

A pan-European study on outcome measures for psychosocial intervention research in dementia

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The Interdem JPND outcomes working group

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- ▶ Interdem working group on outcomes measures

Psychosocial interventions

- ▶ Growing evidence,
 - ▶ Cover a wide range of interventions
 - ▶ People with dementia, formal and informal caregivers
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- ▶ Different types, approaches and theoretical backgrounds

JPND Outcomes Objectives

1. Produce updated evidence based recommendations on the best outcome measures for psychosocial research across Europe
2. Investigate the need for new measures to reflect changes in emphasis and the consequent needs of researchers and of services
3. Involve early career researchers in the working group to increase the workforce capacity in dementia research.

Aims of objective 1

- Identification of a common set of outcome measures for dementia research
- Make recommendations for researchers across Europe engaged in psychosocial research in dementia care.
- Meet the needs of clinicians, identifying measures that are as far as possible cost neutral and can be routinely applied in practice.

Challenge

- ▶ Identifying domains (excluding domain of cognition)
- ▶ Identifying Suitable measures
- ▶ Harmonizing Measures across Europe
- ▶ Data Sharing

Starting point

Objective 1: updated evidence based recommendations on the best outcome measures for psychosocial research across Europe

A European consensus on outcome measures for psychosocial intervention research in dementia care

Moniz-Cook et al., 2008)

Methods

- ▶ Iterative collaborative, evidence-based approach across different European experts to identify and recommend the best currently available dementia outcome measures for **European psychosocial intervention research**.
- ▶ Consensus workshops
- ▶ Systematic reviews (2007-2015)
- ▶ Evaluation of identified measures against agreed criteria.

- ▶ Experts from 12 European countries (The Netherlands, Germany, Ireland, Italy, Luxembourg, The Czech Republic, Finland, Denmark, Norway, Spain, Austria and the UK) contributed.
- ▶ Several face-to-face meetings between members of the project leadership group.

Criteria:

Utility

- ▶ Quality of peer reviewed journals
- ▶ Number of languages translated; Use across Europe

Feasibility

- ▶ Use in psychosocial interventions in dementia.
- ▶ Easily available/ no cost incurred
- ▶ Useful in routine clinical practice
- ▶ Training required for use (no training is better)

Properties

- ▶ Measure across stage: early, moderate, severe
- ▶ Psychometric Properties: validity, reliability, sensitivity to change
- ▶ Value as an outcome measure in intervention and longitudinal studies

Results

- ▶ 11 domains identified
- ▶ 33 scales identified
- ▶ **17 Instrument recommended: Gold standard or commonly used in interventions research.**

Domains

- ▶ **Person with dementia (PwD) Mood**
- ▶ **Person with Dementia (PwD) Quality of Life**
- ▶ **Person with Dementia Health Related QoL (HrQOL)**
- ▶ **Person with Dementia (PwD) ADL/IADL**
- ▶ **Behaviour (Rated by informal/family carer or by Staff Carer)**
- ▶ **Reaction to Behaviour (Rated by informal/family carer or by Staff carer)**
- ▶ **Informal (Family) Carer Mood**
- ▶ **Informal (Family) Carer Burden**
- ▶ **Informal (Family) Carer Health Related QoL (HrQoL)**
- ▶ **Resource Utilisation (Costs)**
- ▶ **Staff Carer Morale**

Results: identified and recommended

Person with dementia (PwD) Mood

- ▶ **Cornell Scale for Depression in Dementia (CSSD) (Alexopoulos et al., 1988)**
- ▶ Geriatric Depression Scale (GDS-15). (Yesavage et al., 1983)
- ▶ Rating Anxiety in Dementia (RAID) (Shankar et al., 1999)

Quality of Life

Person with Dementia (PwD) Quality of Life

- **Quality of life in Alzheimer's disease (QoL-AD) (Logdson et al., 1999)**
- The Dementia Quality of Life Instrument (DQOL) (Brod et al. 1999)
- **QUALIDEM (Ettema et al., 2007) (added 2015)**
- **DEMqoL (Smith et al., 2007)**
- QUALID (Weiner et al., 2000)

Person with Dementia Health Related QoL (HrQoL)

- **EUROQOL (EQ-5D).(EuroQol Group 1990) (added in 2015)**

Functional

Person with Dementia (PwD) ADL/IADL

- **Physical self maintenance Scale and Instrumental Activity of Daily Living (PSMS & IADL) (Lawton et al., 1969);**
- Activity of Daily Living (ADL) (Katz et al., 1963)
- Alzheimer Disease Cooperative Study-activities of daily Living Inventory (ADCS-ADL) (Galasko et al., 1997)
- Bristol Activities of daily Living Scale (BADLS) (Bucks et al., 1996)
- The disability Assessment of Dementia (DAD) (Gelimas et al., 1999)

Behaviour

Behaviour (Rated by informal/family carer separated for Staff Carer)

- Revised Memory and Behaviour problems Checklist (RMBPC) (Teri et al., 1992). For family care setting
- Neuropsychiatric Inventory (NPI) (Cummings et al., 1994). For NPS- Family care setting
- Neuropsychiatric Inventory – Nursing Home (NPI-NH) (Wood et al., 2000) NPS in NS
- Cohen Mansfield Agitation Inventory (CMAI) (Cohen Masfield et al., 1989) in NH

Reaction to Behaviour (Rated by informal/family carer separated for Staff carer)

- Revised Memory and Behaviour problems Checklist -(RMBPC) – Family carer Reaction Domain (Teri et al., 1992). For Family care setting
- Neuropsychiatric Inventory with Caregiver Distress Scale NPI – D – Family Carer Distress Domain (Kaufer et al., 1998). Family care settings
- Neuropsychiatric Inventory in Nursing Homes - NPI – NH – Occupational Disruption Domain (Wood et al., 2000). NPS in NH

Mood and Burden

Informal (Family) Carer Mood

- ▶ **Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983)**
- ▶ General Health Questionnaire (GHQ).(Goldberg & Williams 1999).
- ▶ Center for Epidemiological Studies – Depression Scale (CES-D). (Radloff & Teri , 1986)

Informal (Family) Carer Burden

- ▶ Zarit Burden Interview (ZBI) (Zarit et al., 1980)
- ▶ **Sense of Competence Scale (SCQ 27) & Short Sense of competence Scale (SSCC) (Vernooij-Dassen et al., 1996) & (Vernooij-Dassen et al., 1999). 2015**
- ▶ Relative Stress Scale (RSS) (Greene et al., 1982)

Quality of life –carers- resources and staff

Informal (Family) Carer Health Related QoL (HrQoL)

- The MOS 36 and 12 Item – Health Survey (SF36 & SF12) (Ware & Sherbourne, 1992)
- World Health Organization Quality of Life – Brief (WHOQoL-Brief) (WHOQOL Group, 1998)
- **EUROQOL (EQ-5D).**(EuroQol Group, 1990).

Resource Utilisation (Costs)

- Resource Service Receipt Inventory (CSRI) (Beecham & Knapp, 1992)
- **The Resource Utilization in Dementia Instrument (RUD).** (Wimo et al., 2000)

Staff Carer Morale

- **Maslach Burnout Inventory (MBI).** (Maslach et al., 1996)

Conclusions

- Outcomes measures are mainly symptoms based and traditionally used in drug studies
- Quality of life a promising domain (DEMQOL)
- Psychosocial interventions: a discrepancies between concept, theories and related outcomes.
- Efficacy of interventions and sensitivity of the outcomes measures.
- Preference for open access resources

Perspectives: Objective 2

- ▶ Need to explore new domains and new measures more related to interventions and based on experience rather than on symptoms

(see Bob Woods presentation **Charting new territory: measuring outcomes that have meaning**)

Thanks for your attention