Summary

Informal carers’ experiences of Extended Aged Care at Home Dementia packages: Issues of access, quantity and quality of care

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Abstract

Caring for a relative in the advanced stages of dementia can place incredible strain on family members. Despite this, many families remain committed to providing care at home. In the moderate to advanced stages, behavioural and psychological symptoms of dementia (BPSD) are common and have been associated with increased carer burden and residential aged care placement. With global projections indicating rapid growth in dementia prevalence in coming decades, the need for programs to adequately support people with dementia and their carers will increase. In 2006, Extended Aged Care at Home Dementia (EACHD) packages were introduced in Australia to provide a home-based, high care option for people with dementia and BPSD. This qualitative study aimed to explore carers’ expectations and experiences of EACHD packages, with the goal of informing policy makers and services providers of how these services can better meet the needs of carers and those to whom they provide care. Whilst this study is primarily an evaluation of the EACHD program from the carer’s perspective, it also explores the carer’s experience of looking after someone in the advanced stages of dementia and their interaction with the broader service system.

Participating carers reported that the person they cared for experienced high levels of BPSD, indicating that clients were meeting EACHD eligibility requirements. Carers reported a broad range of psychosocial strategies for managing symptoms but most reported using a small number of strategies. A third of participants who had accessed an EACHD package acquired more knowledge about BPSD management through the package. EACHD packages provided access to a more comprehensive range and amount of services than accessed prior to the package. Many carers, however, felt that the amount of service was insufficient to support them in a full time caring role. Whilst carers were committed to maintaining care at home, many had to place their relative in residential aged care and others felt it would eventually be inevitable. Transitioning to residential aged care was an emotionally distressing event for carers but few received emotional support from their EACHD case manager.

I argue that three factors impede the capacity of EACHD packages and the broader aged care system to optimise the wellbeing of people with high level dementia care needs and their carers:

- Lack of timely access to services;
- Insufficient services to meet the needs of those requiring high level dementia care at home; and
- Insufficient attention paid by EACHD case managers’ to the goals, emotional needs and expertise of family carers. Nolan, Grant and Keady’s (1996) model for understanding informal care is drawn upon as a model for better meeting the needs of people with dementia and their carers.
EACHD packages provide an opportunity for promoting the wellbeing of people in the community experiencing high level dementia care needs and their families and carers, however, issues of access, quantity and quality of care constrain the full potential of this program.

Presentations


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