PMH39

HUMANISTIC BURDEN IN DEMENTIA: WHICH TOOLS WERE MOST COMMONLY USED IN STUDIES PUBLISHED IN PUBMED IN 2014?

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Objectives

To determine which patient-reported outcome (PRO) and caregiver quality of life tools were used in studies on dementia that were published in 2014.

Methods

An evidence surveillance process was established based on a systematic search of PubMed, incorporating all studies published from 2010 and updated weekly, with a final search on 18 May 2015.

Abstracts that were published in 2014 and reported quality of life and patient-reported outcomes in dementia and memory impairment were selected from those identified by the search.

Articles were included if they reported results or a study protocol from a primary research study or were a systematic review. PRO tools were identified, where possible, from the abstract alone.

Search strategy

(“quality of life”[tiab] or QOL[tiab] OR HRQOL[tiab] OR "patient reported outcome"[tiab] OR PRO[tiab] OR "patient-reported"[tiab] OR "clinician-reported"[tiab] OR "carer-reported"[tiab])

AND

(questionnaire[tiab] OR tool[tiab] OR instrument[tiab] OR survey[tiab] OR randomised[tiab] OR randomized[tiab] OR controlled[tiab])

Limits

The search was limited to studies indexed in the PubMed database, in humans, with abstract, published in English in the previous 5 years before the search date of 18 May 2015; study methodology was limited to clinical trial, comparative study, controlled clinical trial, evaluation study, observational study, RCT, systematic review or validation study.

Results

Of 1,980 articles published in 2014 identified by the search for PROs and quality of life, 32 were relevant to patients and/or caregivers of adults with dementia, cognitive impairment or memory loss. The PRO used was not specified in 17 abstracts, but 19 different PRO or caregiver-reported instruments were cited in the remaining 15 abstracts.

Dementia-specific instruments included the Quality of life-Alzheimer's disease (QoL-AD), cited in 6 abstracts, and the Alzheimer's Disease Assessment Scale - Cognition (ADAS-Cog), the Five-Cog test, the Metamemory in Adulthood Questionnaire and the Mild Cognitive Impairment Questionnaire (MCQ), cited in 1 abstract each.

Despite the substantial burden on caregivers, only 8 abstracts reported outcomes related to the humanistic burden in this population. Instruments used in caregivers included generic utility measures, the QOL-AD, and the Zarit Burden Interview, but were not specified in 5 abstracts.

Utilities were measured in only 3 studies, with Short Form (12 or 36) used in all 3 studies and EQ-5D in one. Depression was assessed in 2 studies of patients and one of caregivers.

Evidence map showing PRO tools used in studies on dementia and memory impairment, published in 2014

Numbers refer to number of abstracts citing each tool, each abstract may cite one or more tools

	QoL-AD	MMSE	ADL	ZBI	NPI	CES-D, BDI	WHOQOL	ADAS-Cog	MCQ	MIAQ	5-Cog	SF-12, SF-36	EQ-5D	No. of other PROs	PRO not specified
Studies of patients: all 24 studies	5	3	2		1	1	1	1	1	1	1	1		5	11
Validation study	1								1			1			
Primary research study	5	2	1		1	1	1		1	1	1	1		5	6
Systematic review		1	1					1							
Study protocol															
Studies of caregivers: all 7 studies	1		1	2	1	2						1			5
Validation study															
Primary research study	1		1	2	1	2						1			3
Systematic review															
Study protocol															
Studies of patients and caregivers: 1 study												1	1		
Validation study															
Primary research study												1	1		
Systematic review															
Study protocol															

Key:
5-Cog: Five-Cog test
ADAS –Cog: Alzheimer's Disease Assessment Scale - Cognition
ADL: Activities of Daily Living Questionnaire
BDI: Beck Depression Inventory
CES-D: Center for Epidemiological Studies-Depression Scale
EQ-5D: European Quality of Life Questionnaire, 5 dimensions
MCQ: Mild Cognitive Impairment Questionnaire
MIAQ: Metamemory-In-Adulthood questionnaire
MMSE: Mini-Mental State Examination
NPI: Neuropsychiatric Inventory
QoL-AD: Quality of Life-Alzheimer's Disease scale
SF-12: Short-form 12
SF-36: Short-form 36
WHOQOL: WHO Quality of Life measure
ZBI: Zarit Burden Interview

Conclusions

Most study abstracts reporting on the humanistic burden in dementia in 2014 did not specify use of a dementia-specific instrument. Only 25% of studies assessed burden on caregivers, and utility values were rarely reported.

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