

Helping the family carers of Alzheimer's patients: from theory . to practice. A preliminary study

J.C. Millán-Calenti ^{a,b}, M. Gando-y-Crego ^a, M. Antelo-Martelo ^a, M. López-Martinez ^{a,b}, M.P. Riveiro-López ^a, J.M. Mayán-Santos ^e

^aGerontological Insititute 01 Galicia, Avda, Xoan XXIII s/n, Santiago de Compostela, 15.704 La Coruña, Spain

^bDepartment 01 Medicine, Unioersity 01 La Coruña, Campus Universitario de Oza, /5.006 La Coruña, Spain

^eDepartment 01 Nursing, Unioersity 01 Santiago de Compostela, Xoan XXIII s/n, Santiago de Compostela, J 5.704 La Coruña, Spain

Abstract

Alzheimer's disease (AD) represents one of the most important health issues in the western world. The ongoing care that the AD patient requires typically causes high stress levels, fatigue, irritation and depression in the caregiver, as well as socio-economical problems. The current study aimed to introduce a support program for carers of AD patients, in order to improve their quality of life. A Questionnaire for Carers and an Anxiety State Feature Questionnaire (STAI) was used to assess the carers. Results showed an overall improvement in the carers' health. Their subjective wellbeing increased, and though their situation had not changed, they nevertheless described feeling less trapped. It can be concluded that possibly the mere fact that the carers feel that they have help available is enough to endorse the value of the program.

Keywords: Dementia; Carers; Support program; Anxiety

1. Introduction

Alzheimer's disease (AD) represents one of the most important health issues in the western world. It is estimated that by the year 2000, more than 20% of the European population will be over the age of 60, implying an increase in the possibility of suffering this age related pathology.

According to Mortimer (1981), Jorm (1990), the prevalence of dementia in individuals over the age of 65 is 5% in moderate and severe forms, and 10% in minor forms. Within these, AD represents 50-75% (Mortimer, 1981; Jorm, 1985, 1990; Cummings et al., 1996), with the prevalence doubling every 5 years from 65 onwards, and establishing an incidence of 0.9% annually for those over 65. In Galicia these figures translate to 3500 new cases each year.

Because there is no cure for AD, the aim has been to minimize the symptomology using palliative measures, and providing social and psychological support for the patient and their carers.

It is estimated that ~ 90% of people who suffer with dementia remain in their homes (Herrero et al., 1994) and that of these, the home care falls on a member of the family in 80% of cases.

The figure of family carer, therefore, emerges as the person who provides the majority of care and supervision that the patient requires (Bergmann et al., 1978). Because AD is an incapacitating illness, the level of dependency of the patient on their carer will increase over time.

The ongoing care that the carer is required to provide for the AD patient causes high levels of stress, irritation and fatigue (Lowenthal, 1964; Zarit et al., 1980; Ravins et al., 1982; Boykin and Winland Brown, 1992; Jones and Peters, 1992).

In this situation, family relationships also tend to deteriorate and it is recognized that the availability of family support is one of the most important factors in preventing the institutionalization of patients with dementia (Levine and Lawlor, 1991; Mittelman et al., 1995, 1996; Haley, 1997).

Zarit et al. (1980) introduced the term 'burden' to reflect the feelings of 'oppression', 'obligation', 'without rest', and 'for long periods of time', that families can feel when faced with the level of care generated by the patient with dementia.

It is as important for health professionals to assess the level of physical care required by the patient, as it is for them to assess the emotional implications, degree of social isolation, economic repercussions, personal wellbeing, and the extent of 'burden' on the carer (Pérez et al., 1993; Ernst and Hay, 1997).

Aside from improving their quality of life, an appropriate assessment of the carer can provide an important contribution in predicting or delaying the likelihood of institutionalising the patient (Maddox and Burns, 1997). Once obtained, the assessment can be used to design intervention programmes with the aim of reducing as much as possible the problems faced by family carers (Knight et al., 1993; Bourgeois et al., 1996; Winslow, 1997).

The objectives of the present study are:

1. To provide a support program for carers of patients with Alzheimers.
2. To assess the results obtained after 1 year of the program

2. Subjects and methods

The current study was carried out by the Galician Gerontological Institute, with funding provided by the council of Santiago, in collaboration with the Galician Association of Alzheimers' Sufferers, the Universities of La Coruña and Santiago de Compostela. The sample being family carers of individuals with AD resident in this municipality.

The sample consisted of fourteen carers with an age range of 36- 73 years, with a mean age of 54.61 years; 92.3% being women.

The patients were aged between 57 and 93 years, with a mean age of 78.71 years; nine were women (64.3%) and five men (35.7%).

The assessment protocol which was followed consisted of two completely differentiated sections; one in which the carer was assessed and another in which the patient was assessed. The assessments were carried out by a specially trained research team.

The assessment of the patients, was carried out using two questionnaires: the IGG questionnaire to assess the dependence of the patient with cognitive deterioration and the Lobo Mini Cognitive Exam (Mini Mental State Examination, Spanish version) (Lobo et al., 1979).

Carers were assessed using the Carers' Questionnaire of 56 items (Millán et al., 1998), which included personal data, level of physical and mental health, social life, perception of support, and assessment and index of burden. The Anxiety State-Feature Questionnaire (STAI) was also used (Spielberger et al., 1970), which consists of 40 items and assesses two independent concepts of anxiety: the A State, marked by the changing levels of anxiety; and the A Feature, anxiety as an 'innate' characteristic of the subject.

In as much as the supportive activities of the program, these were divided into two parts

(A) Volunteer Intervention in which volunteers from the University Volunteer Office of Santiago de Compostela, educated about AD, visited the patients' homes, to provide support for the carer in looking after the patient, as well as providing company to both.

These volunteers were able to take on the responsibility of the patient on occasions when the carer needed to leave the home, and as such provide respite for the carer.

(B) Intervention by professionals specialized in care of the elderly who met regularly every fortnight with the carers, to develop a theoretical-practical program which was concerned issues such as: information about AD and its nursing care (Adkins and Mathews, 1997; Baxter, 1997); safety in the home and the removal of environmental obstacles (Teri, 1997); facing the development of AD (Saad et al., 1995); benefits and social services (Homer and Gilleard, 1994; Cox, 1997); and group psychotherapy, among other issues.

The theoretical part of the program was completed with visits to the patients' homes by the professionals, so that the information learnt about the patients' abilities in terms of their mobility, hygiene, safety, and management of disturbing or dangerous behavior etc. could be applied.

3.Results

Functional as well as cognitive deterioration was observed in the patients, as would be expected with the development of Alzheimer's, and bearing in mind this program not having been designed with a specific course of action aimed at the patients.

The first assessment showed a mean dependency value of 56.78%, and a score on the Mini Mental State Examination, Spanish version (Lobo et al., 1979) of 8.92, while in the second assessment, the mean dependency scores were 60% and 9.21 points on the Lobo's questionnaire.

The carers' overall health was observed to have improved (Table 1), such that at the first assessment 38.5% considered themselves well and 53.8% usual, while at the second assessment 53.8% considered themselves well, and 46.2% usual.

As far as visits to the doctor were concerned, the carers began to worry more about their health, with 38.5% going to the doctors' by the time of the second assessment, while at the first assessment it was just 7.7% who regularly sought check-ups. However, medication intake had not varied.

At the time of the second assessment (one year from baseline) 60% of carers asserted that they now knew how to respond to situations compared to 46.2% at the previous assessment. By the end of the study, 92.3% of carers stated that the care of the patient demanded some sacrifice compared with 84.6% previously. In line with these results, 61.7% of carers at the beginning of the program asserted that their plans for the future were affected, at the time of the second assessment, this percentage increased to 69.2%.

At the beginning of the program 69.2% of the carers believed they had drastically curtailed their social lives, but this was now the case for 46.2%. In the first assessment, 10% avoided being visited at their homes because of the patient, while by the end of the program none of the carers avoided receiving visitors.

Table 1
The carers' assessment, by means of the carers' questionnaire

Assessment of the carer of the patient with Alzheimer's Carer's Assessment Questionnaire

Item	First assessment	Final assessment
They consider their health ...	Good 38.5%	Good 53.8%
Visits to the doctor	Regular 7.7%	Regular 38.5%
They respond to the situation ...	Well 46.2%	Well 60%
They have curtailed their social life	Yes 69%	Yes 46.2%
They avoid receiving visitors at home	Yes 10%	No 100%
They are aware of social service support	Yes 15.4%	Yes 76.9%
They have requested some help	Yes 20%	Yes 46.2%
They have thought of the residence	Yes 100%	Yes 23.1%
There is another caregiver	Yes 30.8%	Yes 53.8%

Table 2
Carers' assessment by means of the ST AI

Assessment of the Carer of the patient with Alzheimer's		
Assessment of anxiety by means of the ST AI		
	First assessment	Final assessment
Anxiety feature (AF)	25.6	24.4
Grouping AF	6	6
Anxiety state (AE)	27.7	19.8
Grouping AE	6	5

The time taken to care for the patient had repercussions at work in 50-58.3% of cases, with 16.7% feeling obliged to eventually give up work compared with 8.3% at the beginning, an increase which can be explained by the development of the illness.

With regards to the problems of caring for the patients, at the first assessment 7.7% did not know how to resolve them and for 15.4% they seemed difficult. Currently, 23.1% found them difficult to resolve, but all have some idea of how to resolve them or who to call on for help.

At the beginning of the program, only 15.4% of the carers knew about some of the help offered by the state, but now following the information provided by the program, the percentage had increased to 76.9%.

Previously the 66.7% of the carers believed that their homes met with adequate conditions, while at this point 46.2% considered this to be the case. The district in which they lived was also initially thought to have no influence by 46.2% of carers, while 46.2% felt their district was adequate; currently, due to the development of the illness this now had no influence for 83.3% and was adequate for only 16.7%.

In relation to domestic duties, the patient had ceased to help, even interfering with (23.1%), and increasing these duties (61.5%).

At the first assessment only 20% of the carers had asked for help, while at the second assessment 46.2% asked for help. An emphasis was placed on family associations, domestic help and some economic help.

When asked if they had thought about institutionalising the patient, all of the carers said no, but at present 23.1% were thinking of doing so.

The number of carers who looked after the patient increased, with the majority of the patients being looked after by two people (from 30.8 to 53.8% currently). This meant that the principle caregiver had more time to carry out their own activities. The time needed to care for the patient exceeded 10 h daily in 92.3% of cases, compared to 84.6% previously.

To conclude, the carers felt less trapped (46%, 75% at the previous assessment) even though their duties continued to have major impact on them (38.5%).

In relation to the anxiety assessment measured with the STAI (Table 2); the results showed a decrease in the anxiety state, with anxiety feature decreasing to a lesser degree.

The anxiety-state came down from an initial score of 27.7 points to a final one of 19.8, bringing the carer down from an anxiety grouping of six to five. This difference has significance using the T method, for a sample (safety 95%, 13 degrees of liberty).

The anxiety-feature, showed no significant decreases, going from 25.6 to 24.4%, but remaining at a level six grouping.

4. Discussion

It should be noted to begin with that this was the first program of this type to be developed with any group of carers in this country. Our objective was to address specific issues (Homer and Gilleard, 1994; Saad et al., 1995; Adkins and Mathews, 1997; Baxter, 1997; Cox, 1997; Teri, 1997); and incorporate them in a comprehensive programme in such a way as to involve the carers to as great a degree as possible (Knight et al., 1993; Mittelman et al., 1993; Mittelman et al., 1995, 1996; Bourgeois et al., 1996).

As expected no improvements were produced in the functional state of the patient nor in their development; but there were improved expectations in the carer, which was one of the aims of the intervention.

In general the carers had an improved perception of their health status, illustrated by the fact that they took a greater interest in their own health, with the number of visits to the doctor increasing. They also displayed an awareness that there were certain types of tasks which could impact negatively upon their health and for which they needed to ask for help.

They showed signs of being more receptive to receiving education and information, and above all, outside help.

They attempted to attain a certain level of social life, despite the limitations placed on them by caring for the patient. They also tried to ensure the issue affected family relationships as little as possible, and in particular the marital relationship in those cases in which the person responsible for the care was the patient's son/ daughter.

By the end of the help programme, the carers were aware of the whole range of help available to them from the state. A fact which served as a source of support, in that they knew that when they experienced high levels of stress, felt tired and burnt out, they had a back up.

It appeared that the family took on more of the care and attention of the patient, helping the carer in duties directly related to the care of the patient as well as in carrying out general household tasks.

The group therapy also proved to be a very valuable part of the program because it permitted the sharing of problems and the search for solutions by the carers themselves, which improved their sense of wellbeing.

The carers subjective wellbeing improved, even though feelings of depression required a more specific intervention. It appeared that their self-esteem as carers improved since they believed that they offered a better quality of care to the patient, and were able for the most part to resolve the daily problems which arose concerning the care of the elderly person

At any rate, we were able to recognize that perhaps the magnitude of the problems which carers face are simply too broad to successfully eliminate them all or even to improve them dramatically with whatever intervention.

Maybe the fact that the carers commented that they felt supported is enough to endorse the value of support programs. Such programs can be justified on the basis that they have a positive impact on both the wellbeing of the carer as well as the elderly person being cared for, who is the ultimate objective of the gerontological intervention.

References

- Adkins, V.K., Mathews, R.M., 1997. Prompted voiding to reduce incontinence in community-dwelling older adults. *J. Appl. Behav. Ann.* 30, 153-156.
- Baxter, E., 1997. Patients, caregivers, and managing care. *Geriatrics* 52, S48-S49.
- Bergmann, K., Foster, E.M., Justice, A.W., Mathews, V., 1978. Management of the demented elderly patient in the community. *Br. J. Psychiatry* 132,441-449.
- Bourgeois, M.S., Schulz, R., Burgio, L., 1996. Interventions for caregivers of patients with Alzheimer's disease: a review of content, process and outcomes. *Int. J. Aging Hum. Dev.* 43, 35-92.
- Boykin, A., Winland Brown, J., 1992. The dark side of caring: challenges of caregiving. *Gerontol. Nurs.* 21,13-18.
- Cox, c., 1997. Findings from a statewide program of respite care: a comparison of service users, stoppers and nonusers. *Gerontologist* 37, 511-517.
- Cummings, J.L., Arslan, D., Jarvick, L., 1996. Dementia @. In: Cassel, C.K. (Ed.), *Geriatric Medicine*, 3rd edn. Springer-Verlag, New York.
- Ernst, R.L., Hay, J.W., 1997. Economic research on Alzheimer's disease: a review of the literature. *Alzheimer Dis. Assoc. Disord.* 11 (6), 135-145.
- Haley, W.E., 1997. The family caregiver's role in Alzheimer's disease. *Neurology* 5, S25-S29.
- Herrero, M., Pascual, A., Fernández, c., 1994. Ancianos con demencias; atención de enfermería. *Rev. Rol. Enf.* 185, 69-78 (in Spanish).
- Homer, A.C., Gilleard, c.J., 1994. The effect of inpatient respite care on elderly and their carers. *Age Ageing* 23, 274-276.
- Jones, D.A., Peters, T.J., 1992. Caring for elderly dependants: effects on the carers quality of life. *Age Ageing* 21, 421-428.
- Jorm, A.F., 1985. Subtypes of Alzheimer's disease: a conceptual analysis and critical review. *Psychol. Med.* 15,543-553.
- Jorm, A.F., 1990. *The Epidemiology of Alzheimer*. Chapman and Hall, 'Disease and Related Disorders'. London.
- Knight, B.G., Lutzky, S.M., Macofsky-Urban, F.A., 1993. A meta-analytic review of interventions for caregiver distress: recommendations for future research. *Gerontologist* 33, 240-248.
- Levine, J., Lawlor, B.A., 1991. Family counseling and legal issues in Alzheimer's disease. *Psychiatr. Clin. N. Am.* 14, 385-396.
- Lobo, A., Ezquerro, J., Gómez, F.B., Sala, J.M., Seva, A., 1979. El Mini Examen Cognoscitivo. Un test sencillo y práctico para detectar alteraciones intelectuales en pacientes médicos. *Acta Luso Esp. Neurol. Psiquiatr.* 7, 189-202 (in Spanish).
- Lowenthal, M.F., 1964. *Live in Distress*. Basic books, New York.
- Maddox, M.K., Burns, T., 1997. Positive approaches to dementia care in the home. *Geriatrics* 52, S54-S58.
- Millán, J.c., Gandoy, M., Cambeiro, J., Antelo, M., Mayán, J.M., 1998. Perfil del cuidador de enfermo de Alzheimer en la Comunidad Autónoma Gallega. *Geriatrics* 14, 33-37 (in Spanish).
- Mittelman, M.S., Ferris, S.H., Steinberg, G.S., Shulman, E., Mackell, J.A., Cohen, J., 1995. A comprehensive support program: effect on depression in spouse-caregivers of AD patients. *Gerontologist* 35, 792-802.

- Mittelman, M.S., Ferris, S.H., Shulman, E., Steinberg, G.S., Levin, B., 1996. A family intervention to delay nursing home placement of patients with Alzheimer disease. *J. Am. Med. Assoc.* 276, 1725-1731.
- Mortimer, J.P., 1981. *The Epidemiology of Dementia. Monographs in Epidemiology and Biostatistics.* Oxford University Press, New York.
- Pérez, J., Jiménez, c., Paz, A., 1993. Familiares de pacientes con demencia: un paciente más. *Rev. Esp. Ger. Geront.* 28, 183-188 (in Spanish).
- Ravins, P.Y., Mace, N.L., Lucas, M.J., 1982. The impact of dementia on the family. *J. Am. Med. Assoc.* 248, 333-335.
- Saad, K., Hartman, J., Ballard, c., Kurian, M., Graham, c., Wilcocck, G., 1995. Coping by the carers of dementia sufferers. *Age Ageing* 24, 495-498.
- Spielberger, C.D., Gorsuch, R.L., Lushene, R., 1970. *Manual for the State-Trait Anxiety Inventory (Self-Evaluation Questionnaire).* Consulting Psychologists Press, Palo Alto California.
- Teri, L., 1997. Behaviour and caregiver burden: behavioural problems in patients with Alzheimer disease and its association with caregivers distress. *Alzeimer Dis. Assoc. Disord.* 11, S35-S38.
- Winslow, B.W., 1997. Effects of formal supports on stress outcomes in family caregivers of Alzheimer's patients. *Res. Nurs. Health* 20, 27-37.
- Zarit, S.H., Reever, K.E., Bach, Peterson, J., 1980. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 20, 649-655.

