



Heds FR

Haute école de santé Fribourg
Hochschule für Gesundheit Freiburg

Assessing the diverse needs of dementia informal caregivers

A systematic review of validated instruments



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Hes·so

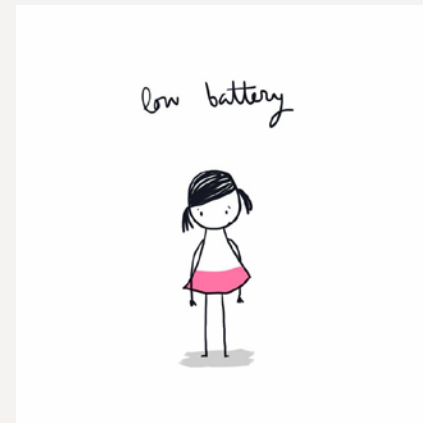
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Insufficiently attended needs...

- **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:

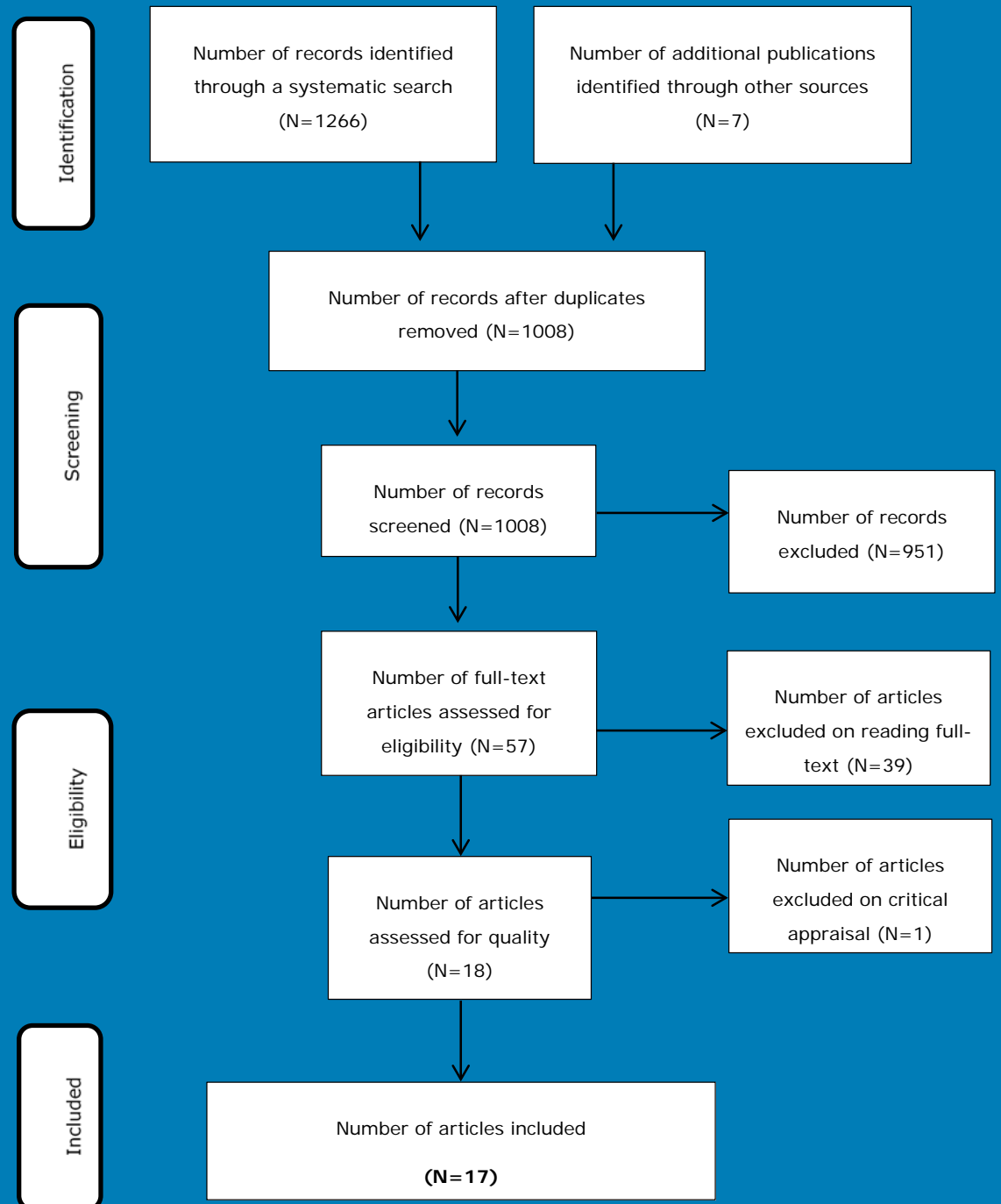
- Reliability (test-retest reliability, inter-rater reliability, internal consistency)
- Validity (content validity, construct validity, structural validity)

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

PRISMA flow diagram from: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.



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)

Acronyme	Instrument name	Authors of included studies
CADI	Carers Assessment of Difficulties Index	Charlesworth et al. (2007) ⁴⁷
CARENAP	The Care Needs Assessment Pack for Dementia	McWalter et al. (1996; 1998) ^{48,49}
CNA-D	The Carers' Needs Assessment for Dementia	Wancata et al. (2005) ⁵⁰ Kaiser et al. (2005) ⁵¹
CNCD	Caregivers' Needs Checklist for Dementia	Vaingankar et al. (2013; 2017) ^{52,53}
JHDCNA	The Johns Hopkins Dementia Care Needs Assessment	Hughes et al. (2014) ⁵⁴
NAS	Needs Assessment Survey	Wackerbarth et al. (2002) ⁵⁵
PBH-LCI:D	Partnering for Better Health - Living with Chronic Illness: Dementia	Sadak et al. (2015) ⁵⁶
RAM	Risk Appraisal Measure	Czaja et al. (2009) ⁵⁷
QCNE	Questionnaire of Carers Needs Evaluation	Dimakopoulou et al. (2015) ⁵⁸
EAC	Questionnaire Consultation Expectations [Echelle d'Attentes de Consultation (EAC)]	Laprise et al. (2001) ⁵⁹
QNP	Questionnaire National Dementia Programme Survey Needs and Problems of Informal Caregivers of Persons with Dementia	Peeters et al. (2010) ⁶⁰ Van der Poel and van Beek (2006) ⁶¹
Tayside	Tayside Profile for Dementia Planning	Gordon et al. (1997) ⁶²
UNM	Unmet Need Measure	Gaugler et al. (2004) ⁶³

Which instruments did we include?

Target population	Only for caregivers	10
	For caregivers & PwD	3
Purpose	Clinical use	4
	Research use	1
	Clinical & research use	3
	Not specified	5
Application method	Self-administered	6
	Professionally interviewed	3
	Self-reported or professionally interv.	2
	Not clearly stated	2
Administration time	Between 5 and 50 minutes	7
Training for clinicians	no training / experienced in assessments and interviewing	2

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

Instrument / Author	Reliability			Validity		
	Internal consistency	Test-retest/Inter-rater Intra-rater	Measurement error	Content validity	Structural validity	Construct validity
JHDCNA - Hughes et al. (2014)	na	na	na	na	na	fair
CADI - Charlesworth et al. (2007)	excellent	na	na	poor	excellent	na
RAM - Cjaza et al. (2009)	poor	na	na	poor	na	fair
QNCE - Dimakopoulou et al. (2015)	poor	na	na	excellent	poor	na
UNM - Gaugler et al. (2004)	poor	na	na	poor	na	fair
Tayside - Gordon et al. (1997)	na	poor	na	fair	na	na
EAC - Laprise et al. (2001)	poor	fair	na	poor	na	fair
CARENAP - McWalter (1996, 1998)	poor	poor	na	excellent	na	na
QNP – Peeters et al. (2010)	poor	na	na	excellent	na	na
PBH-LCI:D - Sadak et al. (2015)	poor	fair	fair	excellent	poor	fair
CNCD - Vaingankar et al. (2013, 2017)	poor	na	na	excellent	poor	fair
NAS - Wackerbarth et al. (2002)55	na	na	na	good	na	na
CNA-D - Wancata et al. (2005)	poor	fair	na	excellent	na	fair
CNA-D- Kaiser et al. (2005)	na	na	na	na	na	good

Quality of evidence according to GRADE

Psychometric property	Summary or pooled results	Factors determining the quality of evidence	Grade of the quality of evidence
Content validity	6 studies with excellent content validity , BUT identified domains not consistent	- 1 inconsistency	Moderate
Internal consistency	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	- 1 risk of bias	Moderate
Structural validity	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	- 1 inconsistency	Moderate
Reliability – test-retest	2 studies with a satisfactory test-retest agreement and good correlations (in the .70 range) Measurement error rated as good for one study		High
Reliability – inter-rater	Inter-rater agreement always evaluated with questionable procedures	- 2 risk of bias	Low
Construct validity	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	- 1 risk of bias - 1 inconsistency	Moderate

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 & α s**
- 3 studies reported only alphas for the full scale (2 low / 1 high)
- 4 studies with good alphas for all dimensions but no proper evaluation of dimensionality
- **3** computed alphas for dimensions based on a **factor analysis** - one with adequate dimensionality analysis BUT **low alphas** (CADI) / two with $\alpha > .70$ 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 accord**ance (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

Content of dimensions

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

Content of dimensions

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



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