

SHORT REPORT

Predictors of institutionalisation in people with dementia

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Objective: To identify what patient and carer characteristics influence transition into residential care for people with dementia.

Method: Longitudinal study of a cohort of people with dementia and their carers in contact with old age psychiatric services in south London.

Results: 100 people with dementia and their main family carer were recruited. At six month follow up 22 were in residential care, 63 in the community, 8 had died, and for 7 there were missing data. Between six and 12 months, 7 of the 63 in the community went into residential care, 4 died, and 12 were lost to follow up. The most striking finding is the 20-fold protective effect of having a co-resident carer (odds ratio 0.05, 95% confidence intervals 0.01 to 0.42, $p=0.006$). Higher ratings of behavioural problems in the person with dementia were also statistically significantly associated with transition into residential care as was the psychological domain of quality of life of the carer.

Conclusion: These findings powerfully illustrate the pivotal role carried out by carers of people with dementia; interventions directly targeted at helping them to maintain this role would be supported by these data. These data also suggest that strategies directed at improving carer quality of life and at the resolution of behavioural disorder in the person with dementia may also have particular value.

The dementias are some of the most common and serious disorders in later life. They cause irreversible decline in global intellectual and physical functioning. There are profound impacts on the person with dementia, their family and carers, and also on health, social and voluntary services, in personal, social, health, and economic terms.¹ The challenge of meeting the health and social care needs of people with dementia and their family carers is profound.² A major element of the economic impact of caring for people with dementia is consequent to their increased risk of requiring

admission into residential care.³ Taken with carer and patient choice, these costs have resulted in a focusing of policy on maintaining people with dementia in the community.

Patient characteristics such as increasing age, lower cognitive function, poorer self related health, increased limitation in activities of daily living, and not being married have all been reported to be associated with institutionalisation.⁴ A recent analysis of the people with Alzheimer's disease receiving Medicare has demonstrated the importance of considering both patient and caregiver characteristics simultaneously when considering nursing home placement in dementia.⁵ To formulate effective packages of support for carers and people with dementia it is necessary to identify what influences transition into residential care. We therefore carried out a study with that aim and we report data from this here.

METHODS

People diagnosed as having dementia by old age psychiatric services in south east London and living in the community were recruited along with their main family carer. They were assessed at baseline with a package of instruments including a record of sociodemographic data and measurement of: carer burden,⁶ carer mental disorder,⁷ carer quality of life,⁸ cognitive impairment in the person with dementia,⁹ and behaviour disturbance in dementia.¹⁰

Subjects were followed up for one year and were assessed at six and 12 months to ascertain place of residence.

To investigate predictors of transition to residential care, logistic regression analyses were completed to control for the effects of potential confounders on exposures of interest. Those for whom there were missing outcome data and those who died before follow up were excluded.

RESULTS

A total of 100 (56%) of the 179 people with dementia and their main family carers approached were recruited. At six month follow up 22 were in residential care, 63 in the community, eight had died, and for seven there were missing data. Between six and 12 months, 7 of the 63 in the community went into residential care, four died, and 12 were lost to follow up.

Table 1 Logistic regression analyses of associations of characteristics measured at baseline and transition into residential care during the study period

	Odds ratio	95% Confidence limits	p Value
Age—person with dementia	1.01	0.96 to 1.28	0.155
Female sex—person with dementia	0.39	0.06 to 2.42	0.313
Female sex—carer	0.96	0.13 to 6.97	0.966
Carer mental health	0.71	0.13 to 3.99	0.697
Carer quality of life—psychological	1.10	1.02 to 1.19	0.018
Person with dementia behaviour problems	1.08	1.01 to 1.15	0.026
Carer burden score	1.02	0.96 to 1.08	0.542
Person with dementia ADAS-Cog score	1.02	0.96 to 1.07	0.532
Spouse carer	2.29	0.27 to 19.6	0.449
Co-resident carer	0.05	0.01 to 0.42	0.006

The results of the logistic regression analyses carried out on the data obtained are summarised in table 1. The most striking finding is the 20-fold protective effect of having a co-resident carer, defined as the family carer living in the same household as the person with dementia (odds ratio 0.05, 95% confidence intervals 0.01 to 0.42, $p=0.006$). Higher ratings of behavioural problems in the person with dementia were also statistically significantly associated with transition into residential care as was the psychological domain of quality of life of the carer.

DISCUSSION

These findings powerfully illustrate the pivotal role carried out by carers of people with dementia; having a co-resident carer made admission to a care home 20 times less likely over a one year period. The vast majority of the care provided for people with dementia is provided free by family carers and this study makes clear the potential value of supporting them.

There are potential limitations to this study, including: an element of response bias given that only 56% of the possible sample participated; the subjects coming from an urban area; and being secondary care contacts. These all may limit generalisability of the data presented here particularly to rural areas and to people with dementia not referred to old age psychiatric services. However, the methodology, which included simultaneous detailed assessment of the carer as well as the person with dementia, does have some strengths. In particular it allows our analyses to control for the effects of important potential confounders (for example, disease severity, behavioural disturbance, carer burden, and carer mental health) to investigate the predictive association of variables of interest with institutionalisation for people with dementia.

These data have practical implications in illustrating the potential value of co-resident carers in dementia and in helping to formulate strategies for the prevention of transition into residential care. Clearly co-resident carers play a vital part; interventions directly targeted at helping them to maintain this role would be supported by these data. Such support might be provided at multiple levels. On a national basis carers could be supported by specific financial benefits and improving public attitudes to and understanding of dementia. Locally, services such as carer support groups and the development of dementia services with a carer focus as outlined in the UK's National Service Framework for Older People² are likely to be of value. On an individual patient basis, early identification with deployment of psychosocial and possibly pharmacological interventions aimed at managing behavioural disorder in dementia alongside specific packages of practical psychosocial carer support directed at the carer for the carer would seem to be of potential worth. These strategies would be directed at preventing breakdown in home based

care, improving carer quality of life, and at the resolution of behavioural disorder in the person with dementia. It has been argued powerfully that comparatively small changes in the balance between people with dementia being cared for at home rather than in institutional settings could unlock substantial funds to improve the quality of community based dementia care.¹ The data presented from this study suggest areas of focus and content for interventions for people with dementia and their carers.

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