

Two-year follow-up study of patients with dementia in an NHS continuing care unit

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The Psychiatrist (2013), 37, 11–14, doi: 10.1192/pb.bp.112.039834

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First received 25 Apr 2012, final
revision 14 Aug 2012, accepted
8 Oct 2012

Aims and method This is a longitudinal, observational prospective study carried out in a 50-bedded dementia care unit. Fifty patients who had been assessed in 2009 as part of an earlier study were reassessed 2 years later.

Results All patients had a diagnosis of dementia, with Alzheimer's dementia being the most common. By 2011, 23 (46%) patients reviewed in 2009 were deceased. We found that there was a reduction in psychotic symptoms in patients 2 years later despite none of them being on antipsychotics. The most common problems on follow-up were apathy, agitation and aggression, irritability and anxiety.

Clinical implications Our findings support the view of the need to regularly review patients with dementia who have psychotic symptoms that require antipsychotics, as long-term treatment may not be required or beneficial in light of known adverse side-effects.

Declaration of interest None.

Patients with dementia who have challenging behavioural problems often end up in long-stay in-patient units as they present with behavioural problems too difficult to manage at home with informal care offered by spouses and family members. These individuals often require pharmacological interventions to help alleviate symptoms when non-pharmacological interventions fail. With increasing concerns over the safety of some pharmacological interventions or lack of sufficient evidence of effectiveness in managing neuropsychiatric symptoms in dementia, there is a constant need to review how such patients are managed. A study in 2008 found that a large group of patients who were on long-term antipsychotic medication did well on discontinuation.¹ The study findings put into question the value of long-term use of antipsychotics in dementia. In a different study looking at patients in the final phase of dementia, there was a high prevalence of apathy, agitation and behavioural problems such as strange noises, grabbing, performing repetitious mannerism, spitting, hitting, screaming and pushing.² These clinical features may not respond to long-term psychotropic use without looking at possible aetiological factors for such behaviour. Professional caregivers found apathy and agitation as the most distressing psychiatric symptoms in patients with Alzheimer's dementia.³ These symptoms may be difficult to distinguish from depressive symptoms in severe dementia.

In 2009, we carried out a survey of all 50 patients admitted to an in-patient continuing care unit for patients with severe behavioural and psychiatric symptoms in dementia.⁴ Only 5 (10%) patients in the survey were not on any form of psychotropic medication and the authors noted the lack of non-pharmacological options. In this

follow-up study of those 50 patients, 2 years later, the outcome of care, neuropsychiatric symptoms and medication were reviewed. The study was carried out in a 50-bedded unit consisting of two purpose-built bungalows in a town about 30 miles north of London. The unit is staffed with qualified and unqualified nurses, general practitioners, old age psychiatrists and one occupational therapist. In the intervening 2 years, improved access to occupational therapy along with structural improvement to the unit took place. The unit won a successful grant bid from the Kings Fund, to improve the entrance and communal areas in one of the bungalows, Elizabeth Court. Some walls were changed to glass so that from the reception area one can see directly out into the natural landscape creating more natural lighting and space. With support from the local carers group, a multisensory room was also provided. Around the time of the redesign, two activity workers were appointed to support the occupational therapist. As a result of the increased concern about the use of antipsychotic medication in dementia to treat behavioural problems, decisions had been taken locally to review and discontinue the use of antipsychotics where possible. The aim of this study was to assess, 2 years after the initial study, the effects that changes in prescribing practices, staffing and structural design had on patients in a continuing care dementia unit.

Method

This is a longitudinal, observational, prospective study involving patients in a long-stay in-patient dementia care

unit using a proforma to collect sociodemographic details obtained from patients' medical notes. The ICD-10 diagnostic criteria were used to classify type of dementia.⁵

The neuropsychiatric symptoms were rated using the Neuropsychiatric Inventory (NPI).⁶ The NPI is a relatively brief interview with a carer, rating 12 behavioural areas in dementia. It is scored from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed. Both the severity and frequency of each symptom are rated on a three- (one to three) and four-point (one to four) Likert scale respectively. For the purpose of this study, clinically relevant neuropsychiatric symptoms measured on the NPI were defined by a $F \times S$ score for each individual symptom ≥ 4 as used in other studies.⁷

The severity of the dementia was rated using the Clinical Dementia Rating (CDR) scale.⁸ The CDR covers six domains consisting of memory; orientation; judgement and problem-solving; community affairs; home and hobbies; and personal care. Each domain is rated 0 – healthy; 0.5 – questionable; 1 – mild; 2 – moderate and 3 – severe. Total scores give a global measure of dementia.

The initial assessments in 2009 and 2 years later were carried out by the same specialty doctor (D.J.) who had over 8 years' experience in psychiatry and a trained nurse staff member who was familiar with the patients. The data collected were analysed using the Statistical Package for the Social Sciences (SPSS) for Windows version 14 to carry out both descriptive and analytical statistics for chi-squared tests, one-tailed *t*-tests and one-way analysis of variance, with level of significance set at $P < 0.05$.

Results

In our previous study conducted in 2009, there were 50 patients in the unit consisting of 26 males and 24 female patients. In 2011, there were 48 patients in the unit as 2 patients had recently been transferred to a nursing home. Of the 48 current patients in the unit, 25 patients were part of the initial study in 2009 and the remaining 23 were new patients. By 2011, 23 of the 50 patients reviewed in 2009 were deceased. There were no significant differences between the patients in the unit in 2009 and 2011 in terms of their ages, gender distribution and duration of dementia (Table 1). In 2009, using the CDR scale scores, there were 39 patients (78%) who were rated severe

Table 1 Sociodemographic data of patients in the continuing care unit in 2009 and 2011

	2009	2011
Patients, <i>n</i>	50	48
Age, years: mean (s.d.)	79.76 (8.02)	78.97 (7.81)
Male, <i>n</i> (%)	26 (52)	25 (52.1)
Duration of illness, years: mean (s.d.)	5.67 (3.57)	5.44 (3.64)

compared with 38 patients (79.2%) rated severe in 2011. The rest of the patients had a rating of moderate dementia in both 2009 and 2011.

Among the 50 patients in the initial study (2009), all patients had a diagnosis of dementia. Alzheimer's dementia was the most frequent form of dementia diagnosed ($n = 31$, 62%), followed by vascular dementia ($n = 6$, 12%) and then dementia with Lewy bodies ($n = 4$, 8%) and frontotemporal lobe dementia ($n = 4$, 8%). Similarly in 2011, all 48 patients had a diagnosis of dementia, with 33 patients (68.8%) diagnosed with Alzheimer's dementia, 5 patients (10.4%) diagnosed with vascular dementia and 5 patients with frontotemporal dementia.

The number of patients prescribed antipsychotic medication had reduced from 32 (64%) in 2009 to none in 2011. There were no significant differences between the mean ages, duration of diagnosis, CDR score and initial total NPI scores of those patients who were deceased at the follow-up compared with those who were still alive (Table 2). In comparing the proportion of patients on antipsychotic medication with those who were not at the time of the initial assessment in 2009, analysis using the chi-squared test revealed no significant difference in their outcome in terms of survivability.

In terms of individual items on the NPI, the most frequent problems identified at the time of initial assessment were agitation and aggression ($n = 21$, 42%) and irritability ($n = 14$, 28%) (Table 3). On follow-up, among the 25 patients who were still alive in 2011 that had been assessed in 2009, there was an increase in the prevalence of apathy ($n = 20$, 80%) and anxiety ($n = 5$, 20%). The most common problems on follow-up were apathy, agitation and aggression, irritability and anxiety. Despite antipsychotics no longer

Table 2 Initial assessment data (2009) of patients, by survival status in 2011

	Deceased by time of follow-up in 2011	Alive at time of follow-up in 2011	<i>P</i>
Patients in 2009, <i>n</i>	23	25	
Age in 2009, years: mean (s.d.)	82.3 (7.66)	78.8 (6.63)	0.09 ^a
Duration of diagnosis in 2009, years: mean (s.d.)	6.04 (2.63)	5.28 (4.36)	0.46 ^a
Total Neuropsychiatric Inventory score in 2009, mean	15.5	15.2	0.95 ^a
Patients with Clinical Dementia Rating severe rating in 2009, <i>n</i> (%)	19 (82.6)	18 (72)	0.52 ^b
On antipsychotics in 2009, <i>n</i> (%)	12 (52.2)	19 (76)	0.21 ^b

a. *t*-test.

b. χ^2 .

Table 3 Prevalence of behavioural and psychological problems identified by using the Neuropsychiatric Inventory among patients assessed in 2009 and on follow-up in 2011

Neuropsychiatric Inventory items	n (%)	
	Patients at onset (n=50)	Patients still alive at follow-up (n=25)
Hallucinations	8 (16)	0
Delusions	6 (12)	0
Irritability	14 (28)	8 (32)
Agitation and aggression	21 (42)	9 (36)
Depression and dysphoria	3 (6)	2 (8)
Anxiety	4 (8)	5 (20)
Elation and euphoria	2 (4)	0
Apathy	13 (26)	20 (80)
Disinhibition	2 (4)	0
Aberrant motor behaviour	10 (20)	4 (16)
Night-time behaviour	8 (16)	1 (4)
Appetite problems	8 (16)	7 (28)

being prescribed, there were no patients who were reported to be experiencing hallucinations or delusions.

There was a general reduction in the proportion of patients on psychotropic medication. The number of patients prescribed antipsychotic medication was reduced from 32 (64%) in 2009 to none in 2011, antidepressants were prescribed to 33 patients (66%) in 2009 and 28 (58.3%) in 2011 and benzodiazepines were prescribed in 26 patients (52%) in 2009 and 21 patients (43.8%) in 2011.

The most frequent drugs prescribed regularly in 2009 were quetiapine in 22 patients (44%), trazodone in 19 patients (38%) and citalopram in 8 patients (16%). In 2011, the most frequent drugs prescribed regularly were trazodone in 15 patients (31.3%) and citalopram in 6 patients (12.5%). Lorazepam was the most frequent benzodiazepine prescribed in both 2009 and 2011. It was mainly prescribed as required, to be administered for episodes of increased aggression and agitation.

There was an increase in the use of memantine from 1 patient (2%) in 2009 to 4 patients (8.3%) in 2011 and a slight increase in use of cholinesterase inhibitors from 3 (6%) in 2009 to 4 patients (8.3%) in 2011.

Discussion

Main findings

This study reviewed aspects of the outcome of care for 50 patients in a National Health Service continuing care unit diagnosed with dementia who had been assessed in an earlier study in 2009. Of the 50 patients assessed in 2009, nearly half were deceased 2 years later. There was no apparent relationship in outcome in terms of mortality, with respect to age, gender, duration of diagnosis and severity of neuropsychological problems (see Table 2). It has been reported that the features at diagnosis that are significantly associated with reduced survival are increased severity of cognitive impairment, decreased functional level, a history of falls, physical examination findings of frontal release signs and abnormal gait.⁹

There is evidence that some atypical antipsychotic drugs confer benefit in the treatment of aggression in people with Alzheimer's disease over a period of up to 12 weeks.¹⁰ These benefits have to be considered in the context of significant adverse events, including extrapyramidal symptoms, accelerated cognitive decline, stroke and death.¹¹ In our study, all patients who were alive at the time of follow-up in 2011 were no longer on antipsychotic medication. When comparing outcome between those who had been on antipsychotic medication and those who had not, no differences were found. It was also noted that none of the patients in 2009 who had delusions or hallucinations were observed to experience either problem in 2011 despite no longer being on antipsychotic medication. This would support the view of the need to review patients with dementia on a regular basis who have psychotic symptoms that require antipsychotics. Long-term treatment with these drugs may not be required or beneficial in light of known adverse side-effects.

Looking at individual neuropsychological problems in our study, the most frequent symptoms identified at the onset were agitation and aggression and irritability. At follow-up, the most common neuropsychological problems were apathy, agitation and aggression, irritability, anxiety and appetite problems. Our findings are similar to a larger study involving nursing home residents with dementia, where apathy tended to increase and agitated behaviour were particularly persistent.¹² It has been observed that aggression, agitation and psychosis are more frequent in moderate/severe stages, and they occur within a context of symptoms that indicate a greater frontotemporal lobe involvement of Alzheimer's dementia pathology.¹³ We are unable to ascertain whether this is the case in our study, as this was not the focus of the study.

Implications

Given the safety concerns related to pharmacological therapies, non-pharmacological interventions are recommended as first-line therapies despite a lack of

strong, consistent evidence, the modest benefits and questions about lasting benefit.¹⁴ There is evidence to suggest that behavioural treatment of depression is effective,¹⁵ music therapy may alleviate agitation and apathy¹⁶ and controlled multisensory stimulation, also known as Snoezelen, might help with apathy, and psychomotor therapy might alleviate agitation.¹⁷ At the time this study was carried out, improved access to occupational therapy activities along with the structural redesign of the reception and activity areas in one of the bungalows of the unit took place as described earlier. The impact of these changes could not be evaluated to find out whether they have contributed towards the successful reduction of antipsychotic use.

Despite the evidence of potential harmful side-effects, antipsychotic medication may be required in severe cases of behavioural and psychological problems in dementia. Medication such as atypical antipsychotics, antidepressants, benzodiazepines, memantine and cholinesterase inhibitors have all shown some, but not always conclusive, benefits in the treatment of neuropsychological symptoms in severe dementia. The potential for harmful side-effects means that such pharmacological approaches require careful monitoring and periodic reassessment to determine whether continued treatment is necessary. In our study, an experienced psychiatrist supported by a senior pharmacist carried out 3-monthly reviews of medication for all patients on psychotropic medication for neuropsychological symptoms to decide on the need for continued use.

Acknowledgements

We wish to acknowledge the support and cooperation of all the nursing staff who took part in this study.

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