

CONFERENCE ABSTRACT

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

17th International Conference on Integrated Care, Dublin, 08-10 May 2017

Louise Hopper¹, Rachael Joyce¹, Hannah Jelley², Bob Woods², Martin Orrell³, Kate Irving¹, Frans Verhey⁴

1: Dublin City University, Dublin, Ireland;

2: Bangor University, Bangor, United Kingdom;

3: University of Nottingham, Nottingham, United Kingdom;

4: Maastricht University, Maastricht, The Netherlands

Introduction: Research shows that PwD and their carers often do not receive the type, quality and amount of support needed from health and social care services. This study, part of the Access to Timely Care (Actifcare) JPND-funded project, aimed to identify the (un)met needs of Irish people with dementia (PwD) living at home and to compare these to needs assessments from a family caregiver and an independent Actifcare researcher.

Theory/Methods: Forty-three PwD (22 female, mean age 74.05, mean MMSE 20.34) and family caregiver (33 female, mean age 58.12) dyads participated. The Camberwell Assessment of Need for the Elderly (CANE) was completed at baseline, 6-months and 12-months. All raters reported met and unmet need. Caregivers and researchers also reported formal and informal supports received. Additional measures included: Quality of life (QoL-AD, ICECAP-O, Carer-QoL), Neuropsychiatric symptoms (NPI-Q) and carer perseverance.

Results: PwD perceived fewer met needs at baseline ($M=4.79$, $SD=3.2$) than caregivers ($M=8.6$, $SD=3.78$) and researchers ($M=8.3$, $SD=3.6$); particularly environmental and physical needs. Researchers identified significantly more unmet need ($M=3.28$, $SD=2.33$) than caregivers ($M=2.19$, $SD=2.05$) and PwD ($M=0.72$, $SD=1.32$). Unmet needs were typically psychological (memory) and social (daytime activities, company) and regularly rated as 'not the right type of care'. PwD sex had no impact on ratings, but group differences in unmet increased with dementia severity. Greater met needs were significantly related to higher NPI scores and greater functional need. Caregiver ratings of met need indicated longer care perseverance. Lower levels of unmet need were significantly associated with better quality of life. Similar patterns were found at 6- and 12-months with researchers increasingly identifying unmet needs.

Discussions: PwD reported fewest needs. Although often unaware of their psychological needs, these are generally identified by caregivers with the exception of support for memory difficulties; these were typically reported by researchers. Addressing unmet need positively

influenced the dyadic quality of life, yet all groups reported high levels of unmet social need and found available services lacking and inappropriate. High levels of met physical need demonstrates a continued primary policy emphasis on solely supporting these needs.

Conclusions: Dementia needs assessments must address the full range of biopsychosocial needs of the PwD and their caregivers such that timely tailored supports can be provided. Case management approaches that integrate the provision of health and social care are recommended.

Lessons learned: Meeting physical need alone is not sufficient to maintain quality of life. It is essential to take a holistic view of the individual and their environment in order to adequately assess the support needed.

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

Suggestions for future research: Future research could formally and regularly assess needs from diagnosis onwards. If coupled with analysis of the type, duration and benefits of supports used, greater insight will be gained to enable the development of integrated dementia care that better supports the complex biopsychosocial needs of PwD and their families.

Keywords: dementia; needs assessment; care; integrated care; case management
