

## YOUNGER PEOPLE WITH DEMENTIA: DIAGNOSTIC ISSUES, EFFECTS ON CARERS AND USE OF SERVICES

GEORGINA LUSCOMBE,<sup>1</sup> HENRY BRODATY<sup>2\*</sup> AND STEPHEN FREETH<sup>3</sup>

<sup>1</sup>Research Officer, Academic Department of Psychogeriatrics, Prince Henry Hospital, Sydney, Australia

<sup>2</sup>Director of the Academic Department of Psychogeriatrics, Prince Henry Hospital, Sydney, Australia;

Professor of Psychogeriatrics, School of Psychiatry, University of New South Wales, Australia

<sup>3</sup>Now Research Consultant, formerly Projects Officer, Alzheimer's Association (Australia)

### SUMMARY

*Objective.* To determine difficulties experienced by carers of younger people with dementia.

*Design.* Cross-sectional self-report questionnaire survey.

*Participants.* 102 eligible carers of persons less than 65 years of age with dementia, recruited through support groups and clinicians' referrals.

*Main outcome measures.* Problems with diagnostic process; professionals/services consulted; psychological, physical, occupational and financial impact of illness on carers and children; use of and satisfaction with services.

*Main results.* Diagnostic problems were reported by 71% of carers. Mean time until diagnosis was 3.4 years (SD 2.8) after consulting 2.8 (1.4) professionals. Carers reported frustration (81%) and grief (73%). Adverse psychological effects were common, more so in female than male carers ( $p < 0.01$ ). The younger the carer, the more psychological and physical effects were experienced ( $p < 0.01$ ). Only 8% of carers considered that their children had encountered no problems because of the dementia. Of 61 working carers, 59% reduced their hours or stopped working after diagnosis, and 89% of all carers had experienced financial problems subsequent to diagnosis. Most carers (89%) had used a support service, but 25% had never used community support, 32% had never used respite. Proportions of carers rating services as 'good' ranged between 43 and 100%.

*Conclusions.* Younger people with dementia, and their carers, face difficulties in obtaining a diagnosis. Carers also experience psychological problems, financial worries, loss of employment and family conflict, and their children are affected. Most carers had used services, but some dissatisfaction existed. © 1998 John Wiley & Sons, Ltd.

Int. J. Geriatr. Psychiatry, 13: 323–330, 1998.

KEY WORDS—presenile dementia; carers; diagnosis; family history; Alzheimer's disease; Huntington's disease

A diagnosis of dementia can be devastating to affected persons and their families, with negative psychological, social, physical and financial effects (eg Morris *et al.*, 1988; Brodaty and Hadzi-Pavlovic, 1990), but there is no clear evidence regarding whether the impact is different for younger people with dementia or whether there are differences in the diagnostic process.

Rates of presenile dementia per 100 000 population have been estimated at 25 for 45–54-year-olds (yo), 72 for 55–64 yo, 20 for 30–59 yo and 30 for 30–64 yo (Mölsä *et al.*, 1982; Sulkava *et al.*,

1985; Rocca *et al.*, 1991). Newens *et al.* (1993) reported prevalence rates of 34.6 with presenile AD per 100 000 45–64 yo compared with 11.7 with presenile vascular dementia and 27.0 with other types of presenile dementia.

In Australia, Jorm (1993) calculated that there were 4184 cases of presenile dementia (moderate to severe), with rates increasing from 14 per 100 000 for the 35–39 yo age group to 225 per 100 000 for the 60–64 yo. Based on these prevalence rates, and 1995 ABS population estimates, we estimated a total of 4282 cases of presenile dementia in Australia.

Difficulties in obtaining a diagnosis of dementia (eg O'Connor *et al.*, 1988; Brodaty *et al.*, 1994) appear to be greater before the age of 65 years (Marsden and Harrison, 1972; Nott and Fleminger,

\*Correspondence to: Professor H. Brodaty, Academic Department of Psychogeriatrics, Prince Henry Hospital, Anzac Parade, Little Bay, Sydney, NSW 2036, Australia. Tel: 61 29382 5007. Fax: 61 29382 5016. e-mail: research.ad.pg@unsw.edu.au.

1975; Ron *et al.*, 1979; Keady and Nolan, 1994; Newens *et al.*, 1994; Ferran *et al.*, 1996). Yet, an early diagnosis is important; it enables patient, family and carers to have an understanding of the prognosis, and a greater opportunity to attend to work and family responsibilities and to plan for the management of the illness and for the future.

The Alzheimer's Association (Australia), a self-help group for people with dementia and their families, concerned about the dearth of information about younger people with dementia and their carers and the relative neglect in planning services for them, commissioned a survey on these issues. The experience of the Association was that the needs of younger people with dementia and their carers for services, counselling and support were different from those of their older counterparts.

This survey of carers of people less than 65 years of age with dementia aimed to find out what experiences and difficulties these carers had had with diagnosis and with service provision; what impact the illness was having on them and their families; and whether these experiences were modified by type of dementia, family history of dementia or demographic variables for patient or carer. Persons with AIDS-related dementia were excluded as their issues are unique.

## METHOD

### *Sample*

A convenience sample was obtained through referrals from clinicians and through support groups of the Alzheimer's Associations and Huntington's Disease Association of Australia. Questionnaires were sent to approximately 250 carers of persons diagnosed as having dementia before the age of 65 years (where appropriate called 'patients').

Only 102 of the 123 completed questionnaires were used for the analysis: one patient was excluded because of inconsistent data and 20 because patients were over 64 years when surveyed. The latter inclusion criterion ensured that the sample represented cases of *presenile* dementia, even if diagnosis before a patient's sixty-fifth year was reported.

### *Procedures*

Metropolitan and non-metropolitan focus groups were formed through State and Territory

Alzheimer's Associations and community groups dealing with early onset dementia. Themes emerging from the focus group discussions formed the basis of a questionnaire, which was piloted and refined. The final 33-item self-completed survey included questions on demographics; diagnosis and diagnostic process; family history; effects on occupation, finances and relationships of the affected person, carer and children (if carer was a spouse); service use; and satisfaction with services as rated on a three-point scale: poor, fair or good.

### *Statistical analysis*

Categorical variables were analysed using chi-square tests, and continuous dependent variables were examined using analysis of variance (ANOVA) except that the non-parametric Kruskal-Wallis ANOVA (*H*) was used for significantly skewed data. The Student's *t*-tests were used for comparison of independent dichotomous groups. The time from first symptoms to diagnosis was based on midpoints between categories (eg <1 year = 0.5 years, 1–2 years = 1.5 years). Spearman's correlations ( $r_s$ ) were used to examine associations between age (which was significantly skewed) and continuous variables. As results regarding age at diagnosis and at survey were similar both for patients and carers, we only report survey age. Also, given that 81% of respondents were caring for a patient of the opposite sex, results by gender are generally given for carers only. Where necessary, analyses were interpreted with Bonferroni adjustments for multiple comparisons.

## RESULTS

### *The sample*

Patient demographic characteristics, both for individual diagnostic groups and in total, are shown in Table 1. Carers' mean age at survey was 51.7 years (SD 12.5). Most ( $N = 77/102$ ) were female, and 69 were spouses or partners, 13 parents, 12 children and the remaining eight had some other type of relation to the patient. Forty-four of 100 carers lived in metropolitan areas.

### *Family history*

Of the 78 carers who could answer questions about the patient's family history, 31 patients (40%) had at least one first-degree relative

Table 1. Demographic information for patients ( $N = 102$ )

	AD $N = 49^*$	HD $N = 24$	OD† $N = 29^*$	Total $N = 102$	Statistics‡	$p$
Age at diagnosis (yr)	52.7 (5.9)	39.7 (9.3)	51.2 (8.4)	49.2 (9.2)	$H = 27.99$	0.000
Age at survey (yr)	56.5 (5.8)	46.3 (10.5)	54.5 (8.4)	53.3 (7.9)	$H = 15.19$	0.000
Years since diagnosis	3.6 (2.5)	6.6 (4.8)	3.1 (2.8)	4.2 (3.3)	$H = 11.58$	0.000
% male	49.0	60.9	75.9	59.4	$\chi^2 = 5.49$	0.064
% in nursing home	28.3	40.9	17.9	28.1	$\chi^2 = 3.24$	0.198

AD, Alzheimer's disease; HD, Huntington's disease; OD, other dementias.

\*Data missing on age at diagnosis and years since diagnosis for one Alzheimer's disease and one other dementia subject, therefore age at diagnosis plus years since diagnosis do not total to age at survey.

†Other dementias comprise Pick's disease ( $N = 6$ ), multi-infarct dementia (5), alcohol-related dementia (5) and dementia of mixed aetiology (11).

‡ $df = 2$  for all analyses;  $H$  represents Kruskal-Wallis one-way ANOVA values.

Table 2. Type of diagnostic service or professional consulted for diagnosis ( $N = 100$ )<sup>\*</sup>

Professional/type of service	AD	HD	OD	Statistics†	
	$N = 47$ (%)	$N = 24$ (%)	$N = 29$ (%)	$\chi^2$	$p‡$
General practitioner	91.5	79.2	93.1	3.17	0.205
Neurologist	68.1	70.8	51.7	2.72	0.256
Psychiatrist	29.8	29.2	69.0	13.21	0.001§
ACAT**	46.8	0	31.0	16.27	0.000§
Psychologist	27.7	12.5	41.4	5.44	0.066
Geriatrician	10.6	12.5	20.7	1.56	0.458
Other	10.6	4.2	27.6	6.81	0.033
Psychogeriatrician	10.6	0	13.8	3.34	0.188

AD, Alzheimer's disease; HD, Huntington's disease; OD, other dementias.

\*Data missing on two patients.

† $df = 2$ .

‡Bonferroni adjusted alpha =  $0.05/8 = 0.006$ .

§Significant after Bonferroni correction.

\*\*Aged Care Assessment Team.

(ie parent or sibling) affected by dementia: 96% of HD, 23% of AD and 10% of OD patients ( $\chi^2 = 40.69$ ,  $df = 2$ ,  $p < 0.001$ ). The 31 included one patient with both parents affected and one patient with a sibling, but neither parent, with dementia.

### Diagnosis (Tables 2 and 3)

The average number of professionals consulted to obtain a diagnosis was 2.8 (SD 1.4), with 2.8 professionals (SD 1.1) for AD, 2.1 (0.9) for HD and 3.5 (1.8) for OD patients ( $F(2,99) = 7.24$ ,  $p < 0.01$ ). General practitioners were the most frequently consulted professionals (89/100 patients), followed by neurologists (64/100). Psychogeriatricians were,

given the patients' mean age, understandably consulted by only nine patients.

The diagnostic process was considered problematic in some respect by 71% (67/95) of the carers: most frequently due to the service's or professionals' lack of knowledge (42%), especially in the OD group (see Table 3). Carers who were younger at survey noted more diagnostic problems ( $r_s = -0.35$ ,  $N = 94$ ,  $p < 0.01$ ), but there was no relationship with patient age. We reanalysed these data without the HD group on the premise that a diagnosis for this group may have been much easier to make, and then found a significant negative relationship between number of diagnostic problems and age for both carers ( $r_s = -0.34$ ,  $N = 71$ ,  $p < 0.01$ ) and patients ( $r_s = -0.31$ ,  $N = 72$ ,  $p < 0.01$ ).

Table 3. Types of problems encountered in getting a diagnosis by diagnostic subtype ( $N = 95$ )\*

Problem type	AD	HD	OD	Statistics†	
	$N = 45$ (%)	$N = 23$ (%)	$N = 27$ (%)	$\chi^2$	$p^\ddagger$
Misdiagnosis	22.2	13.0	25.9	1.31	0.519
Dismissal/disbelief	31.1	8.7	25.9	4.23	0.121
Poor referral	24.4	0	25.9	7.12	0.028
Poor medical management	13.3	4.3	25.9	4.74	0.094
Long travel	26.7	13.0	33.3	2.80	0.247
Lack of knowledge	40.0	21.7	63.0	8.81	0.012
Poor attitude	11.1	8.7	37.0	9.47	0.009
High cost	13.3	4.3	22.2	3.37	0.186
No problems	33.3	47.8	7.4	10.37	0.006§

AD, Alzheimer's disease; HD, Huntington's disease; OD, other dementias.

\*Data missing on seven patients.

† $df = 2$ .

‡Bonferroni adjusted alpha =  $0.05/9 = 0.006$ .

§Significant after Bonferroni correction.

When seeking a diagnosis, 25% of carers found long travel a problem, especially non-metropolitan carers (44%, metropolitan carers 13%;  $\chi^2 = 11.09$ ,  $df = 1$ ,  $p < 0.001$ ). Misdiagnosis was reported by 20 (11%) carers, and was more common for those patients who had seen a psychiatrist (33%, 13/40) compared with those who had not (13% or 7/55;  $\chi^2 = 5.45$ ,  $df = 1$ ,  $p = 0.02$ , NS after Bonferroni); psychiatric referral may have resulted from diagnostic difficulties. Of OD carers, 69% reported consulting a psychiatrist, versus 30% of AD and 29% of HD carers. Types of problems encountered in diagnosis differed by diagnostic group (see Table 3) but not by carer-patient relationship, nor by carer gender.

The reported mean time to diagnosis was 3.4 years (SD 2.8) (AD 3.6 (2.7), HD 4.2 (3.2), OD 2.4 (2.7);  $H = 8.86$ ,  $df = 2$ ,  $p < 0.05$ ). Surprisingly, only 42% of AD and 39% of HD patients were diagnosed in the first 2 years versus 70% of OD patients. At the other extreme, it was 5 or more years from onset of symptoms until a diagnosis was known for 29% of the AD, 35% of the HD and 19% of the OD patients. The questionnaire did not determine whether the diagnosis was of dementia in general or the specific disease, nor did it indicate the dementia severity at time of diagnosis.

#### Effects of the illness

**Carers.** When questioned about the effect the disease had on their life, carers affirmed they felt frustration (81%,  $N = 78/96$ ), grief (73%) and

loneliness (55%) and 57% acknowledged they had psychological or emotional problems. Family conflict was identified as an effect of the dementia by 41% of carers.

Psychological or emotional effects of the disease were reported by significantly more female (65% or 48/74) than male carers (32%;  $\chi^2 = 7.57$ ,  $df = 1$ ,  $p < 0.01$ ), as was grief (female: 81%, male: 46%;  $\chi^2 = 10.90$ ,  $df = 1$ ,  $p < 0.01$ ). Carers who were spouses or partners were most likely (68%) to feel loneliness due to the disease, compared with 39% of parents, 25% of children and none of the remaining five carers ( $\chi^2 = 16.56$ ,  $df = 3$ ,  $p < 0.001$ ). Carers who were children tended to report being psychologically or emotionally affected by the disease ( $N = 11/12$ ) more often than parents (8/13), spouses/partners (34/66) or others (2/5;  $\chi^2 = 7.40$ ,  $df = 3$ , NS). Younger carers affirmed more effects of the illness ( $r_s = -0.32$ ,  $N = 96$ ,  $p < 0.01$ ). Patient age did not correlate with carers' perception of their own psychological health.

**Children.** Analysis of the impact of the illness on children was restricted to responses provided by the 61 spouse carers with children (mean age = 52.3, SD = 9.3 years). The survey did not ask the age of the children nor whether they were living at home. Three-quarters of the carers affirmed that their children had suffered psychological or emotional problems as a consequence of the dementia; only 8% responded that their children had not encountered *any* problems. Half (51%) reported that their

children had been in conflict with their affected parent, more often with their affected father (62%) than mother (19%;  $\chi^2 = 8.92$ ,  $df = 1$ ,  $p < 0.01$ ) and if the affected parent was younger; 79% if parent less than 50 years old, 48% for 50–59-year-olds and 36% for 60–64-year-olds ( $\chi^2 = 6.23$ ,  $df = 2$ ,  $p < 0.05$ , NS after Bonferroni). Children were also more likely to have problems at school or at home if the person with dementia was less than 50 years old ( $\chi^2 = 11.55$ ,  $df = 2$ ,  $p < 0.01$ ;  $\chi^2 = 19.47$ ,  $df = 2$ ,  $p < 0.01$  respectively). More types of problems in children was associated with both youthfulness in the carer ( $r_s = -0.55$ ,  $N = 61$ ,  $p < 0.001$ ) and the patient ( $r_s = -0.43$ ,  $N = 61$ ,  $p < 0.01$ ).

The overall number and types of problems faced by children of carers looking after patients from different diagnostic groups were similar, although there was a trend for more frequent AD carer reports of children with psychological or emotional problems (AD: 88%, HD: 78%, OD: 55%;  $\chi^2 = 7.04$ ,  $df = 2$ ,  $p < 0.05$ , NS after Bonferroni).

**Occupation.** Of 61 carers working at the time of diagnosis, only 25 (41%) retained the same employment status at survey, 54% had 'retired' from full- or part-time employment (includes two carers who reported themselves as unemployed) and 5% had reduced their hours from full- to part-time. Forty-four of 98 carers (45%) were employed full-time at diagnosis, compared with only 18 (18%; includes one carer previously not employed) at survey.

**Finances.** Only 11% of carers ( $N = 10/90$ ) reported no financial problems due to the diagnosis of dementia. The most frequently reported financial problems were reduction in income (70%) and the patient's loss of employment (50%).

Reduction in income causing financial problems was more common among OD carers (92%) than among AD (69%) or HD carers (45%;  $\chi^2 = 11.74$ ,  $df = 2$ ,  $p < 0.01$ ). Similarly, loss of carer employment causing financial problems was more common in OD (52%) than AD (31%) or HD carers (5%;  $\chi^2 = 11.45$ ,  $df = 2$ ,  $p < 0.01$ ).

More female (60%) than male carers (22%) found loss of employment of the person with dementia to be financially difficult ( $\chi^2 = 9.87$ ,  $df = 1$ ,  $p < 0.01$ ). Otherwise there were no significant differences in financial problems by carer gender.

Spouses were significantly more likely (80%) to find reduction in income a problem associated with

the diagnosis of dementia, with 45% of parents and 44% of all children also finding reduced income a problem, compared with only 25% of other carers ( $\chi^2 = 13.15$ ,  $df = 3$ ,  $p < 0.01$ ). Parents were the most likely (73%) to claim to be financially affected by the person with dementia losing employment, compared with 52% of spouses/partners, 50% of carers with other relationships and only 11% of children ( $\chi^2 = 7.78$ ,  $df = 3$ , NS). There was no relationship between the number of types of financial problems and carer or patient age.

#### Use of services (Table 4)

**Community support services.** Carers used 1.6 (SD 1.6) community support services on average, male carers using significantly more (male: 2.3, female: 1.4;  $t = 2.35$ ,  $df = 93$ ,  $p < 0.05$ ). None of the following variables—area of residency (metropolitan vs non-metropolitan), carer or patient age,

Table 4. Use of services at survey

Type of service (total no. of respondents)	N	% rated 'good'
<i>Community (N = 95)</i>		
Day centre	41	77
Domestic help	24	70
Other	24	71
Sitting/minding	17	71
Home nursing	14	100
Home maintenance	13	82
Continence service	8	88
Living skills centre	8	88
Meals on wheels	7	43
Nil	24	NA
<i>Respite (N = 88)</i>		
Day centre	33	85
Hospital	25	68
Nursing home	15	47
In-home	12	92
Hostel	10	70
Other	8	67
Nil	28	NA
<i>Carer support (N = 95)</i>		
Carer support groups	55	77
General practitioner	48	79
Social worker	36	77
Other	18	100
Psychiatrist	13	69
General community centre	6	67
Psychologist	5	60
Nil	10	NA

carer relationship to patient or diagnostic subtype—affected carer service use significantly.

Community services were rated good (43–100%), fair (9–29%) or poor (6–29%). The most frequent complaints concerned hours of service (12%), staff attitude (9%) and staff competence (8%). The problem of services focusing on elderly patients was affirmed in regard to domestic help, day care centres, home maintenance, continence service, sitting/minding and the 'other' services category.

*Respite services.* On average, 1.2 (SD 1.0) types of respite service had been used, 33% of carers using one and 35% two or more. HD carers tended to use fewer respite services (AD mean 1.2, SD 1.1; HD 0.7, 0.7; OD 1.5, 1.2;  $F(2,85) = 3.57$ ,  $p < 0.05$ , NS after Bonferroni). There were no significant differences in the number of respite services used by carer gender, area of residency or relationship to patient. The number of respite services used tended to be positively associated with patient age ( $r_s = 0.23$ ,  $N = 88$ ,  $p < 0.05$ , NS after Bonferroni), but not with carer age.

*Carer support services.* Male and female carers each reported having used approximately 1.9 services over the course of the dementia. More spouses and partners had used a carer support service (69%;  $\chi^2 = 12.91$ ,  $df = 3$ ,  $p < 0.01$ ) and this group also used more support services (mean 2.2) compared to children (1.1), parents (1.2) or others (2.0;  $F(3,91) = 3.99$ ,  $p < 0.05$ , NS after Bonferroni). Area of residency, patient age and carer age were not associated with overall level of use of carer support services.

## DISCUSSION

There have been few studies regarding younger persons with dementia, even fewer examining the impact on family carers, and none on the children of affected persons. Despite this being the largest sample so far in the literature describing psychosocial issues for the carers and family of persons with presenile dementia, the study is preliminary and the derivation of this sample imposes certain restrictions upon the generalizability of the results. Limitations include sampling bias, lack of an older comparison group, unvalidated patient diagnoses and selective attrition because of premature death; (Newens *et al.* (1993) calculated a 64% 5-year

cumulative survival following diagnosis of presenile dementia of the Alzheimer's type and our average time from diagnosis to survey was 4.2 years). Despite these limitations, we believe that the paucity of research in this area justifies the reporting of these pilot data.

In this sample, the average duration from symptom onset to diagnosis was 3.4 years and about 30% of carers reported a period of greater than 5 years. In contrast, Sperlinger and Furst (1994) reported that the range in time between recognition of symptoms and diagnosis in their British sample of 15 younger people with dementia was between 1 month and 3 years. Newens *et al.* (1994) reported that 76.3% of their 186 hospital-derived cases with presenile Alzheimer's disease received this diagnosis within 12 months of symptom onset. Unfortunately, without data on severity of dementia for these samples, it is difficult to comment on such differences.

Approximately 70% of this sample reported encountering some type of problem with obtaining a diagnosis. Diagnosis is more easily missed when not suspected because of patient age, when behavioural or personality changes are the first symptoms (Keady and Nolan, 1994), when symptoms are denied by patient, family and colleagues (given the profound consequences and perceived lack of treatment possibilities), or when symptoms are misdiagnosed, usually as functional disorders (Nott and Fleminger, 1975). These difficulties were apparent here, with almost three clinicians consulted before diagnosis was reached, lack of knowledge being cited as a problem by 42% of carers and misdiagnosis by 21%.

As in other surveys (Brodaty *et al.*, 1990; Sperlinger and Furst, 1994), the most commonly seen health professionals were general practitioners, but those persons with difficult diagnoses, ie those who were initially misdiagnosed and/or were diagnosed with 'other dementias', also tended to consult psychiatrists. Ferran *et al.* (1996) reported general practitioners were able to diagnose presenile AD with 60% sensitivity, compared with 57% for psychiatrists and 100% for neurologists against the gold standard of a multidisciplinary early onset dementia service diagnosis.

We postulate, given the low prevalence of the disorder, that younger patients or carers would be relatively psychologically unprepared for and more resistant to a diagnosis of dementia compared with older groups. Evidence for this in our sample is that carer age and psychological stress were negatively

correlated and younger carers reported more diagnostic problems. The exception was the HD group, who were the youngest at diagnosis, had consulted the fewest professionals for a diagnosis and had the least number of difficulties with the diagnostic process. We reasoned that the strong family history of HD (96% reported having an affected first-degree relative) psychologically prepared them more for the diagnosis of presenile dementia.

Given that 38% of the OD group were diagnosed with dementia of uncertain aetiology, it is surprising that this group experienced the shortest average time to diagnosis. Patients with OD may have had a more rapid course (eg the stepwise progression of multi-infarct dementia), more associated behavioural changes and other overt symptoms, or other reasons for earlier assessment.

We confirm that carers of younger people with dementia are stressed (Baldwin, 1994; Sperlinger and Furst, 1994; Delany and Rosenvinge, 1995). The picture which emerges from our data is one of an harassed person, beset by psychological problems, financial worries, loss of employment and family conflicts. Carers most vulnerable to psychological distress were younger females caring for males with presenile dementia and children caring for parents. This study also verifies that presenile dementia has widespread economic implications. Not only does a diagnosis of dementia have occupational ramifications for patients, many carers (59% of those 61 working at diagnosis) gave up work or reduced their hours and most (89%) reported financial hardship. Sperlinger and Furst (1994) and Delany and Rosenvinge (1995) also found that just over half the carers in their sample had either stopped working or changed their employment conditions in order to care.

The ripple effects of dementia across generations have been described (eg Lieberman and Fisher, 1995), but little is known about the effects on children of *young* dementing parents. Carers in our sample reported that their children suffered emotional problems, problems at school and conflict with the person with presenile dementia, especially when the affected parent was their father.

Many carers expressed dissatisfaction with residential and community services. In Australia, dementia services, be they day centres, hostels or nursing homes, generally cater for older people whose average age is over 80 years and who are three times more likely to be female than male (personal communication, Department of Health

and Family Services, 1996). Anecdotally, even in support groups, carers who are young spouses feel different from older spouses or similarly aged children of older people with dementia.

### *Implications*

Greater awareness of dementia in the community could encourage earlier presentation, reduce denial and inspire community initiatives to help. Counselling services need to be cognisant of the special issues facing younger people with dementia and their families. Children of younger people with dementia are prone to experience stigma, shame and bewilderment; special counselling is often required. Educational packages, videos and books are needed for families of younger patients.

Community and residential services could make special provision for younger people with dementia, who are in danger of being overlooked while aged care services are increasing (Williams, 1995). While the low geographical density of presenile dementia militates against regional organization of services, other strategies such as supraregional centres, support groups focusing on younger people with dementia, telephone conferencing to link carers, allocation of special days in day centres and linkage with other groups such as young people with head injuries or AIDS may be useful. A policy of 'clustering' younger people with dementia requiring residential care may be reassuring to patients and carers alike.

### *Conclusions*

This study highlights some of the difficulties experienced by carers of younger people with dementia, in particular with diagnosis; psychological, social and financial effects; and service provision. Earlier diagnosis could be assisted by greater awareness among clinicians of the possibility of dementia in younger people. Clinicians' interest and willingness to diagnose dementia is likely to increase with the advent of specific drug treatments for AD. While it is encouraging that many of the carers in this survey were accessing services, dissatisfaction was common. Specific requirements of service provision for younger persons with dementia require more thorough investigation. Further studies could usefully compare matched community samples of young and old people with and without dementia.

## ACKNOWLEDGEMENTS

We thank Brian Draper and Kerrie Eyers for their comments on an earlier draft of this article, the Alzheimer's Association and Huntington's Disease Association for their assistance, and the carers who generously gave of their time.

## REFERENCES

- Baldwin, R. C. (1994) Acquired cognitive impairment in the presenium. *Psych. Bull.* **18**, 463–465.
- Brodaty, H., Griffin, D. and Hadzi-Pavlovic, D. (1990) A survey of dementia carers: Doctors' communications, problem behaviours and institutional care. *Aust. N.Z. J. Psychiat.* **24**, 362–370.
- Brodaty, H. and Hadzi-Pavlovic, D. (1990) Psychosocial effects on carers of living with persons with dementia. *Aust. N.Z. J. Psychiat.* **24**, 351–361.
- Brodaty, H., Howarth, G. C., Mant, A. and Kurrle, S. E. (1994) General practice and dementia. A national survey of Australian GPs. *Med. J. Aust.* **160**, 10–14.
- Delany, N. and Rosenvinge, H. (1995) Presenile dementia: Sufferers, carers and services. *Int. J. Geriatr. Psychiat.* **10**, 597–601.
- Ferran, J., Wilson, K., Doran, M. *et al.* (1996) The early onset dementias: A study of clinical characteristics and service use. *Int. J. Geriatr. Psychiat.* **11**, 863–869.
- Jorm, A. (1993) Figures supplied to the National Alzheimer's Secretariat, as cited by Freeth, S. in *The Young Mind: Issues in Relation to Young People and Dementia* (1994) Alzheimer's Association Australia.
- Keady, J. and Nolan, M. (1994) Younger onset dementia: Developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers. *J. Adv. Nurs.* **19**, 659–669.
- Lieberman, M. and Fisher, L. (1995) The impact of chronic illness on the health and well-being of family members. *Gerontologist* **35**, 94–102.
- Marsden, C. D. and Harrison, M. J. G. (1972) Outcome of investigation of patients with presenile dementia. *Brit. Med. J.* **2**, 249–252.
- Mölsä, P. K., Marttila, R. J. and Rinne, U. K. (1982) Epidemiology of dementia in a Finnish population. *Acta Neurol. Scand.* **65**, 541–552.
- Morris, R. G., Morris, L. W. and Britton, P. G. (1988) Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *Brit. J. Psychiat.* **153**, 147–156.
- Newens, A. J., Forster, D. P., Kay, D. W. *et al.* (1993) Clinically diagnosed presenile dementia of the Alzheimer's type in the Northern Health Region: Ascertainment, prevalence, incidence and survival. *Psychol. Med.* **23**, 631–644.
- Newens, A. J., Forster, D. P. and Kay, D. W. (1994) Referral patterns and diagnosis in presenile Alzheimer's disease: Implications for general practice. *Brit. J. Gen. Pract.* **44**, 405–407.
- Nott, P. N. and Fleminger, J. (1975) Presenile dementia: The difficulties of early diagnosis. *Acta Psychiatr. Scand.* **51**, 210–217.
- O'Connor, D. W., Pollitt, P. A., Hyde, J. B. *et al.* (1988) Do general practitioners miss dementia in elderly patients? *Brit. Med. J.* **297**, 1107–1110.
- Rocca, W. A., Hofman, A., Brayne, C. *et al.* (1991) Frequency and distribution of Alzheimer's disease in Europe: A collaborative study of 1980–1990 prevalence findings. The EURODEM-Prevalence Research Group. *Ann. Neurol.* **30**, 381–390.
- Ron, M. A., Toone, B. K., Garralda, M. E. *et al.* (1979) Diagnostic accuracy in presenile dementia. *Brit. J. Psychiat.* **134**, 161–168.
- Sperlinger, D. and Furst, M. (1994) The service experiences of people with presenile dementia: A study of carers in one London borough. *Int. J. Geriatr. Psychiat.* **9**, 47–50.
- Sulkava, R., Wikstrom, J., Aromaa, A. *et al.* (1985) Prevalence of severe dementia in Finland. *Neurology* **35**, 1025–1029.
- Williams, D. D. R. (1995) Services for younger sufferers of Alzheimer's disease. *Brit. J. Psychiat.* **166**, 699–700.