The need for holistic care provision to meet the umet needs of community dwelling people with dementia

Actifcare

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Access to timely formal care

JPND research
EU Joint Programme – Neurodegenerative Disease Research

Background

- People with dementia and their caregivers have a **wide range of needs** as their condition develops[1-2], yet they **use fewer services** in comparison to other people needing care[3].
- They often do not receive the type, quality and amount of support from health and social services needed to live well at home with dementia[4].
- Home care services in Ireland are **not underpinned by legislation**; no requirement for local health and/or social welfare offices to provide services to people in need[5].

The Actifcare Project (www.actifcare.eu)

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ACcess to Timely Formal Care (Actifcare) analyses the pathways to care for people with dementia and their families, to better understand the reasons for inequalities in access to healthcare.

- This study examined the (un)met needs of Irish people with dementia living at home (*n* = 43) from three perspectives
  - the person with dementia, a family caregiver and a researcher

- Data were gathered at baseline, 6-months, 12-months
  - Camberwell Assessment of Need for the Elderly (CANE)[7]
  - Demographic, QoL, NPI and carer perseverance also gathered

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Irish Participants (*n*=43)

- People with dementia
  - 21 Male and 22 Female
  - Mean age was 74.05 (min 50, max 92)
  - CDR 0.5 = 5 (questionable); CDR 1 (mild) = 27; CDR 2 (moderate) = 11
  - Significantly more people with mild dementia; $\chi^2 = 18.407$, $df = 2$ $p < .001$.
- Family Caregivers
  - 10 Male and 33 Female
  - Significantly more female carers, even though there were roughly equal numbers of males and females with dementia; $\chi^2 = 12.302$, $df = 1$, $p < .001$.
  - 23 Spouse/Partner, 18 child and 1 grandchild
  - Mean age was 58.12 (min 28, max 85).

CANE: Camberwell Assessment of Need for the Elderly

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Clustering (Stein, 2015)	Environmental needs	Physical needs	Psychological needs	Social needs
CANE items **24 areas of life covering four main clusters**	Accommodation	Self-care	Memory	Daytime activities
	Looking after the home	Eyesight/hearing/communication	Psychotic symptoms	Information
	Food	Mobility/falls	Psychological distress	Abuse/neglect
	Caring for someone else	Continence	Deliberate self-harm	Company
	Money	Physical health	Accidental self-harm	Intimate relationship
	Benefits	Medication	Behaviour	
			Alcohol	

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CANE: Camberwell Assessment of Need for the Elderly

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21. COMPANY

ASSESSMENTS			
user	carer	staff	rater
		notes	

DOES THE PERSON NEED HELP WITH SOCIAL CONTACT?

Are you happy with your social life? Do you wish you had more social contact with others?

0 = NO NEED	e.g. Able to organise enough social contact, has enough contact with friends.
1 = MET NEED	e.g. Lack of company identified as a problem. Has specific intervention for company needs e.g., lonely at night but attends drop-in or day centre or Lunch Club. Social work involvement.
2 = UNMET NEED	e.g. Frequently feels lonely and isolated. Very few social contacts.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 22

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CANE: Camberwell Assessment of Need for the Elderly

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HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH SOCIAL CONTACT?				
0 = NONE				
1 = LOW HELP	e.g. Friends help with social contact or visit less than weekly to provide company.			
2 = MODERATE HELP	e.g. Friends help with social contact weekly or more often.			
3 = HIGH HELP	e.g. Friends help with social contact at least four times a week.			
9 = NOT KNOWN				

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?				
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?				
0 = NONE				
1 = LOW HELP	e.g. Occasional visits from befriender or voluntary worker. Referral to centre.			
2 = MODERATE HELP	e.g. Regular attendance at day centre: regular luncheon club, organised social activity.			
3 = HIGH HELP	e.g. Day centre or social home visits 3 or more times a week, social skills training, social worker involvement.			
9 = NOT KNOWN				

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Baseline Cross-country Comparison

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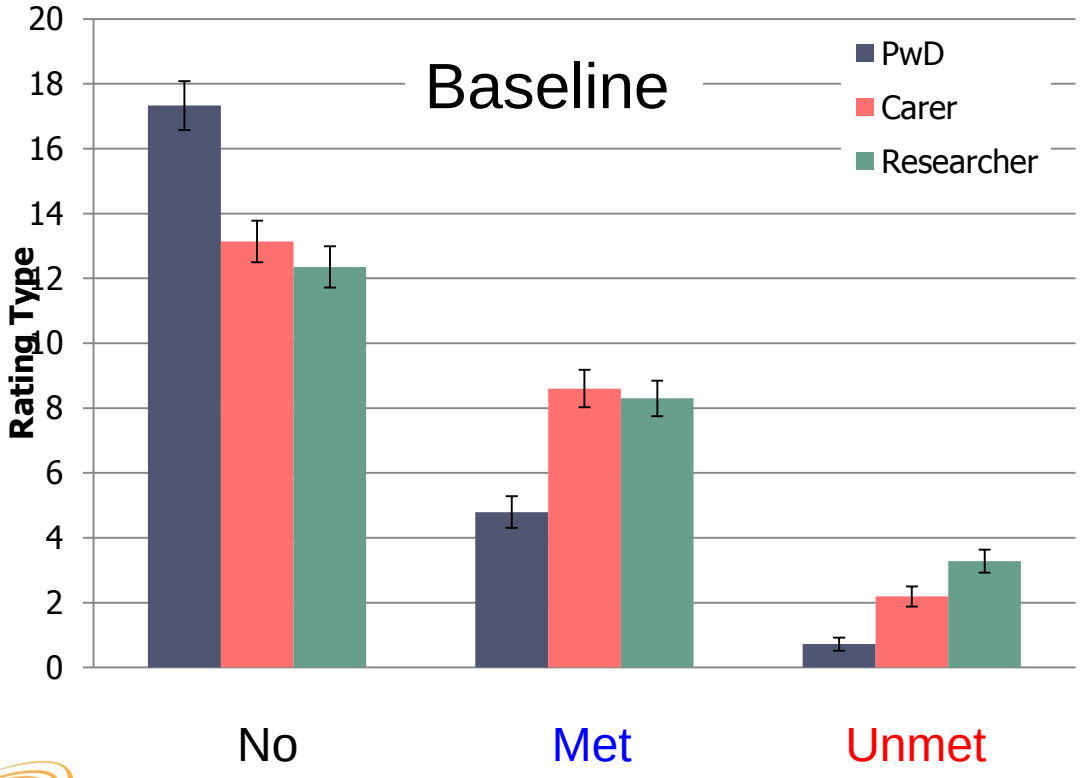
	Norway (n=60)	Sweden (n=50)	Germany (n=54)	Ireland (n=43)	Netherlands (n=51)	United Kingdom (n=76)	Italy (n=53)	Portugal (n=66)	All (n=453)
	North	North	West	West	West	West	South	South	
Person with dementia									
Age*	78 (7)	80 (7)	77 (8)	74 (9)	76 (8)	79 (8)	79 (8)	77 (6)	78 (8)
Female gender*	60%	52%	41%	51%	57%	43%	70%	62%	54%
Lives together with carer*	73%	82%	78%	58%	80%	52%	55%	85%	72%
Clinical characteristics person with dementia									
MMSE (0-30)*	19.1 (4.9)	20.4 (4.4)	20.2 (5.8)	20.3 (5.4)	19.8 (4.3)	18.8 (5.4)	16.9 (3.7)	17.8 (4.8)	19.0 (5.0)
IADL (0-8)*	4.2 (1.8)	3.0 (2.0)	3.2 (2.1)	3.4 (2.6)	3.9 (1.7)	3.0 (1.7)	3.0 (1.8)	3.7 (2.0)	3.4 (2.0)
PSMS (0-6)*	4.5 (1.3)	4.0 (1.8)	3.1 (2.1)	3.4 (2.0)	4.1 (1.8)	3.4 (1.8)	2.8 (1.8)	3.7 (2.0)	3.6 (1.9)
NPI (0-30)*	8.8 (5.1)	5.6 (4.4)	6.6 (5.4)	8.9 (5.5)	9.4 (6.7)	7.9 (5.5)	8.7 (5.8)	6.8 (5.5)	7.8 (5.6)
CANE met needs (0-26)*	9.2 (2.5)	4.6 (2.0)	11.0 (4.8)	8.8 (3.8)	7.7 (2.8)	9.6 (3.6)	9.4 (2.1)	8.4 (2.8)	8.6 (3.5)
CANE unmet needs*	2.8 (1.9)	0.3 (0.8)	2.0 (2.1)	4.2 (2.9)	3.1 (2.9)	2.2 (2.0)	2.2 (2.2)	1.8 (2.0)	2.3 (2.3)

IE Cohort Data – (Un)Met Needs

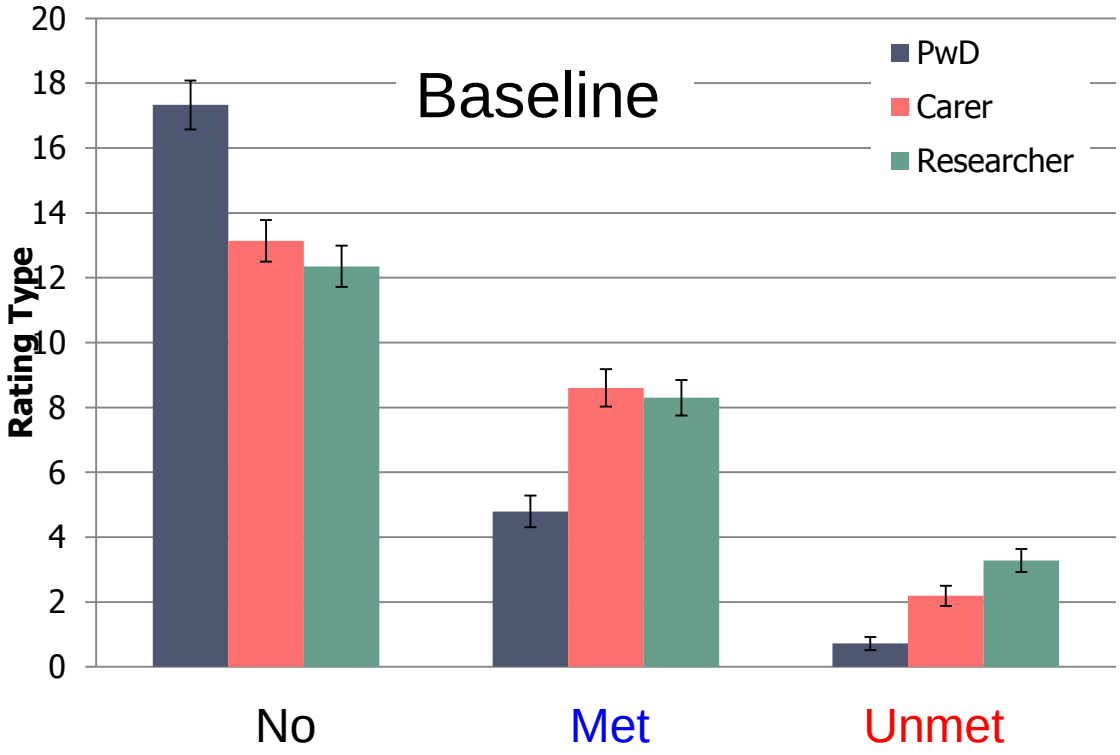
- People with dementia
  - Perceived fewest needs (high 'No Needs' responding)
  - Reported significantly fewest environmental and physical met needs



- Group differences increased with dementia severity
- Unmet need typically increased over time
- Similar patterns were seen at 6-months and at 12-months
- Fewer people with dementia able to self-report at 6- (*n*=38) and 12-months (*n*=33)

IE Group differences in needs

- Met Needs: PwD < Carers (p<.001) and Researchers (p<.001)
- Unmet Needs: Researchers > Carers (p<.001) and PwD (p<.001)
- Group differences increased with dementia severity
- Similar patterns seen at T1 and T2; unmet need increasing over time



IE Cohort Data – (Un)Met Needs

- Higher met needs were significantly related to higher NPI scores (r = .47, p<.005) and greater functional need
  - Caregiver rating of met need indicated longer care perseverance
- Unmet needs usually memory and social needs (company, daytime activities)
  - Increased with dementia severity and over time
  - Lower levels of unmet need were significantly associated with better quality of life for people with dementia and caregivers
  - No association was found with carer perseverance time
- Social supports often rated as '*not the right type of care*'; 63% of carers, 74% of researchers.

Conclusions

- Addressing unmet needs positively influenced dyadic QoL yet all groups reported high levels of unmet social need and found available services lacking and inappropriate.
- High levels of met physical needs demonstrates a continued policy emphasis on supporting these needs (in isolation of other areas).
- Primary Care assessment must address the full range of biopsychosocial needs of the person with dementia and their carer in order to provide timely tailored supports.
- Case management approaches that integrate the provision of health and social care are recommended.

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