurrent validity and reliability** *Caregivers:* M = 60.9 (SD = 11.9) 73% female *Care recipients:* M = 77.5 years (SD = 9.3), 48% female *Caregiver relationship to care recipient:* 52% were children of the care recipient. *Proportion cohabitating:* 49% cohabitating

CNA-D, Carers Needs Assessment for Dementia; CNCD, Caregivers Needs Checklist for Dementia; PSS, primary subjective stressor.

Characteristics of validation samples. Sample sizes ranged from 40 (Wancata *et al.*, 2005) to 694 (Gaugler *et al.*, 2004). Caregiver and care recipient gender and age was not reported comprehensively for two of the studies (Vaingankar *et al.*, 2013; Wancata *et al.*, 2005). Where reported, caregivers' mean age ranged from 51.1 (Wancata *et al.*, 2005) to 69 years (Bass *et al.*, 2012), and the proportion of female caregivers ranged from 60% (Vaingankar *et al.*, 2013) to 95% (Bass *et al.*, 2012). The mean age of people with dementia ranged from 76.4 (Gaugler *et al.*, 2004) to 80.5 years (Gaugler *et al.*, 2004), and the proportion of females ranged from 3% (Bass *et al.*, 2012) to 76% (Gaugler *et al.*, 2004). The proportion of caregivers who were children of the care recipient ranged from 52% (Wancata *et al.*, 2005) to 60% (Vaingankar *et al.*, 2013), and the proportion who were spouses of the care recipient ranged from 20% (Vaingankar *et al.*, 2013) to 71% (Bass *et al.*, 2012). The proportion of caregivers who lived with the person with dementia ranged from 49% (Wancata *et al.*, 2005) to 85% (Bass *et al.*, 2012). Two studies (Gaugler *et al.*, 2004; Vaingankar *et al.*, 2013) did not report whether the caregiver was living with the care recipient.

Psychometric properties of measures

Reliability. Table 3 shows the reliability indices for each of the four measures.

Internal consistency. Internal reliability at either the domain level or total scale level was reported for three of the measures (Bass *et al.*, 2012; Gaugler *et al.*, 2004; Wancata *et al.*, 2005). Criteria for internal consistency were met for the PSS (Bass *et al.*, 2012), CNA-D (Wancata *et al.*, 2005) and for all domains except one for the Gaugler *et al.*, (2004) unmet needs measure.

Test–retest reliability. Test–retest reliability was assessed for one measure only (Wancata *et al.*, 2005). The CNA-D showed acceptable levels of test–retest reliability after 14 days for both the problem areas and interventions offered.

Validity. Table 4 shows the validity indices for each of the four measures.

Face/content validity. Three of the studies reported the measure's face/content validity (Gaugler *et al.*, 2004; Vaingankar *et al.*, 2013; Wancata *et al.*, 2005).

Table 3 Reported reliability (internal consistency and test–retest reliability) of included measures

Measure	Internal consistency *Cronbach's $\alpha > 0.70$*	Test–retest *Repeated administration after 6–14 days* $\kappa > 0.60$
PSS (Bass *et al.*, 2012)	Total scale = 0.92 Domain-specific: not reported	Not assessed
Gaugler *et al.*, (2004) unmet needs measure	Total scale: not reported Activities of daily living = 0.85 Instrumental activities of daily living = 0.86 Timing of care = 0.79 Support = 0.77 Information = 0.68 Confidante = 0.79 Dementia symptoms (two items) $r = 0.54$, $p < .01$.	Not assessed
CNCD (Vaingankar *et al.*, 2013)	Not reported	Not assessed
CNA-D (Wancata *et al.*, 2005)	Number of moderate or serious problems: Caregivers = 0.70 Interviewers = 0.72 Number of met needs: Caregivers = 0.95 Interviewers = 0.96 Number of unmet needs: Caregivers = 0.88 Interviewers = 0.90	Repeated administration after 14 days Problems: 0.844 Interventions: 0.806

CNA-D, Carers Needs Assessment for Dementia; CNCD, Caregivers Needs Checklist for Dementia; PSS, primary subjective stressor.

Table 4 Reported validity of included measures

| Measure | Face/content validity | Construct | | Criterion validity | |
		Convergent *Pearson correlation* >0.40	Factor analysis *Eigenvalues >1 or factor loadings >0.4*	Concurrent	Predictive
PSS (Bass *et al.*, 2012)	Not assessed	Not assessed	Factor loadings ranged from 0.63 to 0.84.	Not assessed	Not assessed
Gaugler *et al.*, (2004) unmet needs measure	Development of measure involved extensive literature review and consultation with clinical and research experts in dementia care.	Not assessed	Not assessed	Not assessed	Not assessed
CNCD (Vaingankar *et al.*, 2013)	Developed using focus groups and semi-structured interviews with caregivers, combined with input from an expert panel comprising individuals engaged in geriatric research and care services.	Not assessed	Not reported	Not assessed	Not assessed
CNA-D (Wancata *et al.*, 2005)	Developed based on a literature search as well as in-depth focus groups and interviews with both caregivers and experts in dementia care. Caregivers and healthcare providers asked to rate relevance of each problem area and intervention. All problem areas rated as 'very or extremely important' by at least 85% of respondents. All interventions were rated as 'often or very often helpful;' by at least 65% of caregivers and 77% of healthcare providers.	Zarit Burden Interview scores correlated positively with: moderate or serious problems Caregivers = 0.68 Interviewers = 0.67. Met needs Caregivers = 0.52 Interviewers = 0.50 Unmet needs Caregivers = −0.33 Interviewers = −0.46	Not assessed	Not assessed	Not assessed

CNA-D, Carers Needs Assessment for Dementia; CNCD, Caregivers Needs Checklist for Dementia; PSS, primary subjective stressor.

For all three measures, the views of clinicians and researchers involved in dementia care were incorporated during measure development. However, only two of the measures (Vaingankar *et al.*, 2013; Wancata *et al.*, 2005) incorporated the views of caregivers in the development of the measure.

Construct validity. Construct validity was assessed for two of the measures. Scores on the CNA-D (Wancata *et al.*, 2005) showed adequate convergent validity with scores on the Zarit Burden Interview, except for the association with the number of unmet needs reported by caregivers. Factor analysis for the PSS (Bass *et al.*, 2012) revealed acceptable factor loadings of between 0.63 and 0.84.

Criterion validity. Criterion validity was not assessed for any of the measures.

Acceptability, feasibility, responsiveness and cross-cultural validation. Only the CNA-D (Wancata *et al.*, 2005) was assessed for acceptability. The

measure took one-hour for most caregivers to complete, indicating that use of this measure may be time-intensive for both researchers and clinicians.

Feasibility, responsiveness and cross-cultural validation were not reported for any measure.

Table 5 shows a summary of the psychometric properties reported for each measure, including whether the predefined criteria for each property was met.

Discussion

Assessment of caregiver burden provides information about the types of problems experienced by caregivers, but not the extent to which they are currently receiving help or having these problems addressed. Assessment of unmet need is important as it allows the elucidation of specific issues where additional action or resources can improve overall well-being (Sanson-Fisher *et al.*, 2000). This allows for the targeted and prioritised delivery of services and/or support. Despite the known benefits of assessing unmet needs (Hansen *et al.*,

Table 5 Summary of evidence of psychometric properties for each measure

| Instrument | Internal consistency | Test–retest reliability | Face/content validity | Construct validity | | | Criterion validity | | Acceptability | Feasibility | Responsiveness | Cross-cultural adaptation |
				Convergent/divergent	Factor analysis	Other methods	Concurrent	Predictive				
PSS (Bass et al., 2012)	++	0	0	0	++	0	0	0	0	0	0	0
Gaugler et al., (2004) unmet needs measure	+	0	+	00	0	0	0	0	0	0	0	0
CNCD (Vaingankar et al., 2013)	00	0	++	0	00	0	0	0	0	0	0	0
CNA-D (Wancata et al., 2005)	++	++	++	++	0	0	0	0	+	0	0	0

CNA-D, Carers Needs Assessment for Dementia; CNCD, Caregivers Needs Checklist for Dementia; PSS, primary subjective stressor.

Key:
0 = not assessed.
00 = not reported.
+ = partially met the psychometric criteria.
++ = all results met psychometric criteria.

2013), only four measures that described the development, psychometric properties or acceptability of a measure of unmet needs for caregivers of people with dementia were identified in this review.

Comprehensiveness of unmet needs measures for caregivers of people with dementia

Assessment of the unmet needs of caregivers of people with dementia should involve recognition of needs across all aspects of the caregiving experience, to ensure that the outcomes of assessment have a meaningful impact on well-being. This includes the caregiver's own physical, emotional, social and support needs, as well as caregivers' need for help with providing care to the person with dementia (Ontario Dementia Caregivers Needs Project, 2004). However, only the caregiver's need for information, emotional support and services/formal support were covered by all measures included in this review, while the need for financial/legal support and for assistance with managing symptoms or activities of daily living was reported for most measures. However, no measures assessed unmet needs across other important caregiving tasks, such as advocating on behalf of the person with dementia in healthcare systems, assisting in maintaining functional independence and self-determination and providing emotional support and validation to the individual. Future measure development should involve extensive consultation with caregivers focused on both the caregiving role and the impact of that role on their well-being, to ensure that the caregiver's experience is comprehensively represented.

The response scales used by some of the measures also limit their utility. The PSS and Gaugler et al., unmet needs measure (Bass et al., 2012; Gaugler et al., 2004) included only dichotomous response options, which prevents an assessment of the extent to which help is needed. This approach precludes the ability to tease apart those areas in which respondents report a greater desire for help, relative to other areas, so that limited resources can be directed appropriately.

The time frame over which caregivers were asked to report their needs was not consistently reported. Two studies did not report the time frame over which the caregiver was asked about their unmet needs in the measure. Without defining a time period, it is impossible to establish the extent to which factors such as recall or recency biases may influence caregivers' reporting of their needs.

Finally, all measures were developed for use in research settings. It was not possible to assess the

feasibility of clinical use for three of the measures, as completion time was not reported. The completion time for the remaining measure (Wancata *et al.*, 2005) was one-hour, limiting feasibility in clinical settings. This finding highlights the need for measures that are designed for use in clinical, as well as research settings.

Samples used to test psychometric properties limit generalisability

Studies conducted with large samples in the USA have found that caregivers of people with dementia are more likely to be women, aged under 65 years (Bouldin and Andresen, 2010) and caring for a parent (Fisher *et al.*, 2011). Care recipients are also more likely to be female and aged over 75 years (Bouldin and Andresen, 2010). The age and gender of caregivers and care recipients and the relationship between the caregiver and care recipient reported in validation samples were largely in line with these characteristics for three of the measures. However, the sample used to test the properties of the PSS reported on caregivers of veterans with dementia, 71% of whom were spouses of the veteran (Bass *et al.*, 2012), limiting the generalisability of the measure.

An additional limitation is the small sample sizes used in the studies to conduct validation. While there are no accepted standards for sample sizes required to adequately test psychometric properties (Anthoine *et al.*, 2014), some have recommended that a minimum of 400 participants is needed to achieve adequate estimates of validity and reliability (Charter, 1999; Charter, 2003). Only the samples used to test the PSS and Gaugler *et al.*, unmet needs measures (Bass *et al.*, 2012; Gaugler *et al.*, 2004) met this recommendation. Samples of less than 100 caregivers were used to test the properties of the Caregiver Needs Checklist for Dementia (CNCD) (Vaingankar *et al.*, 2013) and CNA-D (Wancata *et al.*, 2005). Further, the response rate was either not reported (Vaingankar *et al.*, 2013) or only partially reported (Wancata *et al.*, 2005) for these samples, limiting the generalisation of findings.

Existing dementia caregiver unmet needs measures are methodologically flawed

Psychometric properties of the included measures were generally poorly assessed. When examining the reliability of measures, all but one met the criteria for adequate internal consistency reliability, suggesting that the items included in the domain or total scale reflected a consistent construct. However, only the CNA-D (Wancata *et al.*, 2005) was assessed for test–retest reliability, while responsiveness was not assessed for any of the included measures. Given that caregiver needs are likely to change in line with the progressive nature of the illness, it is important to determine if the measure is sensitive to clinically important changes over time. Therefore, it is unclear whether the remaining measures are able to accurately detect changes over time in caregivers' unmet needs.

Validity of included measures was also generally poorly assessed. Only two measures reported indices of construct validity. Both the PSS (Bass *et al.*, 2012) and CNA-D (Wancata *et al.*, 2005) met the criteria for this property. However, none of the studies reported the criterion validity of the measures. This suggests there may be significant problems in interpreting the meaningfulness of scores obtained on these measures, or the ability of these measures to predict future important health outcomes of caregivers. The lack of evidence for criterion validity may reflect difficulties in identifying appropriate 'gold standard' outcome measures for comparison with unmet needs scores.

The acceptability and feasibility of measures was not adequately assessed. The administration time was reported for only one of the measures (Wancata *et al.*, 2005). Reading age was not assessed for any of the measures. Furthermore, none of the studies reported on the proportion of missing items, making it difficult to assess whether items were acceptable and adequately comprehended by respondents. Examination of the feasibility of measures was not assessed for any of the studies.

Overall, it appears that the psychometric properties were strongest for the CNA-D. When tested in German, this measure showed adequate inter-rater and test–retest reliability, and internal consistency. It also shows acceptable content and construct validity. However, it is important to note that the measure was only translated to English following testing of these properties, making it unclear whether the reported psychometric properties apply to the English-language version. In addition, the CNA-D relies on ratings by both caregivers and trained interviewers. The need for a trained interviewer limits the utility of the tool in settings where personnel resources are limited. Finally, the one-hour administration time may result in significant fatigue effects towards the end of the scale.

An innovative approach to needs assessment will result in meaningful benefits for caregivers

This review identifies a clear need for a self-report instrument to assess the needs of caregivers of people with dementia that can be used to reliably measure outcomes for research purposes, as well as identify individuals at risk of adverse outcomes in a clinical setting.

Traditional approaches to needs assessment have been criticised for their limited clinical utility and capacity to predict future outcomes. To ensure any needs measure that is developed for caregivers of people with dementia is maximally beneficial to both research and practice, an innovative approach to needs assessment is required, incorporating the following considerations:

Establishing clinically relevant cut-points. Most caregivers will experience at least some unmet needs, which are likely to fluctuate over time as existing needs are met and the disease progresses. However, there must be some way of identifying those who are experiencing unmet needs at a level that places them 'at risk' of experiencing adverse outcomes. Unmet needs measures are often criticised for their lack of clinically relevant cut-points, or thresholds to identify those who are in need of professional help. To identify relevant cut-points, scores obtained on the unmet needs measure must be compared with cut-points on other measures of related constructs, such as caregiver burden and quality of life. Identifying cut-points will significantly increase the clinical utility of an unmet needs measure.

Assessing the relative importance of needs. Another limitation of current approaches to assessing unmet needs is the inability to determine which unmet need caregivers perceive as the most important to address or receive help for. The relative importance that caregivers place on needs may be assessed by asking caregivers to select, for example, the top five needs which, if they were to be met, would have the greatest impact on their well-being. Assessment of the relative importance of needs could be particularly useful to ensure that intervention strategies are responsive to the most important identified needs of caregivers. This approach would have particular utility in the case of adaptive intervention strategies, whereby the intervention is adapted and readapted sequentially in response to the needs of the individual (Almirall *et al.*, 2014). The approach would also be valuable in informing tailored service recommendations, which would ensure appropriate allocation of increasingly stretched resources.

Prediction of adverse outcomes. The assessment of need relies on the assumption that meeting needs results in improved well-being. However, the predictive validity of needs measures has not been rigorously investigated. Studies suggest that outcomes including quality of life and depression may be related to the extent to which needs are met (Choi and Mcdougall, 2009; Slade *et al.*, 2004). There is also evidence that having more needs is related to greater reliance on healthcare services (Zuckerman and Shen, 2004). Longitudinal studies are required to establish whether greater proportion of unmet needs at baseline is associated with more adverse outcomes at follow-up time points.

Limitations of the review

This review included only searches of databases of peer-reviewed publications. Therefore, there may be additional measures available in the grey literature that were not identified. However, any such measure not published in the peer-reviewed literature is unlikely to have robust psychometric properties.

It is also possible that some of the psychometric properties of the included measures that were recorded as 'not assessed' or 'not reported' in this review may be reported in the grey literature. However, we contacted all authors of the included studies to establish whether the psychometric properties had been published elsewhere. Therefore, it is unlikely that any relevant psychometric properties were not included.

Conclusion

The findings of this review highlight a paucity of measures to assess the unmet needs of caregivers of people with dementia. Further measure development in this area is needed. Future measure development in this area should ensure that a comprehensive range of domains is included and that an appropriate response scale is utilised. The psychometric properties of these measures should be tested with sufficiently large and representative samples and include testing of all criteria used to assess adequate reliability and validity.

Conflict of interest

Key points

- There are few measures available to assess the unmet needs of caregivers of people with dementia.
- Psychometric properties of available measures have been poorly assessed.
- There is a need to develop a psychometrically rigorous instrument to assess the unmet needs of caregivers of people with dementia.

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