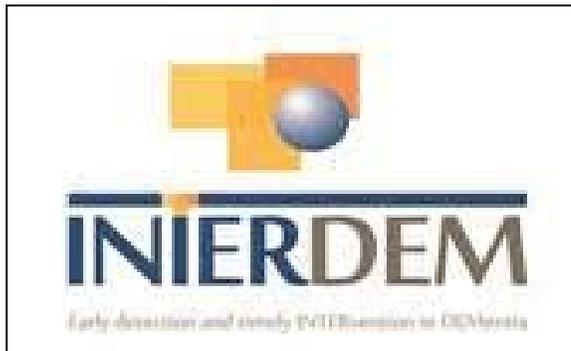


Towards family sensitive practices for behavioural and psychological symptoms of dementia (BPSD) at home



M.M. Gonçalves-Pereira⁽¹⁾, S.H. Zarit⁽²⁾,

A. Cardoso⁽¹⁾, J. Alves da Silva⁽¹⁾, A. Papoila⁽¹⁾, R. Mateos⁽³⁾

(1) Comprehensive Health Research Center – CHRC, Nova Medical School, UNL, Lisboa, Portugal

(2) Penn State University, USA

(3) Univ. Santiago de Compostela, Spain

Introduction

- Where interventions are directed at families who support people with dementia, the focus is usually on a **'primary carer'** i.e. the family member who is in most contact with the person with dementia.
- However, families constitute more than one person, and can act as a reactive system where family dynamics are involved.
- Other members may have both positive interpersonal resources and also contribute to triggers or maintenance of BPSD and 'challenges in caregiving'.
- Little is known about the needs and contribution of **'secondary' family carers**.

- Most studies compare primary and secondary carers as groups - only a few consider primary and secondary carers of the same patient.

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Coping with the caregiving role: Differences between primary and secondary caregivers of dependent elderly people

Ana Barbosa^{a*}, Daniela Figueiredo^{bc}, Liliana Sousa^{ac} and Sara Demain^d

^aDepartment of Health Sciences, University of Aveiro, Campus Universitário de Santiago, Aveiro, Portugal; ^bSchool of Health Sciences, University of Aveiro, Aveiro, Portugal; ^cUnidade de Investigação e Formação sobre Adultos e Idosos, University of Porto, Porto, Portugal; ^dSchool of Health Sciences, University of Southampton, Southampton, UK

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The Experience of Primary and Secondary Caregivers Caring for the Same Adult With Alzheimer's Disease

Michel Bédard, PhD

Lakehead Psychiatric Hospital, Thunder Bay, Ontario, Canada

Debbie Raney, MA

Grand River Hospital, Kitchener, Ontario, Canada

D. William Molloy, MB

McMaster University, Hamilton, Ontario, Canada

Judy Lever, MSc(A), RN

Hamilton Health Sciences Corporation, Hamilton, Ontario, Canada

David Pedlar, PhD

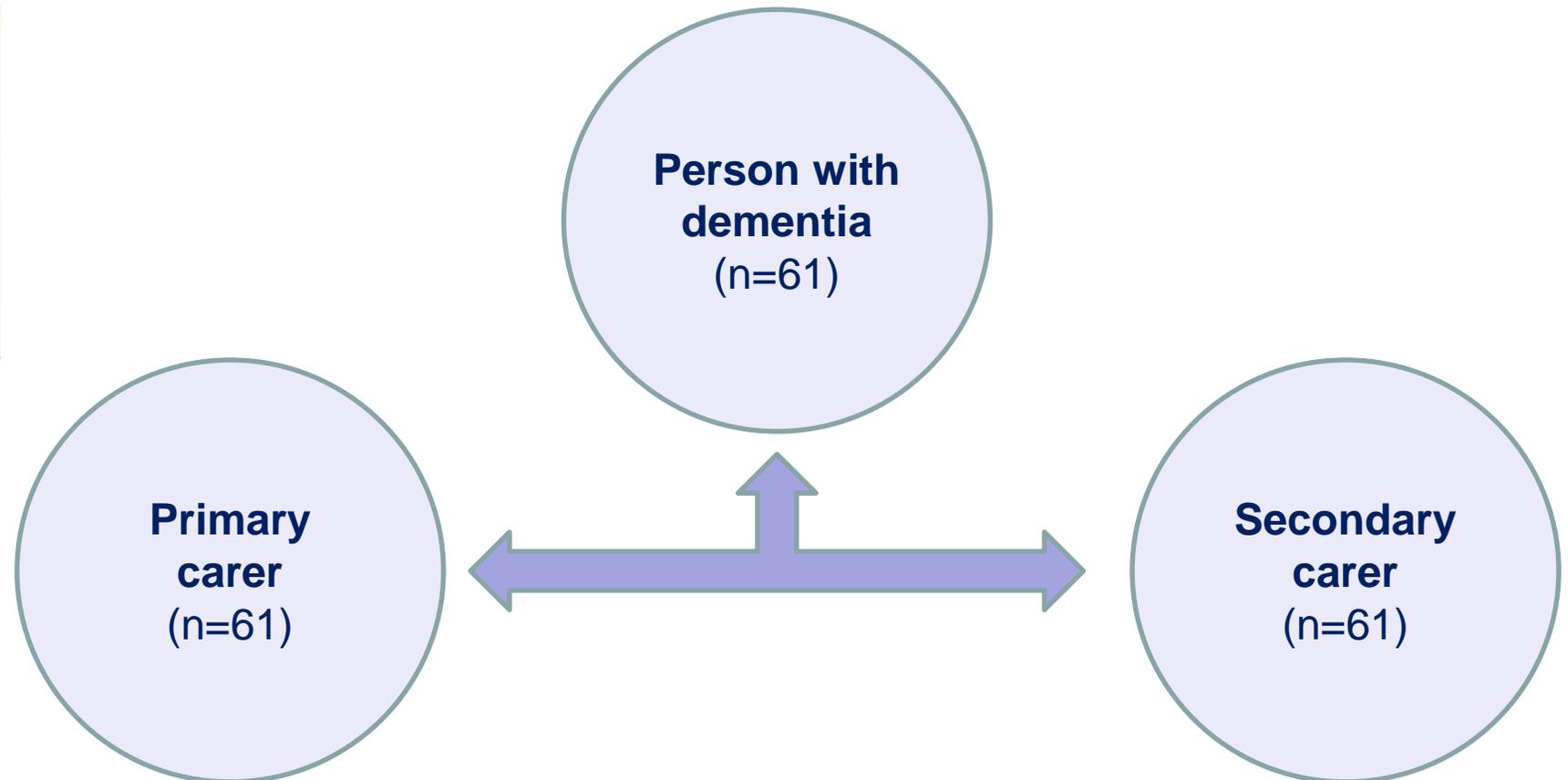
Veterans Affairs Canada, Charlottetown, Prince Edward Island, Canada

Sacha Dubois, BA

McMaster University, Hamilton, Ontario, Canada

The FAMIDEM III wave: Aim and Methods

- Cross-sectional study of two related samples of primary and secondary carers of persons with dementia (Gonçalves-Pereira et al, 2019 – Psychology and Aging, in press).



FAMIDEM (Families of People with Dementia - Nova Medical School, Lisbon)

- Cross-sectional, quantitative and qualitative approaches, waves I-III.
- Index patients: ICD10-DCR dementia; outpatient psychiatry or neurology public hospital services, and Sisters Hospitallers (Lisbon).
- Demographic and clinical data - comprehensive assessments.

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Caregiving experiences and knowledge about dementia in Portuguese clinical outpatient settings

Manuel Gonçalves-Pereira,¹ Isabel Carmo,² Joaquim Alves da Silva,^{1,3}
Ana L. Papoila,⁴ Raimundo Mateos⁵ and Steven H. Zarit⁶

¹*CEDOC, Department of Mental Health, Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisbon, Portugal*

²*Neurology Service, Hospital Egas Moniz, CHLO, Portugal*

³*Department of Psychiatry and Mental Health, Hospital San Francisco Xavier, CHLO, Portugal*

⁴*Department of Biostatistics and Informatics, Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisbon, and CEAUL, Portugal*

⁵*Department of Psychiatry (USC) and CHUS University Hospital, Santiago de Compostela, Spain*

⁶*Department of Human Development and Family Studies, Penn State University, Pennsylvania, U.S.A.*

Measures - FAMIDEM project

CAREGIVERS	
Experience of caregiving	<i>Burden Interview (Zarit et al., 1980) - ZBI</i> <i>Caregiving Activity Survey (Davis et al., 1997) - CAS</i> <i>PAC- positive aspects of caregiving - NIA/NINR-REACH II 2002</i>
Psychological distress	<i>General Health Questionnaire (Goldberg, 1988) – GHQ 12</i>
Knowledge about dementia	<i>Dementia Knowledge Questionnaire (Graham, 1997) - DKQ</i>
Social support	<i>Social Network Questionnaire (Magliano, 1994) - SNQ</i>
Sense of coherence	<i>Orientation to Life Questionnaire (Antonovsky, 1987) - SOC</i>
Coping	<i>Caregivers' Assessment Management Index (Nolan et al, 1995) - CAMI</i>
Needs	<i>CANE – Camberwell Assessment of Need for the Elderly (Reynolds et al., 2000)</i>
PATIENTS	
Cognitive symptoms BPSD	<i>Global Deterioration Scale (Reisberg, 1982)</i> <i>Dysfunctional Behaviour Rating Scale (Molloy et al, 1991) - DBRI</i>
Disability Activities of daily living	<i>Barthel Index (Mahoney & Barthel, 1965)</i> <i>Instrumental ADL scale (Lawton & Brody, 1969)</i>

Demographics and caregiving arrangements

	Primary caregivers (n=61)	Secondary caregivers (n=61)	P-value
Age – median (min-max)	60 (28-87)	44 (18-84)	<0.001
Relationship to the patient:			<0.001
Spouses	28 (45.9%)	1 (1.6%)	
Children	30 (49.2%)	42 (68.9%)	
Other	3 (4.9%)	18 (29.5%)	
Living with the patient	47 (77.0%)	19 (31.1%)	<0.001

“A comparison of primary and secondary caregivers of persons with dementia” (*Psychology and Aging*, in press)

- In our comparative study of primary and secondary carers we found great variability in carer experience of BPSD, with notable associations between BPSD and distress. But we did not find significant differences between primary and secondary carers' distress.

“A comparison of primary and secondary caregivers of persons with dementia” (*Psychology and Aging*, in press)

PRESENT ANALYSIS:

- We now compare the **needs** of this cohort of primary and secondary carers who support the person with dementia at home (analysable sample, n=60).
- Measure: **Camberwell Assessment of Need for the Elderly – CANE** (Reynolds et al, 2000) - two ‘carer items’ (dementia knowledge and distress).

Results

- Fourteen (23.3%) **primary carers** had an unmet need for dementia knowledge and 16 (26.7%) had unmet needs in the ‘psychological distress’ domain.
- Thirteen (21.7%) **secondary carers** had an unmet need for dementia knowledge and 10 (16.7%) had unmet needs in the ‘psychological distress’ domain.
- **Primary and secondary carers did not differ on these two domains of ‘need’** ($p = 1.000$ and $p = 0.180$, respectively).

Discussion

- Are we underestimating the risks of 'second-line' caregiving in dementia, namely concerning psychological distress?
- Despite the limitations of this small-scale study, our Portuguese FAMIDEM/ wave III primary and secondary family carers did not differ regarding knowledge about dementia and psychological distress.

- Caregiving can have great impact on several family members. However, family interventions and services are usually targeted to the primary carer...
- Evidence-based psychoeducational family interventions in severe mental illness rely on the active engagement of several family members and not only of primary carers:
 - BFT (Falloon *et al*, 1984)
 - Multiple family groups (McFarlane *et al*, 1995)
 - “Expressed emotion” family work (Kuipers, Leff & Lam, 1992).
- The same obviously applies to family systems approaches, either in severe mental illness or in dementia.

Toward a family-sensitive practice in dementia

(2017)

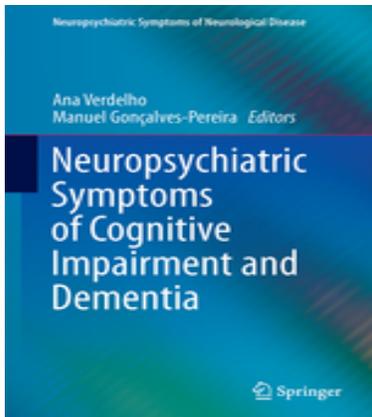
Perplexity - Shock - Revolt - Shame - Humiliation -
Sadness - Anxiety - Fears - Mistrust - Ambivalence
- Emptiness - Frustration - Impotence - Guilt –
Egocentrism – Positive aspects ...

[person with dementia]

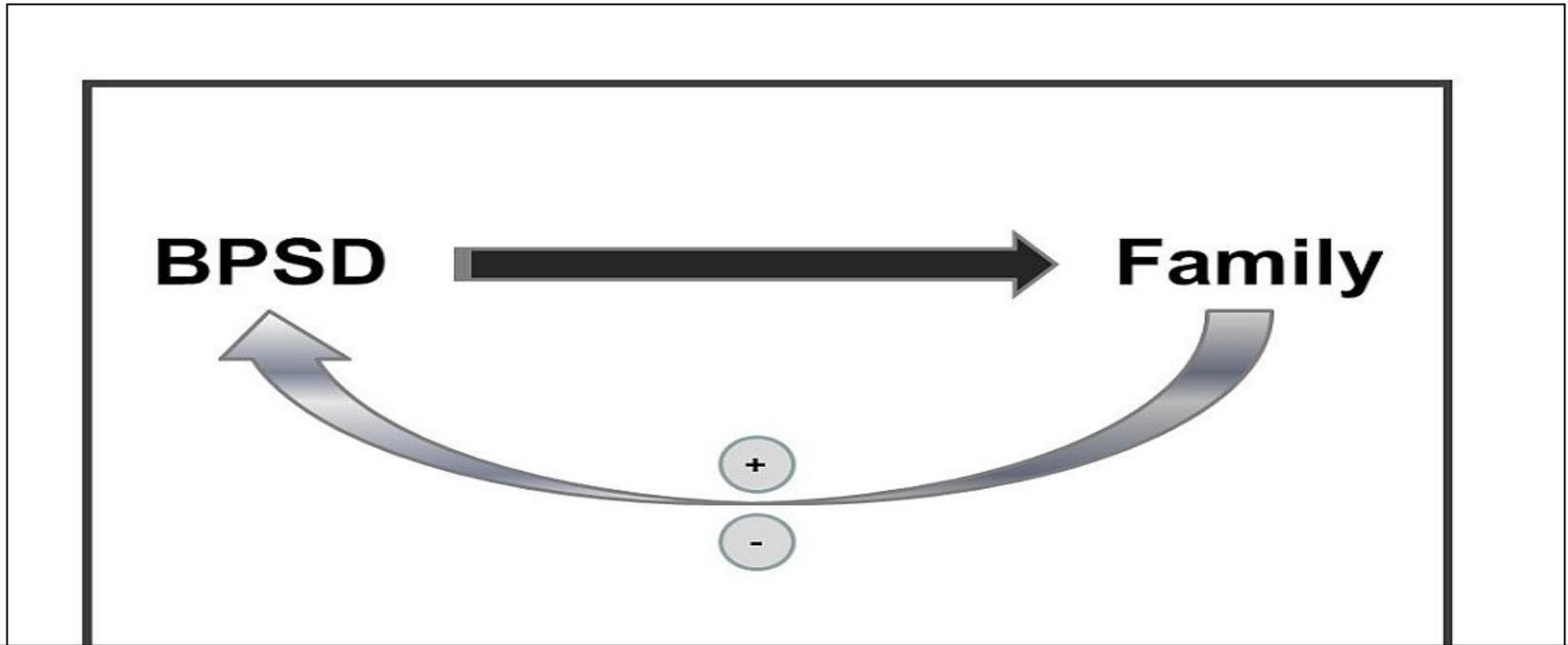
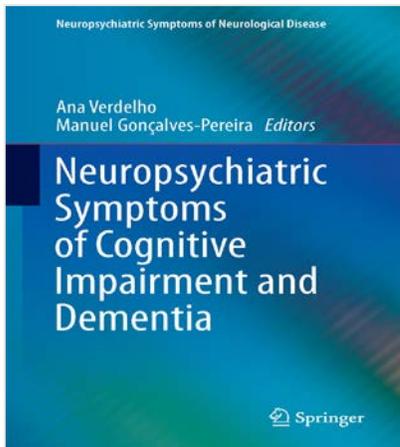


Mourning - Grief – Burden – Ambivalence – Guilt -
Sadness – Depression - Anxiety - Fears - Responsibility -
Impotence - Stigma – Positive aspects ...

[primary carer]



... and what about other family members?



*Family Issues in Behavioral and Psychological Symptoms of Dementia:
Unraveling Circular Pathways? (2017)*

Table 16.1 Practical tips – a checklist for clinicians

Find your way: assessment comes first

Standardized tools may be helpful, but do not replace clinical judgment

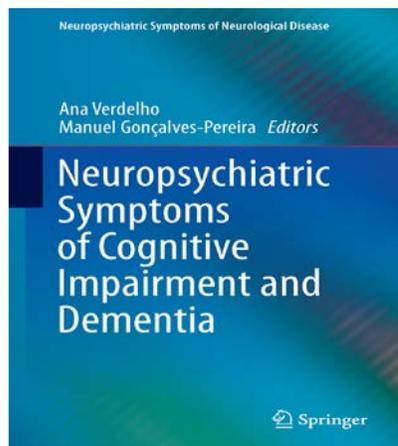
A genogram is simple to use

Be attentive: circularity is always there to be found...

Assessment is a form of intervention *per se*

Do not lose your time trying to find the guilty party: try to stop unhelpful interactions

Family interventions (if needed) should be tailored and timely



Take home messages

- Our results suggest that secondary carers should not be forgotten in needs assessments and family interventions.
- Thinking systemically and involving the family as a whole may contribute to address the needs of persons with dementia and their family members altogether.
- Family-sensitive tailored support would decisively improve the management of BPSD at home.

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