

## **Supplemental materials for:**

Khanassov V, Vedel I. Family physician-case manager collaboration and needs of patients with dementia and their caregivers: a systematic mixed studies review. *Ann Fam Med*. 2016;14(2):166-177.

## Supplemental Appendix 1.

Search strategy in PsycINFO

### Needs assessment of caregivers and/or patients with dementia

Database: PsycINFO <1967 to September Week 3 2014>

Search Strategy:

-----

1	needs/ or health service needs/ or psychological needs/ or need satisfaction/ or needs assessment/ or special needs/
2	need? assessment?.mp.
3	((need? or burden) adj (assessment? or estimat* or evaluat* or analys*)).ti,ab.
4	((need? or burden) adj1 (instrument? or scal* or survey* or measur* or inventor* or questionnaire? or interview*)).ti,ab.
5	((caregiver* adj1 need?) or (patient? adj1 need*)).ti,ab.
6	1 or 2 or 3 or 4 or 5

7	dementia/ or aids dementia complex/ or dementia with lewy bodies/ or presenile dementia/ or semantic dementia/ or senile dementia/ or vascular dementia/ or alzheimer's disease/ or cognitive impairment/ or corticobasal degeneration/ or creutzfeldt jakob syndrome/ or melas/ or neurodegenerative diseases/ or neurofibrillary tangles/ or parkinson's disease/ or picks disease/ or pseudodementia/ or senile plaques/
8	exp Cognitive Impairment/
9	((cognit* adj1 disorder?) or (cognit* adj1 impairment?)).mp.
10	(dementia? or alzheimer*).mp.
11	7 or 8 or 9 or 10

12 6 and 11

13 limit 12 to (english or french or russian)

### Case management of dementia in Primary care

Database: PsycINFO <1967 to September Week 3 2014>

Search Strategy:

-----

1.	dementia/ or aids dementia complex/ or dementia with lewy bodies/ or presenile dementia/ or semantic dementia/ or senile dementia/ or vascular dementia/ or alzheimer's disease/ or cognitive impairment/ or corticobasal degeneration/ or creutzfeldt jakob syndrome/ or melas/ or neurodegenerative diseases/ or neurofibrillary tangles/ or parkinson's disease/ or picks disease/ or pseudodementia/ or senile plaques/
2.	exp Cognitive Impairment/
3.	((cognit* adj1 disorder?) or (cognit* adj1 impairment?)).mp.
4.	(dementia? or alzheimer*).mp.
5.	1 or 2 or 3 or 4

6. exp Disease Management/
7. exp Case Management/
8. treatment planning/
9. ((care adj coordinat\*) or (care adj manag\*) or (case adj manag\*) or (critical adj pathway?) or (clinical adj pathway?)).mp.
10. (patient? adj1 (planning or management)).mp.
11. 6 or 7 or 8 or 9 or 10

12. exp Primary Health Care/
13. family physicians/ or family medicine/ or general practitioners/
14. ((family adj1 practi\*) or (general adj1 practi\*)).mp.
15. ((family adj1 physic\*) or (general adj1 physic\*)).mp.
16. (family nurs\* or communit\* nurs\*).mp.
17. exp Home Care/
18. communit\*.mp.
19. (primary adj1 care).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
20. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19

22. 5 and 20 and 21
23. limit 22 to (english or french or russian)

## Supplemental Appendix 2.

Author, Year, Country	Characteristics of Study		Characteristics of Sample				Quality Appraisal
	Setting of Recruitment	Method of Data Collection	Number of Participants	Age of Participants	Sex of Participants <sup>a</sup>	Diagnosis and Severity of Dementia	
Johnston, 2011, USA <sup>1</sup>	List of individuals participated in a demographic study	Assessment by clinicians after in-home visit	P: 29 C: 18	P: 85.4±5.2 C: No data	P: 47 C: No data	Dementia and MCI, mild	3
Cammissaris, 1995, Netherlands <sup>2</sup>	Memory clinic, mental health institute	Structured questionnaire	P: 26 C: 26	P: 70 C: 68	P: 34.6 C: 69.2	AD, VD	2
Mirando – Castillo, 2010, UK <sup>3,4</sup>	Health and social services, voluntary organizations	Semi-structured interview using questionnaire	P: 152 C: 128	P: 81.7±5.9 C: 54.3±7.5	P: 76 C: 86.7	Dementia, moderate	3
Der Roest, 2009, Netherlands <sup>5</sup>	Alzheimer's café, memory clinic, support center, daycare	Semi-structured interview using questionnaire	P: 236 C: 322	P: 79.8±7.6 C: 65.4±14.1	P: 54.8 C: 68.6	AD – 51.4%, VD – 17.7%, Mixed dementia – 17.7%; mild-moderate – 53.8%.	4
Rosa, 2010, Italy <sup>6</sup>	Memory clinic	Structured questionnaire	P: 112 C: 112	P: 80±8 C: 55±10	P: C: 69	Dementia, moderate-severe	4
Hirakawa, 2011, Japan <sup>7</sup>	Health care centers	Structured questionnaire	P: 475 C: 475	P: 81.2±8.7 C: 64.9±12.2	P: 53.5 C: 77.1	Dementia, mild	3
Philp, 1995, UK <sup>8</sup>	Primary health care, psychiatric services	Unstructured questionnaire	P: 113 C: 113	P: 80.7 C: 59.2	P: 86 C: 64	Dementia	3
Meaney, 2005, Ireland <sup>9</sup>	Community psychiatric outpatient clinic	Structured questionnaire	P: 82	P: 76±7.8	P: 67	Dementia, moderate	2
Black, 2013, USA <sup>10</sup>	Community services, mailed letters, via media	Assessment by clinicians after in-home visit	P: 254 C: 246	P: 83.6±5.9 C: 66.1±13.3	P: 65 C: 74.8	Dementia and MCI, moderate	4
Wolfs, 2010, Netherlands <sup>11</sup>	Memory clinic, outpatient facility, community mental health service	Semi-structured telephone interview	P: 252 C: 252	P: 78.6±8.0 C: 61.9±12.9	P: 58.7 C: 62.7	AD – 57.6%, VD – 9.6%, Other – 32.8%	3

						MCI – 38.7%; mild.	
Li, 2011, USA <sup>12</sup>	Research centers, outpatient clinics, caregiver support groups	Telephone interview questionnaire	P: No data C: 109	P: 78.4±7.7 C: 66.6±13.6	P: 48.6 C: 78.9	AD	2
Leggett, 2010, USA <sup>13</sup>	From previously conducted web-based survey	Web-based questionnaire	P: C: 611	P: 75.1±8.5 C: 56.3±11.8	P: 38 C: 87	Lewy Body dementia	3
AD = Alzheimer's disease; C = caregiver; EOD = early onset of dementia; FTD = frontotemporal dementia; MCI = mild cognitive impairment; P = patient; VD = vascular dementia.							
<sup>a</sup> Percentage of female.							

**Table 1.2. Characteristics of Included Quantitative Descriptive Studies (Surveys) On the Needs of Patients With Dementia and Their Caregivers**

Author, year, country	Characteristics of study		Characteristics of sample				Quality appraisal
	Setting of recruitment	Method of data collection	Number of participants	Age of participants (mean ± SD)	Sex of participants <sup>a</sup>	Diagnosis and severity of dementia	
Nurock, 2007, UK - Poland <sup>14</sup>	Consumer network	No data	C: 94	C: 69	C: 74	Dementia	0
Li, 2012, USA <sup>15</sup>	Random-digit dial method	No data	C: 208	C: 49.7±15.5	C: 57.7	Dementia	3
Rosness, 2012, Norway <sup>16</sup>	Community services	Mailed survey	C: 45	No data	C: 68.9	AD – 60%, FTD - 24%, VD – 7%, other dementias – 11%	2
Wackerbarth, 2002, USA <sup>17</sup>	Daycare	Mailed survey	P: 128 C: 128	P: 78.5 C: 58.7	P: 75.6 C: 74.6	Dementia	3
Georges, 2008, Germany – UK – France – Poland – Spain - Luxembourg <sup>18</sup>	Mailing list	Mailed survey	C: 1181	P: 87% over 66 C: 65% over 55	C: 67	AD – 74%, VD – 11%; mild-moderate – 46%, late-severe – 26%	2
Judge, 2011, USA <sup>19</sup>	Direct referral and electronic medical records	In-person	P: 93 C: 90	P: 80 C: 69.2	P: 5.4 C: 92.2	Dementia	3
Lai, 2007, Hong Kong <sup>20</sup>	Community services	Mailed and in-person	C: 144	C: 44% between 25 and 44	C: 63	Dementia	3
Armari, 2013, Australia <sup>21</sup>	Public symposium	In-person	P: 18 C: 39	P: 59.13 C: 53.13	P: 55.6 C: 61.5	EOD: AD – 77.8%, FTD – 7.7%.	2
Chow, 2011, Canada <sup>22</sup>	Mailing list	Online survey	C: 79	C: 58 (median)	C: 59	FTD	3
Chung, 2007, Hong Kong <sup>23</sup>	List of patients from Alzheimer’s Disease association, memory clinics, daycare centers	Semi-structured interview	P: 197	P: 77	P: 64	Dementia: early stage – 36%, middle stage – 51%, late stage – 13%.	3
Hinton, 2006, USA <sup>24</sup>	Prospective cohort on dementia	In-person	P: 38 C: 38	P: 74.9±7.7 C: 59.7±17.4	P: 52.6 C: 71.1	Dementia	3

AD = Alzheimer's disease; C = caregiver; EOD = early onset of dementia; FTD = frontotemporal dementia; MCI = mild cognitive impairment; P = patient; VD = vascular dementia.

<sup>a</sup> Percentage of female.

**Table 1.3. Characteristics of Included Qualitative Studies On the Needs of Patients With Dementia and Their Caregivers**

Author, year, country	Characteristics of study			Characteristics of sample				Quality appraisal
	Study design	Setting of recruitment	Method of data collection	Number of participants	Age of participants	Sex of participants <sup>a</sup>	Diagnosis and severity of dementia	
Gorska, 2013, UK <sup>25</sup>	Qualitative descriptive Thematic analysis	Health, social services, voluntary sector	Semi-structured individual interview	P: 20 C: 13	P: 84 C: 65	P: 92 C: 74	AD – 50%, VD – 15%, mixed – 5%, other dementias – 30%; mild (40%) - moderate (25%).	3
Flynn, 2013, Ireland <sup>26</sup>	Qualitative descriptive Thematic analysis	Alzheimer's society	Semi-structured individual interview	C: 7	C: 71% between 56-65	C: 29	EOD	3
Bakker, 2010, Netherlands <sup>27</sup>	Single case study Thematic analysis	Randomly from previously conducted study	Semi-structured individual interview	P: 1 C: 1	P: 59 C: No data	P: 0 C: No data	EOD, AD; severe	3
Mushi, 2014, Tanzania <sup>28</sup>	Qualitative descriptive Thematic analysis	No data	Semi-structured paired and individual (with caregivers) interviews	P: 25 C: 16	P: 84 (median) C: No data	No data	Dementia	3
Nichols, 2013, USA - Canada <sup>29</sup>	Qualitative descriptive Thematic analysis	Self-identification by caregivers	Focus group interview via skype/phone	C: 14	C: 11-18 (range)	C: 71	FTD	3
Qadir, 2013, Pakistan <sup>30</sup>	Qualitative descriptive Thematic analysis	Psychiatric outpatient department	Semi-structured individual interview	P: 12 C: 12	P: 55-90 (range) C: 19-47 (range)	P: 33 C: 58	AD – 75%, VD – 8%, other dementias – 17%.	3
Tasc, 2012, Turkey <sup>31</sup>	Qualitative descriptive Thematic analysis	Outpatient neurology clinic	Focus group interview	C: 8	C: 48.87±11.37	C: No data	Dementia	1



Vaingankar, 2013, Singapore <sup>32</sup>	Qualitative descriptive Thematic analysis	Outpatient clinics, voluntary sector, social services	Semi-structured individual interview	C: 63	P: 54-93 (range) C: 52.9	No data	Dementia	3
Bowes, 2003, UK <sup>33</sup>	Multiple case studies Thematic analysis	Health services working with ethnic minority	Semi-structured individual interview	P: 4 C: 4	No data	No data	Dementia	3
Lin, 2004, USA <sup>34</sup>	Qualitative descriptive Thematic analysis	Home care agency	Semi-structured individual interview	P: 4 C: 4	P: 80-90 (range) C: 36-62 (range)	P: 100 C: 75	AD	3
Kuhn, 1998, USA <sup>35</sup>	Qualitative descriptive Thematic analysis	No data	Semi-structured individual interview	P: 20 C: 20	P: 70 C: 66	P: 65 C: 55	AD; mild.	2
Shaji, 2003, India <sup>36</sup>	Qualitative descriptive Thematic analysis	Rural community care services	Semi-structured individual interview	P: 33 C: 33	No data	P: 76 C: 60	AD	3
Samsi, 2014, UK <sup>37</sup>	Qualitative descriptive Thematic analysis	Outpatient memory services	Semi-structured individual interview	P: 27 C: 26	P: 80±5 C: 80±1	P: 52 C: 77	78% - dementia, 22% - MCI.	4
Singh, 2014, Australia <sup>38</sup>	Qualitative descriptive Thematic analysis	Health centers	Semi-structured individual interview	C: 17	C: No data	C: 88	Dementia	3
Smith, 2001, USA <sup>39</sup>	Ethnography Thematic analysis	Rural community services	Semi-structured individual interview	P: 45 C: 45	P: over 75 C: 65-75 (range)	P: 49 C: 87	AD, 22% - early stage, 47% - moderate stage, 24% - late stage.	3
Smith, 2011, Australia <sup>40</sup>	Qualitative descriptive Thematic analysis	Various health services	Semi-structured individual interview	C: 13	No data	No data	Dementia	3
Chan, 2010,	Phenomenology	Community	Semi-	C: 27	P: 78 (median)	P: No data	Dementia	3

China <sup>41</sup>	Thematic analysis	rehabilitation network	structured focus interviews		C: 52 (median)	C: 78		
Innes, 2005, UK <sup>42</sup>	Qualitative descriptive Thematic analysis	Voluntary rural services	Semi-structured individual and focus interviews	P: 15 C: 16	P: 78% between 70-89 C: 73% between 50-79	P: 52 C: 73	Dementia	3
Holst, 2003, Sweden <sup>43</sup>	Hermeneutic approach Thematic analysis	Psychogeriatric outpatient clinic	Semi-structured individual interview	P: 11	No data	No data	Dementia	3
Gilmore, 2005, New Zealand <sup>44</sup>	Qualitative descriptive Thematic analysis	No data	Semi-structured individual interview	P: 9	P: 56-79 (range)	P: 44	AD VD	2
Marzanski, 2000, UK <sup>45</sup>	Qualitative descriptive Thematic analysis	Psychiatric outpatient clinic	No data/unclear	P: 30	P: 81	P: 67	AD – 37%, VD – 30%, other dementias – 33%; moderate.	1
Wuest, 2010, USA <sup>46</sup>	Grounded theory Continuous comparative analysis	Agency referral and snowball	Semi-structured individual interview	C: 15	No data	C: 73.3	Dementia	3
AD = Alzheimer's disease; C = caregiver; EOD = early onset of dementia; FTD = frontotemporal dementia; MCI = mild cognitive impairment; P = patient; VD = vascular dementia.								
<sup>a</sup> Percentage of female.								

<b>Table 1.4. Characteristics of Included Mixed Methods Study On the Needs of Patients With Dementia and Their Caregivers</b>								
Author, year, country	Characteristics of study			Characteristics of sample				Quality appraisal
	Study design	Setting of recruitment	Method of data collection	Number of participants	Age of participants	Sex of participants <sup>a</sup>	Diagnosis and severity of dementia	
Stirling, 2010, Australia <sup>47</sup>	Sequential explanatory design	Local Alzheimer's organizations	Structured questionnaires followed by focus groups interviews	P: 20 C: 20	P: 73% over 75 C: 50% over 66	P: 25 C: 90	AD – 55% VD – 15% unknown – 20% Parkinson's/FTD – 5%.	5
AD = Alzheimer's disease; C = caregiver; EOD = early onset of dementia; FTD = frontotemporal dementia; MCI = mild cognitive impairment; P = patient; VD = vascular dementia.								
<sup>a</sup> Percentage of female.								

## Supplemental Appendix 2 References

1. Johnston D, Samus QM, Morrison A, et al. Identification of community-residing individuals with dementia and their unmet needs for care. *Int J Geriatr Psychiatry*. 2011;26(3):292-298.
2. Commissaris CJ, Jolles J, Verhey FR Jr, Kok GJ. Problems of caregiving spouses of patients with dementia. *Patient Educ Couns*. 1995;25(2):143-149.
3. Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. Unmet needs, quality of life and support networks of people with dementia living at home. *Health Qual Life Outcomes*. 2010;8:132.
4. Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr*. 2010;22(4):607-617.
5. van der Roest HG, Meiland FJ, Comijs HC, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatr*. 2009;21(5):949-965.
6. Rosa E, Lussignoli G, Sabbatini F, et al. Needs of caregivers of the patients with dementia. *Arch Gerontol Geriatr*. 2010;51(1):54-58.

7. Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. *Arch Gerontol Geriatr*. 2011;52(2):202-205.
8. Philp I, McKee KJ, Meldrum P, et al. Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters. *BMJ*. 1995;310(6993):1503-1506.
9. Meaney AM, Croke M, Kirby M. Needs assessment in dementia. *Int J Geriatr Psychiatry*. 2005;20(4):322-329.
10. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc*. 2013;61(12):2087-2095.
11. Wolfs CA, de Vugt ME, Verkaaik M, Verkade PJ, Verhey FR. Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *Int J Geriatr Psychiatry*. 2010;25(10):1006-1012.
12. Li H, Kyrouac GA, McManus DQ, Cranston RE, Hughes S. Unmet home care service needs of rural older adults with Alzheimer's disease: a perspective of informal caregivers. *J Gerontol Soc Work*. 2012;55(5):409-425.
13. Leggett AN, Zarit S, Taylor A, Galvin JE. Stress and burden among caregivers of patients with Lewy body dementia. *Gerontologist*. 2011;51(1):76-85.
14. Nurock S, Wojciechowska M. What real outcomes matter to caregivers? *Int Psychogeriatr*. 2007;19(3):355-362.
15. Li H. Unmet service needs: a comparison between dementia and non-dementia caregivers. *Home Health Care Serv Q*. 2012;31(1):41-59.
16. Rosness TA, Haugen PK, Gausdal M, Gjøra L, Engedal K. Carers of patients with early-onset dementia, their burden and needs: a pilot study using a new questionnaire—care-EOD. *Int J Geriatr Psychiatry*. 2012;27(10):1095-1096.
17. Wackerbarth SB, Johnson MM. Essential information and support needs of family caregivers. *Patient Educ Couns*. 2002;47(2):95-100.
18. Georges J, Jansen S, Jackson J, Meyrieux A, Sadowska A, Selmes M. Alzheimer's disease in real life--the dementia carer's survey. *Int J Geriatr Psychiatry*. 2008;23(5):546-51.

19. Judge K, Bass D, Snow A, Wilson N, Morgan R, Looman W. Partners in dementia care: a care coordination intervention for individuals with dementia and their family caregivers. *Gerontologist*. 2011;51(2):261-72.
20. Lai C, Chung JC. Caregivers' informational needs on dementia and dementia care. *Asian J Gerontol Geriatr*. 2007;2:78-87.
21. Armari E, Jarmolowicz A, Panegyres PK. The needs of patients with early onset dementia. *Am J Alzheimers Dis Other Demen*. 2013;28(1):42-46.
22. Chow TW, Pio FJ, Rockwood K. An international needs assessment of caregivers for frontotemporal dementia. *Can J Neurol Sci*. 2011;38(5):753-757.
23. Chung JC. Care needs assessment of older Chinese individuals with dementia of Hong Kong. *Aging Ment Health*. 2006;10(6):631-637.
24. Hinton L, Chambers D, Velasquez A, Gonzalez H, Haan M. Dementia Neuropsychiatric Symptom Severity, Help-Seeking Patterns, and Family Caregiver Unmet Needs in the Sacramento Area Latino Study on Aging (SALSA). *Clin Gerontologist*. 2006;29(4):1-15.
25. Górska S, Forsyth K, Irvine L, et al. Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *Int Psychogeriatr*. 2013;25(7):1107-1114.
26. Flynn R, Mulcahy H. Early-onset dementia: the impact on family care-givers. *Br J Community Nurs*. 2013;18(12):598-606.
27. Bakker C, de Vugt ME, Vernooij-Dassen M, van Vliet D, Verhey FR, Koopmans RT. Needs in early onset dementia: A qualitative case from the NeedYD study. *Am J Alzheimers Dis Other Demen*. 2010;25(8):634-640.
28. Mushi D, Rongai A, Paddick SM, Dotchin C, Mtuya C, Walker R. Social representation and practices related to dementia in Hai District of Tanzania. *BMC Public Health*. 2014;14:260.
29. Nichols KR, Fam D, Cook C, et al. When dementia is in the house: needs assessment survey for young caregivers. *Can J Neurol Sci*. 2013;40(1):21-28.

30. Qadir F, Gulzar W, Haqqani S, Khalid A. A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Manag J*. 2013;14(4):230-240.
31. Taşç S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Göriş S. Living with an Alzheimer patient in Turkey. *J Neurosci Nurs*. 2012;44(4):228-234.
32. Vaingankar JA, Subramaniam M, Picco L, et al. Perceived unmet needs of informal caregivers of people with dementia in Singapore. *Int Psychogeriatr*. 2013;25(10):1605-1619.
33. Bowes A, Wilkinson H. 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health Soc Care Community*. 2003;11(5):387-396.
34. Zhan L. Caring for family members with Alzheimer's disease: perspectives from Chinese American caregivers. *J Gerontol Nurs*. 2004;30(8):19-29.
35. Kuhn D. Caring for relatives with early stage Alzheimer's disease: An exploratory study. *Am J Alzheimers Dis Other Demen*. 1998;13(4):189-196.
36. Shaji KS, Smitha K, Lal KP, Prince MJ. Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network. *Int J Geriatr Psychiatry*. 2003;18(1):1-6.
37. Samsi K, Abley C, Campbell S, et al. Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *Int J Geriatr Psychiatry*. 2014;29(1):58-67.
38. Singh P, Hussain R, Khan A, Irwin L, Foskey R. Dementia care: intersecting informal family care and formal care systems. *J Aging Res*. 2014;2014:486521.
39. Smith A. Caregiver Needs. *Clin Gerontol*. 2001;24(1-2):3-26.
40. Smith K, Flicker L, Shadforth G, et al. 'Gotta be sit down and worked out together': views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians. *Rural Remote Health*. 2011;11(2):1650.
41. Chan WC, Ng C, Mok CC, Wong FL, Pang SL, Chiu HF. Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. *East Asian Arch Psychiatry*. 2010;20(4):163-168.
42. Innes A, Blackstock K, Mason A, Smith A, Cox S. Dementia care provision in rural Scotland: service users' and carers' experiences. *Health Soc Care Community*. 2005;13(4):354-365.

43. Holst G, Hallberg IR. Exploring the meaning of everyday life, for those suffering from dementia. *Am J Alzheimers Dis Other Demen.* 2003;18(6):359-365.
44. Gilmour JA, Huntington AD. Finding the balance: living with memory loss. *Int J Nurs Pract.* 2005;11(3):118-124.
45. Marzanski M. Would you like to know what is wrong with you? On telling the truth to patients with dementia. *J Med Ethics.* 2000;26(2):108-113.
46. Wuest J, Ericson PK, Stern PN, Irwin GW Jr. Connected and disconnected support: the impact on the caregiving process in Alzheimer's disease. *Health Care Women Int.* 2001;22(1-2):115-130.
47. Stirling C, Andrews S, Croft T, Vickers J, Turner P, Robinson A. Measuring dementia carers' unmet need for services—an exploratory mixed method study. *BMC Health Serv Res.* 2010;10:122.

### Supplemental Appendix 3.

<b>Table 2. Characteristics of Included Studies On CM of Patients With Dementia and Their Caregivers</b>					
<b>Author, year, country</b>	<b>Study design</b>	<b>Main characteristics of CM</b>	<b>Detailed description<sup>a</sup></b>	<b>Involved health care professionals</b>	<b>Quality appraisal</b>
Callahan, 2006, USA <sup>1</sup>	RCT	<ul style="list-style-type: none"> <li>- Development of individualized care plan for the patient-caregiver dyad;</li> <li>- Regular assessment of patients' behavior and memory;</li> <li>- Weekly review of care and adherence to guidelines by multidisciplinary team.</li> <li>- Prescription of anticholinesterase inhibitors and memantine;</li> <li>- Monitoring of health condition and communication of healthcare professionals via Web-based system.</li> </ul>	<ul style="list-style-type: none"> <li>- Education of caregivers on communication and coping skills, legal and financial advice;</li> <li>- Support sessions focused on caregiver stress;</li> <li>- Patient exercise guidelines (e.g., group chair-based exercises);</li> <li>- Specific behavioral protocol of non-pharmacological interventions for personal care, repetitive behavior, mobility, sleep disturbances, depression, agitation, aggression, delusions or hallucinations; if this failed, drug therapy was initiated.</li> </ul>	FP, geriatrician, geriatric psychiatrist, psychologist, geriatric nurse practitioner (case manager).	3
Vickrey, 2006, USA <sup>2</sup>	RCT	<ul style="list-style-type: none"> <li>- Problem list development with further elaborated care plan including guidelines for caregiver;</li> <li>- Regular reassessment of the patient's condition;</li> <li>- Liaison of the patient to support services by case manager;</li> <li>- Prescription of anticholinesterase inhibitors;</li> <li>- Monitoring of health condition and communication of healthcare professionals via Web-based system.</li> </ul>	<ul style="list-style-type: none"> <li>- Interactive seminars for caregivers on relevant care issues included evaluation of acute behavior changes, depression management, determination of decision-making capacity;</li> <li>- Use of dementia guideline recommendations on assessment, treatment, education, support, and safety;</li> <li>- Involvement of caregivers in care plan development;</li> <li>- Advice on implementation of predictable routine of daily activities;</li> <li>- Non-pharmacological approaches for behavior problems;</li> <li>- Recommendations on caregiver support group, dementia-related financial planning referral and respite care;</li> <li>- Recommendations on caregiver resources,</li> </ul>	FP, social worker (case manager).	3



			Alzheimer's Association, meals and wheels, safe return program (for wandering); - Advice on advance directives.		
Schoenmakers, 2010, Belgium <sup>3</sup>	RCT	- Guidance of the caregiver in organizing home care; - Exploring problematic home care situations; - Monthly telephone call to the caregiver; - Regular home follow-up; - Permanent reach for advice.	- Assistance through day care; - Safety – personal alarms; - Extra in-home help.	FP, primary care professional with a bachelor degree (case manager).	3
Jansen, 2011, the Netherlands <sup>4</sup>	RCT	- In-home assessment; - Elaborated care plan development for the patient-caregiver dyad; - Liaison to support service; - Regular communication of case manager with FP to inform about patient's health condition; - Referral to specialists, if needed.	- Organization of family meetings aimed at educating relatives, improving social support, and relieving the primary caregiver; - Assistance with home care; - Dinner services; - Support centers for caregivers; - Provision of information by phone to caregivers.	FP, district nurse specialized in geriatric care (case manager).	4
Laurant, 2004, the Netherlands <sup>5</sup>	RCT	- Assessment of the patient's health and home situation; - Education of patients; - Coordination of the care and assistance with community health services and other health care professionals.	- Education of patient and the family to explain the disease, prognosis, rationale of treatment	FP, nurse (case manager).	2
Fortinsky, 2014, USA <sup>6</sup>	NRS	- Development of individualized care plan for the patient-caregiver dyad; - Monthly in-home visits to assess patients' behavior, memory and health; - Medication management; - Electronic update sent to FPs.	- Non-pharmacological protocols that included stress management, exercises for physical health, communication techniques, legal and financial considerations, depression and anxiety prevention, repetitive questioning and agitation, mobility management, personal care concerns, paranoia, delusions, and hallucinations.	FP, nurse practitioner (case manager).	3
Stevenson, 2006, UK <sup>7</sup>	NRS	- Initial in-home assessment; - Care plan development; - Regular follow-up and readjustment; - Case conferences to discuss the findings.	- Assistance with access to services (day care, respite care)	FP, psychogeriatrician, support workers, occupational therapist, social worker and F grade	4

				registered mental health nurse (case managers).	
Jedenius, 2008, Sweden <sup>8,9</sup>	QD	<ul style="list-style-type: none"> <li>- Gathering necessary information by nurses to enable FPs to establish a diagnosis;</li> <li>- Medical treatment evaluation;</li> <li>- Support of the patient-caregiver dyad;</li> <li>- Care planning.</li> </ul>	<ul style="list-style-type: none"> <li>- Guidance and support of the patient and family according to the different aspects of dementia.</li> </ul>	FP, registered dementia nurse (case manager).	3
<p>FP = family physician; NRS = non-randomized study; QD = quantitative descriptive study; RCT = randomized controlled trial.  <sup>a</sup> Detailed description is presented according to the needs expressed by patients and their caregivers.</p>					

### Supplemental Appendix 3 References

1. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148-2157.
2. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.
3. Schoenmakers B, Buntinx F, Delepeleire J. Supporting family carers of community-dwelling elder with cognitive decline: a randomized controlled trial. *Int J Family Med*. 2010;2010:184152.
4. Jansen AP, van Hout HP, Nijpels G, et al. Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: a randomized clinical trial. *Int J Nurs Stud*. 2011;48(8):933-943.
5. Laurant MG, Hermens RP, Braspenning JC, Sibbald B, Grol RP. Impact of nurse practitioners on workload of general practitioners: randomised controlled trial. *BMJ*. 2004;328(7445):927.
6. Fortinsky RH, Delaney C, Harel O, et al. Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Res Gerontol Nurs*. 2014;7(3):126-137.
7. Stevenson G, Herschell JDK. An enhanced assessment and support team (EAST) for dementing elders – review of a Scottish regional initiative. *J Ment Health*. 2006;15(2):251-258.
8. Jedenius E, Johnell K, Fastbom J, Strömquist J, Winblad B, Andreasen N. Dementia management programme in a community setting and the use of psychotropic drugs in the elderly population. *Scand J Prim Health Care*. 2011;29(3):181-186.
9. Jedenius E, Wimo A, Strömquist J, Andreasen N. A Swedish programme for dementia diagnostics in primary healthcare. *Scand J Prim Health Care*. 2008;26(4):235-240.

## Supplemental Appendix 4.

Table 3. Meta-Analysis of the Effects of CM On the Needs						
Type of Needs	No. of Studies	No. of Participants Intervention/Control	SMD	95% CI	P value	
<b>Patient needs</b>						
Behavior disturbance <sup>1,2</sup>	2	127/107	- 0.27	[-0.53; -0.01]	0.0456	
<b>Caregiver needs</b>						
Depression of caregivers <sup>1-3</sup>	3	151/128	- 0.23	[-0.46; 0.01]	0.062	
Burden of caregivers <sup>2,3</sup>	2	67/60	0.17	[-0.18; 0.52]	0.3351	
Confidence in caregiving <sup>2,4</sup>	2	279/208	0.19	[0.01; 0.37]	0.0434	5
SMD = standardized mean difference						

## Supplemental Appendix 4 References

1. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148-2157.
2. Jansen AP, van Hout HP, Nijpels G, et al. Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: a randomized clinical trial. *Int J Nurs Stud*. 2011;48(8):933-943.
3. Schoenmakers B, Buntinx F, Delepeleire J. Supporting family carers of community dwelling elder with cognitive decline: a randomized controlled trial. *Int J Family Med*. 2010;2010:184152.
4. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.

## Appendix 5.

<b>Table 4. MMAT Quality Appraisal for Studies With Diverse Designs</b>					
Study reference	Quality appraisal				
	Randomization	Blinding	Outcome data	Drop-out rate	Overall score
<b>Randomized controlled trials</b>					
Callahan, 2006 <sup>1</sup>	1	1	0	1	3
Vickrey, 2006 <sup>2</sup>	1	1	1	0	3
Schoenmakers, 2010 <sup>3</sup>	1	1	0	1	3
Jansen, 2011 <sup>4</sup>	1	1	1	1	4
Laurant, 2004 <sup>5</sup>	1	0	0	1	2
	Selection bias	Appropriate measurements	Compared groups	Outcome data	Overall score
<b>Non-randomized studies</b>					
Fortinsky, 2014 <sup>6</sup>	1	1	1	0	3
Stevenson, 2006 <sup>7</sup>	1	1	1	1	4
Johnston, 2011 <sup>8</sup>	1	1	1	0	3
Cammissaris, 1995 <sup>9</sup>	0	0	1	1	2
Li, 2011 <sup>10</sup>	1	0	1	0	2
Mirando – Castillo, 2010 <sup>11,12</sup>	1	1	1	0	3
Der Roest, 2009 <sup>13</sup>	1	1	1	1	4
Rosa, 2010 <sup>14</sup>	1	1	1	1	4
Leggett, 2010 <sup>15</sup>	1	1	1	0	3
Hirakawa, 2011 <sup>16</sup>	1	1	1	0	3
Philp, 1995 <sup>17</sup>	1	0	1	1	3
Meaney, 2005 <sup>18</sup>	1	1	0	0	2
Black, 2013 <sup>19</sup>	1	1	1	1	4
Wolfs, 2010 <sup>20</sup>	1	0	1	1	3
	Sampling strategy	Sample representativeness	Appropriate measurements	Response rate	Overall score
<b>Quantitative descriptive studies</b>					
Nurock, 2007 <sup>21</sup>	0	0	0	0	0
Armari, 2013 <sup>22</sup>	1	1	0	0	2
Chow, 2011 <sup>23</sup>	1	1	0	1	3
Chung, 2007 <sup>24</sup>	1	1	1	0	3
Li, 2012 <sup>25</sup>	1	1	1	0	3
Rosness, 2012 <sup>26</sup>	1	1	0	0	2
Wackerbarth, 2002 <sup>27</sup>	1	1	1	0	3
Georges, 2008 <sup>28</sup>	1	1	0	0	2
Hinton, 2006 <sup>29</sup>	1	1	0	1	3
Judge, 2011 <sup>30</sup>	1	1	0	1	3
Lai, 2007 <sup>31</sup>	1	1	1	0	3
Jedenius, 2008 <sup>32, 33</sup>	1	1	1	0	3
	Source of data	Methods of analysis	Context	Reflexivity	Overall score
<b>Qualitative studies</b>					
Gorska, 2013 <sup>34</sup>	1	1	1	0	3

Flynn, 2013 <sup>35</sup>	1	1	0	1	3
Bakker, 2010 <sup>36</sup>	1	1	1	0	3
Mushi, 2014 <sup>37</sup>	1	1	1	0	3
Nichols, 2013 <sup>38</sup>	1	1	0	1	3
Qadir, 2013 <sup>39</sup>	1	1	1	0	3
Tasc, 2012 <sup>40</sup>	1	0	0	0	1
Vaingankar, 2013 <sup>41</sup>	1	1	1	0	3
Bowes, 2003 <sup>42</sup>	1	1	1	0	3
Lin, 2004 <sup>43</sup>	1	1	1	0	3
Kuhn, 1998 <sup>44</sup>	1	0	1	0	2
Shaji, 2003 <sup>45</sup>	1	1	1	0	3
Samsi, 2014 <sup>46</sup>	1	1	1	1	4
Singh, 2014 <sup>47</sup>	1	1	1	0	3
Smith, 2001 <sup>48</sup>	1	1	0	1	3
Smith, 2011 <sup>49</sup>	1	1	1	0	3
Chan, 2010 <sup>50</sup>	1	1	1	0	3
Innes, 2005 <sup>51</sup>	1	1	1	0	3
Holst, 2003 <sup>52</sup>	1	1	0	1	3
Gilmore, 2005 <sup>53</sup>	1	1	0	0	2
Marzanski, 2000 <sup>54</sup>	1	0	0	0	1
Wuest, 2010 <sup>55</sup>	1	1	1	0	3

1 = met criterion; 0 = unmet criterion.

## Supplemental Appendix 5 References

1. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148-2157.
2. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.
3. Schoenmakers B, Buntinx F, Delepeleire J. Supporting family carers of community-dwelling elder with cognitive decline: a randomized controlled trial. *Int J Family Med*. 2010;2010:184152.
4. Jansen AP, van Hout HP, Nijpels G, et al. Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: a randomized clinical trial. *Int J Nurs Stud*. 2011;48(8):933-943.
5. Laurant MG, Hermens RP, Braspenning JC, Sibbald B, Grol RP. Impact of nurse practitioners on workload of general practitioners: randomised controlled trial. *BMJ*. 2004;328(7445):927.
6. Fortinsky RH, Delaney C, Harel O, et al. Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Res Gerontol Nurs*. 2014;7(3):126-137.
7. Stevenson G, Herschell JDK. An enhanced assessment and support team (EAST) for dementing elders – review of a Scottish regional initiative. *J Ment Health*. 2006;15(2):251-258.

8. Johnston D, Samus QM, Morrison A, et al. Identification of community-residing individuals with dementia and their unmet needs for care. *Int J Geriatr Psychiatry*. 2011;26(3):292-298.
9. Commissaris CJ, Jolles J, Verhey FR Jr, Kok GJ. Problems of caregiving spouses of patients with dementia. *Patient Educ Couns*. 1995;25(2):143-149.
10. Li H, Kyrouac GA, McManus DQ, Cranston RE, Hughes S. Unmet home care service needs of rural older adults with Alzheimer's disease: a perspective of informal caregivers. *J Gerontol Soc Work*. 2012;55(5):409-425.
11. Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. Unmet needs, quality of life and support networks of people with dementia living at home. *Health Qual Life Outcomes*. 2010;8:132.
12. Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr*. 2010;22(4):607-617.
13. van der Roest HG, Meiland FJ, Comijs HC, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatr*. 2009;21(5):949-965.
14. Rosa E, Lussignoli G, Sabbatini F, et al. Needs of caregivers of the patients with dementia. *Arch Gerontol Geriatr*. 2010;51(1):54-58.
15. Leggett AN, Zarit S, Taylor A, Galvin JE. Stress and burden among caregivers of patients with Lewy body dementia. *Gerontologist*. 2011;51(1):76-85.
16. Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. *Arch Gerontol Geriatr*. 2011;52(2):202-205.
17. Philp I, McKee KJ, Meldrum P, et al. Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters. *BMJ*. 1995;310(6993):1503-1506.
18. Meaney AM, Croke M, Kirby M. Needs assessment in dementia. *Int J Geriatr Psychiatry*. 2005;20(4):322-329.
19. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc*. 2013;61(12):2087-2095.
20. Wolfs CA, de Vugt ME, Verkaaik M, Verkade PJ, Verhey FR. Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *Int J Geriatr Psychiatry*. 2010;25(10):1006-1012.
21. Nurock S, Wojciechowska M. What real outcomes matter to caregivers? *Int Psychogeriatr*. 2007;19(3):355-362.
22. Armari E, Jarmolowicz A, Panegyres PK. The needs of patients with early onset dementia. *Am J Alzheimers Dis Other Demen*. 2013;28(1):42-46.

23. Chow TW, Pio FJ, Rockwood K. An international needs assessment of caregivers for frontotemporal dementia. *Can J Neurol Sci.* 2011;38(5):753-757.
24. Chung JC. Care needs assessment of older Chinese individuals with dementia of Hong Kong. *Aging Ment Health.* 2006;10(6):631-637.
25. Li H. Unmet service needs: a comparison between dementia and non-dementia caregivers. *Home Health Care Serv Q.* 2012;31(1):41-59.
26. Rosness TA, Haugen PK, Gausdal M, GjØra L, Engedal K. Carers of patients with early-onset dementia, their burden and needs: a pilot study using a new questionnaire—care-EOD. *Int J Geriatr Psychiatry.* 2012;27(10):1095-1096.
27. Wackerbarth SB, Johnson MM. Essential information and support needs of family caregivers. *Patient Educ Couns.* 2002;47(2):95-100.
28. Georges J, Jansen S, Jackson J, Meyrieux A, Sadowska A, Selmes M. Alzheimer's disease in real life--the dementia carer's survey. *Int J Geriatr Psychiatry.* 2008;23(5):546-51.
29. Hinton L, Chambers D, Velasquez A, Gonzalez H, Haan M. Dementia Neuropsychiatric Symptom Severity, Help-Seeking Patterns, and Family Caregiver Unmet Needs in the Sacramento Area Latino Study on Aging (SALSA). *Clin Gerontologist.* 2006;29(4):1-15.
30. Judge K, Bass D, Snow A, Wilson N, Morgan R, Looman W. Partners in dementia care: a care coordination intervention for individuals with dementia and their family caregivers. *Gerontologist.* 2011;51(2):261-72.
31. Lai C, Chung JC. Caregivers' informational needs on dementia and dementia care. *Asian J Gerontol Geriatr.* 2007;2:78-87.
32. Jedenius E, Johnell K, Fastbom J, Strömquist J, Winblad B, Andreasen N. Dementia management programme in a community setting and the use of psychotropic drugs in the elderly population. *Scand J Prim Health Care.* 2011;29(3):181-186.
33. Jedenius E, Wimo A, Strömquist J, Andreasen N. A Swedish programme for dementia diagnostics in primary healthcare. *Scand J Prim Health Care.* 2008;26(4):235-240.
34. Gorska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, et al. Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *Int Psychogeriatr.* 2013;25(7):1107-14.

35. Flynn R, Mulcahy H. Early-onset dementia: the impact on family care-givers. *Br J Community Nurs*. 2013;18(12):598-606.
36. Bakker C, de Vugt ME, Vernooij-Dassen M, van Vliet D, Verhey FR, Koopmans RT. Needs in early onset dementia: A qualitative case from the NeedYD study. *Am J Alzheimers Dis Other Demen*. 2010;25(8):634-40.
37. Mushi D, Rongai A, Paddick SM, Dotchin C, Mtuya C, Walker R. Social representation and practices related to dementia in Hai District of Tanzania. *BMC Public Health*. 2014;14:260.
38. Nichols KR, Fam D, Cook C, Pearce M, Elliot G, Baago S, et al. When dementia is in the house: needs assessment survey for young caregivers. *Can J Neurol Sci*. 2013;40(1):21-8.
39. Qadir F, Gulzar W, Haqqani S, Khalid A. A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Manag J*. 2013;14(4):230-40.
40. Tasc S, Tekinsoy Kartn P, Ceyhan O, Sungur G, Goris S. Living with an Alzheimer patient in Turkey. *J Neurosci Nurs*. 2012;44(4):228-34.
41. Vaingankar JA, Subramaniam M, Picco L, Eng GK, Shafie S, Sambasivam R, et al. Perceived unmet needs of informal caregivers of people with dementia in Singapore. *Int Psychogeriatr*. 2013;25(10):1605-19.
42. Bowes A, Wilkinson H. 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health Soc Care Community*. 2003;11(5):387-96.
43. Lin Z. Caring for family members with Alzheimer's disease" Perspectives from Chinese American caregivers. *J Ger Nursing*. 2004;30(8):19.
44. Kuhn D. Caring for relatives with early stage Alzheimer's disease: An exploratory study. *Am J Alzheimers Dis Other Demen*. 1998;13:189.
45. Shaji KS, Smitha K, Lal KP, Prince MJ. Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network. *Int J Geriatr Psychiatry*. 2003;18(1):1-6.



46. Samsi K, Abley C, Campbell S, Keady J, Manthorpe J, Robinson L, et al. Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *Int J Geriatr Psychiatry*. 2014;29(1):58-67.
47. Singh P, Hussain R, Khan A, Irwin L, Foskey R. Dementia care: intersecting informal family care and formal care systems. *J Aging Res*. 2014;2014:486521.
48. Smith A. Caregiver Needs. *Clinical Gerontologist*. 2001;24(1-2):3-26.
49. Smith K, Flicker L, Shadforth G, Carroll E, Ralph N, Atkinson D, et al. 'Gotta be sit down and worked out together': views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians. *Rural Remote Health*. 2011;11(2):1650.
50. Chan WC, Ng C, Mok CC, Wong FL, Pang SL, Chiu HF. Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. *East Asian Arch Psychiatry*. 2010;20(4):163-8.
51. Innes A, Blackstock K, Mason A, Smith A, Cox S. Dementia care provision in rural Scotland: service users' and carers' experiences. *Health Soc Care Community*. 2005;13(4):354-65.
52. Holst G, Hallberg IR. Exploring the meaning of everyday life, for those suffering from dementia. *Am J Alzheimers Dis Other Demen*. 2003;18(6):359-65.
53. Gilmour JA, Huntington AD. Finding the balance: living with memory loss. *Int J Nurs Pract*. 2005;11(3):118-24.
54. Marzanski M. Would you like to know what is wrong with you? On telling the truth to patients with dementia. *J Med Ethics*. 2000;26(2):108-13.
55. Wuest J, Ericson PK, Stern PN, Irwin GW, Jr. Connected and disconnected support: the impact on the caregiving process in Alzheimer's disease