

## Background

Research shows that people with dementia and their caregivers have a wide range of needs as their condition develops<sup>1-2</sup>, yet they use fewer services in comparison to other people needing care<sup>3</sup>. In addition, 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<sup>4</sup>.

As home care services in Ireland are not underpinned by legislation, there is no requirement for local health offices to provide services to people in need<sup>5</sup>. Reductions in health service care budgets mean that the individual also has less say in what is provided, when and how<sup>6</sup>. This has led to considerable variation in the amount and types of services available across the country.

This study, which is part of the JPND-funded Access to Timely Formal Care (Actifcare) project, aimed to identify the (un)met needs of Irish people with dementia living at home and to compare these to needs assessments from a family carer and from an independent Actifcare researcher.

## Method

**Design:** Data were gathered at baseline, 6-months (T1), and 12-months (T2). For this study, baseline, T1 and T2 demographic data, (un)met needs, quality of life and dementia severity are examined.

**Participants:** 43 people with dementia (M = 21; F = 22) and carer (M = 10; F = 33) dyads were recruited through GPs, memory clinics, and local adverts. The mean age of people with dementia was 74.05 (SD = 9.14, min 50, max 92). The mean age of carers was 58.12 (SD = 15.05, min 28, max 85).

**Materials:** The Camberwell Assessment of Need for the Elderly (CANE)<sup>7</sup> was completed at each time period. The CANE is a comprehensive instrument suitable for both research and clinical use. Needs are assessed in 24 areas of life and cover a broad range of health, social and psychological domains. All raters reported met and unmet need. Carers and researchers also reported formal and informal supports received. Additional measures included: Quality of Life (QoL-AD<sup>8</sup>, ICECAP-O<sup>9</sup>, Carer-QoL<sup>10</sup>), Neuropsychiatric symptoms (NPI-Q<sup>11</sup>) and carer perseverance.

**Procedure:** Data was collected in interviews (approx. 2 hours long) with the dyads in their own homes. Data was analysed using SPSS.

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## Results

### Participant Group Differences

- There were significantly more female carers, even though there were roughly equal numbers of males and females with dementia;  $\chi^2 = 12.302$ ,  $df = 1$ ,  $p < .001$ .
- Significantly more PwD had a Clinical Dementia Rating (CDR) of 1 ( $n=27$ ) than CDR of 0.5 ( $n=5$ ) or CDR of 2 ( $n=11$ );  $\chi^2 = 18.407$ ,  $df = 2$   $p < .001$ .

### CANE areas of no need, met need and unmet need over time

Area of need:	BASELINE									T1: 6-months									T2: 12-months								
	PwD			Carer			Researcher			PwD			Carer			Researcher			PwD			Carer			Researcher		
	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet	No	Met	Unmet
Accommodation	37	4	2	34	7	2	33	7	3	33	2	0	32	4	2	32	4	2	25	3	0	22	14	1	25	15	1
Looking after home	22	20	1	10	31	2	10	29	4	14	20	2	8	25	5	8	26	4	12	14	1	4	28	5	5	25	8
Food	20	20	1	9	34	0	9	33	1	11	24	1	8	29	1	8	29	1	12	15	0	5	30	2	6	29	3
Self-care	32	8	3	16	24	3	16	24	3	26	9	0	10	25	3	10	23	5	24	3	0	8	27	2	9	25	4
Care for someone else	42	0	0	39	2	2	38	2	3	36	0	0	37	1	0	37	1	0	27	0	0	35	1	1	36	1	1
Daytime activities	27	10	5	12	14	17	11	7	25	25	5	5	7	15	16	7	13	18	17	9	1	5	23	9	5	21	12
Memory	9	31	2	0	33	10	0	28	15	15	17	3	0	32	6	0	27	11	11	17	0	0	33	4	0	33	5
Eyesight/hearing	30	11	1	25	14	4	25	14	4	23	9	2	20	15	3	20	14	4	19	8	1	16	17	4	17	13	8
Mobility/falls	30	11	1	22	17	4	22	15	6	27	6	1	20	13	5	20	11	7	22	6	0	16	18	3	17	15	6
Contingence	35	3	0	27	15	1	26	15	2	31	0	0	25	11	2	25	10	3	25	1	0	22	11	3	23	12	3
Physical Health	10	33	0	5	36	2	4	37	2	17	17	1	11	24	3	10	26	2	14	13	1	6	30	1	5	31	2
Drugs	28	12	1	20	19	4	16	21	6	25	9	1	18	17	3	15	19	4	16	11	1	9	26	2	9	26	3
Psychotic symptoms	38	0	0	32	9	1	30	7	5	29	0	0	29	5	3	28	6	3	26	0	0	25	8	3	26	8	3
Psychological distress	33	9	0	24	13	5	17	18	8	31	3	2	13	20	5	11	16	11	21	5	1	9	25	3	9	24	5
Information	35	1	7	33	3	7	30	2	11	30	1	2	32	3	3	31	3	4	22	0	13	31	2	4	32	2	4
Deliberate self-harm	38	0	0	41	1	1	41	1	1	31	0	1	36	2	0	37	1	0	24	0	0	36	1	0	37	1	0
Inadvertent self-harm	39	2	0	15	26	2	13	25	5	31	3	1	10	20	8	8	31	9	24	2	0	13	22	2	13	22	3
Abuse/neglect	38	3	0	33	10	0	28	14	1	34	0	0	33	3	2	33	3	2	27	0	0	36	1	0	37	1	0
Behaviour	42	0	0	37	4	2	37	3	3	35	0	0	31	3	4	30	3	5	25	0	0	25	10	2	23	10	5
Alcohol	42	0	0	35	7	1	35	7	1	35	0	0	32	5	1	32	5	1	27	0	1	32	4	1	32	5	1
Company	28	8	6	16	11	16	12	9	22	25	4	7	9	16	13	8	14	16	19	6	2	7	20	10	6	19	13
Intimate Relationships	0	0	0	41	2	0	40	2	1	34	0	0	38	0	0	38	0	0	27	0	0	37	0	0	38	0	0
Homes	22	18	3	8	35	0	8	34	1	18	17	0	4	33	1	4	33	1	10	18	0	2	34	1	3	34	1
Benefits	25	2	3	31	3	8	30	3	8	17	4	0	28	4	5	28	4	5	20	3	0	28	3	6	28	4	6

Figure 1 Comparison of met and unmet needs at baseline, T1 and T2 as rated by people with dementia, carers and an independent researcher

### Baseline assessment of total number of met and unmet needs of people with dementia

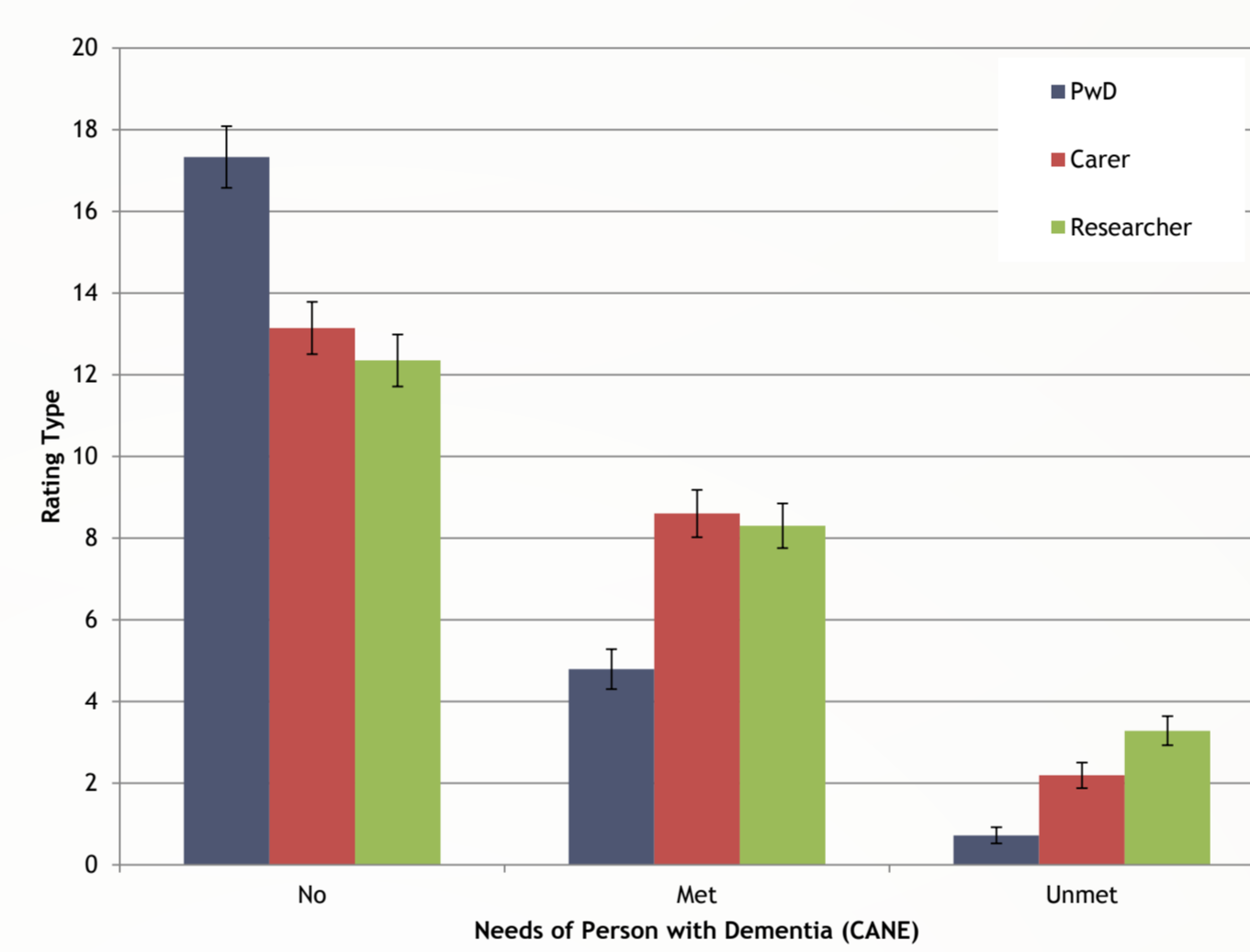


Figure 2 Baseline levels of no need and total met and unmet need

- Higher levels of **met needs** were significantly associated with higher NPI scores for carers ( $r = .47$ ,  $p < .005$ ) and researchers ( $r = .44$ ,  $p < .005$ ) and with greater PwD functional need.
- Researchers identified significantly more **unmet need** ( $M = 3.28$ ,  $SD = 2.33$ ) than carers ( $M = 2.19$ ,  $SD = 2.05$ ,  $p < .001$ ) and PwD ( $M = 0.72$ ,  $SD = 1.32$ ,  $p < .001$ ). Group differences in unmet need increased with dementia severity. PwD sex was not significant.
- Unmet needs** were usually memory related or social needs (daytime activity, company). The latter were often rated as 'not the right type of care' (63% carers, 74% researchers).
- Carer **unmet need** correlated with lower carer proxy rating of PwD QoL (QoL-AD  $r = -.45$ ,  $p < .001$ ; ICECAP-O  $r = -.50$ ,  $p < .005$ ) and lower Carer-QoL ( $r = -.35$ ,  $p < .05$ ), but no association was found with carer perseverance time.

**T1 and T2:** Similar patterns were seen over time with researchers identifying increasing unmet need at T1 and some increase in service use to meet this need at T2.

**Limitation:** Although all PwD were able report their needs at baseline, fewer were able to do so at 6-month ( $n=38$ ) and 12 months ( $n=33$ ).

## Conclusions

- Although people with dementia are often unaware of their psychological and social needs, these are generally identified by their caregivers, with the exception of support for memory difficulties; these were typically reported as unmet needs by researchers.
- High levels of met physical need demonstrate a continued primary policy emphasis on solely supporting these needs. Yet, this is insufficient to maintain quality of life.
- In line with previous studies<sup>1,3,5</sup>, addressing unmet need positively influenced the dyadic quality of life. However, all groups reported high levels of unmet social need and found available services lacking and inappropriate.
- Assessment for home support must address the full range of biopsychosocial needs of the person with dementia and carer such that timely tailored supports can be provided.
- Case management approaches that integrate the provision of health and social care and meet the holistic needs of the individual and their environment are recommended.