Assessing the diverse needs of dementia informal caregivers

A systematic review of validated instruments

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Insufficiently attended needs…

• **Diverse needs** at all stages of the disease (information, emotional concerns, respite, practical or financial support)

• **CG difficulties to express needs** and required support

• **Insufficiently adapted** support services
... negative outcomes

- Care fragmentation & poor coordination
- Stress ↑
- Underutilization of support services
- CG Exhaustion
- Institutionalization
- Health care costs ↑

→ Systematic and person-centered evaluation to promote quality of life and to maintain the caring situation at home
Overview of the existing needs assessment instruments

Limited relevance for clinical practice and research

- **Qualitative measures:**
  - Time intensive to conduct and to document
  - Limited availability and transfer of data
  - Impossible to manage on a large scale (economic pressure)

- **Quantitative measures:**
  - Few items for caregivers
  - Poor validation
  - Lack of empirical evidence regarding need dimensions (factor structure)
Research questions

Which needs assessment instruments for informal dementia caregivers are:

1) **relevant** for clinical practice and research (according to their instrument characteristics)?

2) **reliable and valid** in measuring the needs of informal dementia caregivers?
Systematic review – JBI & COSMIN

- **JBI** (Johanna Briggs Institute) Approach for systematic reviews

- **COSMIN** Guidelines for reviews of psychometric properties
Inclusion criteria

- Informal caregivers of persons with dementia living at home
- Multidimensional needs assessment instruments
- Measuring needs as an explicit objective
- Providing sufficient psychometric data
Outcomes

**Instrument characteristics:**
- Purpose (clinical / research)
- Application method (self-reported, professionally interviewed)
- Administration burden (training for clinicians, time for completion)
- Number of items and domain structure

**Psychometric properties:**
- Reliability (test-retest reliability, inter-rater reliability, internal consistency)
- Validity (content validity, construct validity, structural validity)
Search strategy & methodology

- MEDLINE, OVID Nursing, Psychinfo, PSYNDExplus, CINHAL
- ResearchGate, contact with researchers, relevant websites
- English, German & French
- 1946 – July 2018

- Methodological quality: COSMIN Checklist
- Quality of the psychometric outcomes: Quality criteria from Terwee et al. 2011
Study selection

Number of records identified through a systematic search (N=1266)

Number of additional publications identified through other sources (N=7)

Number of records after duplicates removed (N=1008)

Number of records screened (N=1008)

Number of records excluded (N=951)

Number of full-text articles assessed for eligibility (N=57)

Number of articles excluded on reading full-text (N=39)

Number of articles assessed for quality (N=18)

Number of articles excluded on critical appraisal (N=1)

Number of articles included (N=17)

Which studies did we include?

Design:
- 10 psychometric studies (instrument development or evaluation)
- 1 development report, 1 instrument manual
- 5 other studies, not primarily aiming at validation but containing sufficient information to assess methodological quality

Setting & sample characteristics:
- 8 with PwD living in the community
- 9 with PwD living in the community or in institutions
- Caregivers mostly spouses or children
- Majority of caregivers female
- Different countries (6 US, 3 UK, 2 each from Austria, Singapore and the Netherlands, 1 each from Greece, Canada)
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Instrument name</th>
<th>Authors of included studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>CADI</td>
<td>Carers Assessment of Difficulties Index</td>
<td>Charlesworth et al. (2007)(^{47})</td>
</tr>
<tr>
<td>CARENAP</td>
<td>The Care Needs Assessment Pack for Dementia</td>
<td>McWalter et al. (1996; 1998)(^{48,49})</td>
</tr>
<tr>
<td>CNA-D</td>
<td>The Carers’ Needs Assessment for Dementia</td>
<td>Wancata et al. (2005)(^{50}) Kaiser et al. (2005)(^{51})</td>
</tr>
<tr>
<td>CNCD</td>
<td>Caregivers’ Needs Checklist for Dementia</td>
<td>Vaingankar et al. (2013; 2017)(^{52,53})</td>
</tr>
<tr>
<td>JHDCNA</td>
<td>The Johns Hopkins Dementia Care Needs Assessment</td>
<td>Hughes et al. (2014)(^{54})</td>
</tr>
<tr>
<td>NAS</td>
<td>Needs Assessment Survey</td>
<td>Wackerbarth et al. (2002)(^{55})</td>
</tr>
<tr>
<td>PBH-LCI:D</td>
<td>Partnering for Better Health - Living with Chronic Illness: Dementia</td>
<td>Sadak et al. (2015)(^{56})</td>
</tr>
<tr>
<td>RAM</td>
<td>Risk Appraisal Measure</td>
<td>Czaja et al. (2009)(^{57})</td>
</tr>
<tr>
<td>QCNE</td>
<td>Questionnaire of Carers Needs Evaluation</td>
<td>Dimakopoulou et al. (2015)(^{58})</td>
</tr>
<tr>
<td>EAC</td>
<td>Questionnaire Consultation Expectations [Echelle d’Attentes de Consultation (EAC)]</td>
<td>Laprisme et al. (2001)(^{59})</td>
</tr>
<tr>
<td>QNP</td>
<td>Questionnaire National Dementia Programme Survey Needs and Problems of Informal Caregivers of Persons with Dementia</td>
<td>Peeters et al. (2010)(^{60}) Van der Poel and van Beek (2006)(^{61})</td>
</tr>
<tr>
<td>Tayside</td>
<td>Tayside Profile for Dementia Planning</td>
<td>Gordon et al. (1997)(^{62})</td>
</tr>
<tr>
<td>UNM</td>
<td>Unmet Need Measure</td>
<td>Gaugler et al. (2004)(^{63})</td>
</tr>
</tbody>
</table>
### Which instruments did we include?

<table>
<thead>
<tr>
<th>Target population</th>
<th>Only for caregivers</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For caregivers &amp; PwD</td>
<td>3</td>
</tr>
<tr>
<td>Purpose</td>
<td>Clinical use</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Research use</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Clinical &amp; research use</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td><strong>Not specified</strong></td>
<td>5</td>
</tr>
<tr>
<td>Application method</td>
<td>Self-administered</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Professionally interviewed</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Self-reported or professionally interv.</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Not clearly stated</td>
<td>2</td>
</tr>
<tr>
<td>Administration time</td>
<td>Between 5 and 50 minutes</td>
<td>7</td>
</tr>
<tr>
<td>Training for clinicians</td>
<td>no training / experienced in assessments and interviewing</td>
<td>2</td>
</tr>
</tbody>
</table>
Which instruments did we include?

- Response options: nominally or ordinally scaled
- 9 instruments with a total or mean score
- Between 12 and 39 items for caregivers
# Methodological quality

<table>
<thead>
<tr>
<th>Instrument / Author</th>
<th>Internal consistency</th>
<th>Test-retest/Inter-rater</th>
<th>Measurement error</th>
<th>Content validity</th>
<th>Structural validity</th>
<th>Construct validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>JHDCNA - Hughes et al. (2014)</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>fair</td>
</tr>
<tr>
<td>CADI - Charlesworth et al. (2007)</td>
<td>excellent</td>
<td>na</td>
<td>na</td>
<td>poor</td>
<td>excellent</td>
<td>na</td>
</tr>
<tr>
<td>RAM - Cjaza et al. (2009)</td>
<td>poor</td>
<td>na</td>
<td>na</td>
<td>poor</td>
<td>na</td>
<td>fair</td>
</tr>
<tr>
<td>QNCE - Dimakopoulou et al. (2015)</td>
<td>poor</td>
<td>na</td>
<td>na</td>
<td>excellent</td>
<td>poor</td>
<td>na</td>
</tr>
<tr>
<td>UNM - Gaugler et al. (2004)</td>
<td>poor</td>
<td>na</td>
<td>na</td>
<td>poor</td>
<td>na</td>
<td>fair</td>
</tr>
<tr>
<td>Tayside - Gordon et al. (1997)</td>
<td>na</td>
<td>poor</td>
<td>na</td>
<td>fair</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>EAC - Laprise et al. (2001)</td>
<td>poor</td>
<td>fair</td>
<td>na</td>
<td>poor</td>
<td>na</td>
<td>fair</td>
</tr>
<tr>
<td>QNP – Peeters et al. (2010)</td>
<td>poor</td>
<td>na</td>
<td>na</td>
<td>excellent</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>PBH-LCI:D - Sadak et al. (2015)</td>
<td>poor</td>
<td>fair</td>
<td>fair</td>
<td>excellent</td>
<td>poor</td>
<td>fair</td>
</tr>
<tr>
<td>CNCD - Vaingankar et al. (2013, 2017)</td>
<td>poor</td>
<td>na</td>
<td>na</td>
<td>excellent</td>
<td>poor</td>
<td>fair</td>
</tr>
<tr>
<td>NAS - Wackerbarth et al. (2002)</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>good</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>CNA-D - Wancata et al. (2005)</td>
<td>poor</td>
<td>fair</td>
<td>na</td>
<td>excellent</td>
<td>na</td>
<td>fair</td>
</tr>
<tr>
<td>CNA-D- Kaiser et al. (2005)</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>good</td>
</tr>
</tbody>
</table>
# Quality of evidence according to GRADE

<table>
<thead>
<tr>
<th>Psychometric property</th>
<th>Summary or pooled results</th>
<th>Factors determining the quality of evidence</th>
<th>Grade of the quality of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content validity</strong></td>
<td>6 studies with excellent content validity, BUT identified domains not consistent</td>
<td>- 1 inconsistency</td>
<td><strong>Moderate</strong></td>
</tr>
<tr>
<td><strong>Internal consistency</strong></td>
<td>1 study with adequate dimensionality analysis BUT low alphas all others evaluated dimensionality with small samples, or no proper evaluation of their dimensionality – although some had high alphas</td>
<td>- 1 risk of bias</td>
<td><strong>Moderate</strong></td>
</tr>
<tr>
<td><strong>Structural validity</strong></td>
<td>4 studies evaluated the factor structure: 1 with excellently factor analysis, 2 with an adequate factor analysis BUT too limited sample size, one with a inadequately performed factor analysis Identified factor structures varied from 5 – 8 dimensions</td>
<td>- 1 inconsistency</td>
<td><strong>Moderate</strong></td>
</tr>
<tr>
<td><strong>Reliability – test-retest</strong></td>
<td>2 studies with a satisfactory test-retest agreement and good correlations (in the .70 range) Measurement error rated as good for one study</td>
<td></td>
<td><strong>High</strong></td>
</tr>
<tr>
<td><strong>Reliability – inter-rater</strong></td>
<td>Inter-rater agreement always evaluated with questionable procedures</td>
<td>- 2 risk of bias</td>
<td><strong>Low</strong></td>
</tr>
<tr>
<td><strong>Construct validity</strong></td>
<td>4 studies with precise a priori hypothesis and at least 75% of the results in accordance with them Instruments seemed to contain items overlapping with the variables tested for association (e.g. burden, depression) Associations tested included very diverse outcomes and rarely based on theoretical model</td>
<td>- 1 risk of bias - 1 inconsistency</td>
<td><strong>Moderate</strong></td>
</tr>
</tbody>
</table>
Content validity

• documented for 12 of the 13 instruments reviewed
• 6 instruments with satisfactory evaluation
• items mostly generated based on literature review and/or expert consultation, and reviewed in collaboration with experts and at least five informal dementia caregivers
• 3 instruments used a doubtful design and 3 failed to include target population in the process of item development
Internal consistency & structural validity

- assessed for 10/13 instruments, none with good procedure & αs
- 3 studies reported only αs for the full scale (2 low / 1 high)
- 4 studies with good αs for all dimensions but no proper evaluation of dimensionality
- 3 computed αs for dimensions based on a factor analysis - one with adequate dimensionality analysis BUT low αs (CADI) / two with αs>.70 BUT with insufficient sample size (CNCD, PBH-LCI:D)
- Factor analysis supported 5 to 8 dimensions
Reliability

- evaluated for 4 of the 13 instruments
- 4 with test-retest agreement: 2 with satisfactory procedure and good correlations in .70 range (CNA-D, PBL-LCI:D)
- 3 with inter-rater reliability (CARENAP, CNA-D, Tayside), BUT evaluated with questionable procedures
- 1 evaluated measurement error with good results (PBL-LCI:D)

→ Evidence regarding reproducibility is still limited
Validity: Construct validity

- evaluated for 7 of the 13 instruments
- 4 with precise a priori hypotheses & at least 75% of results in accordance (CNA-D, PBH-LCI:D, RAM, EAC)
- associations mostly with caregiver’s objective or subjective burden; depression, anxiety or psychological distress; formal or social support; self-care; or quality of life
- associations based on plausible links with common outcomes for informal dementia caregivers (e.g. subjective burden) or theoretical models
Content of dimensions

1) Need for information & education

• Information about dementia & treatment
• Caring tasks / Dementia specific skills
• Information resources
• Formal help / Services in the region / Community resources
• Characteristics, access and availability of services
• Organizing care / Type of provider
2) Needs related to emotional support

- Respite support
- Family time / Shared activities
- Mental health counseling / Psychiatric care
- Informal network / Support from family and friends
- Support from society
  - Relationship to person with dementia
  - Counselling negative emotions
- Being a caregiver / Assume caregiver role
- Sleep
3) Need for other accessible & appropriate services

- Medical care for CG
- General assistance or household chores
- Financial & legal support
Which are the best validated instruments?

**PBH-LCI:D** (Partnering for Better Health - Living with Chronic Illness: Dementia by Sadak et al. 2015)

- **appropriate** procedure regarding **content validity**
- six domains confirmed in **factor analysis**, **good** internal consistency
- **adequate test-retest stability** after two weeks
- showed expected correlations with other variables indicating **construct validity**
- **English, clinical & research use**, covering **most common topics**, self-administered, **scoring system**
- **Administration burden?**
Which are the best validated instruments?

**EAC** (Questionnaire consultation expectations [Echelle d'attentes de consultation] by Laprise et al., 2001)

- **appropriate** evidence of **test-retest reliability** and **construct validity**
- **BUT** informal **caregivers not involved** in item development process
- **BUT** Cronbach alphas computed **without dimensionality analysis**

- French, **clinical** use, covering **most common topics**, self-administered, **scoring system**
- **Administration burden?**
Which are the best validated instruments?

- 4 instruments with adequate support for **content validity**, BUT insufficient evidence for all other psychometric properties (CARENAP, CNCD, QNP, NAS)
- 2 instruments with **good evidence** for **construct validity**, BUT inconclusive evidence for all other properties (CAN-D, RAM)
- 5 instruments with **no convincing evidence** for any psychometric property (CADI, JHDCNA, QCNE, Tayside, UNM)
Further development needed…

Currently no established theoretical model to organize the diverse and complex needs of informal dementia caregivers and their associations with other constructs

- Needed to inform further explorations of the factorial structure, with sufficient sample size (number of domains to cover the needs)
- Needed to strengthen the nomological net & a more solid examination of construct validity
Further development needed…

Test-retest stability scarcely assessed:

• Difficulties: **fragile population, unstable situations** and contexts → short time interval

• BUT: difficult to obtain two assessments within one or two weeks from **chronically stressed** and often **exhausted caregivers**

Sensitivity to change not assessed:

• **Longitudinal measures** → evolution of needs, impact of interventions
Strengths and limitations

• COSMIN criteria as a highly structured procedure, but also very stringent
• Studies in English, French and German, no Asian or Arabic languages
• Limited access to grey literature; no replies, commercial processes, persons in charge gone
MERCI & DANKE
FOR YOUR ATTENTION

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