(Un)Met needs of community dwelling people with dementia: the importance of providing integrated holistic care

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Background

Research shows that people with dementia and their caregivers have a wide range of needs as their condition develops1,2, yet they use fewer services in comparison to other people needing care3. 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 dementia4,5. 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 need5. Reductions in health care service budgets mean that the individual also less say in what is provided, when and how6. 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)7 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 both met and unmet need. Carers and researchers also reported formal and informal supports received. Additional measures included: Quality of Life (QoL-AD8, ICECAP-O9, Carer-QoL10), Neuropsychiatric symptoms (NPI11) 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.

Results

Participant Group Differences

- There were significantly more female carers, even though there were roughly equal numbers of males and females with dementia; χ² = 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); χ² = 18.407, df = 2 p < .001.

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

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

- 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 <0.01) and PwD (M = 0.72, SD = 1.32, p <0.01). Group differences in unmet need increased with dementia severity. PwD sex was not significant.
- 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.

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 studies11,12, 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.

References

2. Camberwell Assessment of Need for the Elderly (CANE)7 project. The project is supported through the following funding organisations: a) the [funding organisation 1]; b) the [funding organisation 2].

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