

Profile and Burden of Care in Caregivers of Patients With Dementia Included in the ALOIS Program

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Aim. To study the profile and burden of care in carers of patients with dementia who participated in the ALOIS program. A second objective was to evaluate caregiver satisfaction with the intervention, and changes in caregiver burden after participation in the program.

Design. Descriptive study of a specific intervention with no control group.

Setting. Primary care centers.

Participants. Principal caregivers of patients with dementia.

Interventions. Group education sessions led by multidisciplinary teams comprising physicians, nurses and social workers.

Measures. Caregiver profile; mean caregiver burden before and 3 months after the intervention (Caregiver Burden Interview, Zarit); caregivers' evaluation of the program.

Results. Participants N=245. Profile (N=173): women (83%), mean age 54.6 years (range, 26-83 years), married (82.5%), no formal education or primary school only (70.2%), housewife (54.3%), patient's daughter (58.5%). More than 60% of the caregivers received informal help, and fewer than 5% received formal help. 72.5% of the caregivers were considered overburdened at the start of the intervention, and the burden was greater in older caregivers. No differences were detected in caregiver relation to the patient, marital status or employment status of the caregiver. Participants rated the program very highly, emphasizing the opportunity to share their experiences with other caregivers and to obtain knowledge and skills that helped them provide better care. Pre- and postintervention burden of care was compared in 68 participants (54.76±15.16 points vs 53.02±12.55), and no statistically significant difference was found.

Conclusions. The burden of care was high among caregivers, and increased as caregivers aged. Caregivers considered participation in the program to be highly useful. Care for caregivers should form part of care provided for patients with dementia.

Key words: Caregiver. Dementia. Health education.

PERFIL Y SOBRECARGA DE LOS CUIDADORES DE PACIENTES CON DEMENCIA INCLUIDOS EN EL PROGRAMA ALOIS

Objetivo. Estudiar el perfil y la sobrecarga de los cuidadores de pacientes con demencia incluidos en el programa ALOIS. Como objetivo secundario se pretendía valorar la satisfacción de los cuidadores con la intervención y la evolución de la sobrecarga tras el desarrollo del programa.

Diseño. Estudio descriptivo. Estudio de intervención no controlado.

Emplazamiento. Atención primaria.

Participantes. Cuidadores principales de pacientes con demencia.

Intervenciones. Sesiones educativas grupales impartidas por equipos multidisciplinares integrados por médicos, enfermeras y trabajadores sociales.

Mediciones. Perfil del cuidador; medida de la «carga» del cuidador antes y 3 meses después de la intervención (Escala de Sobrecarga del Cuidador de Zarit); evaluación del programa por los cuidadores.

Resultados. Participaron en el estudio 245 sujetos. El perfil (n = 173) se correspondía con el de una mujer (83%) de 54,6 años (rango, 26-83 años), casada (82,5%), sin estudios o con estudios primarios (70,2%), ama de casa (54,3%) e hija del paciente (58,5%). Más del 60% recibía ayuda informal y menos del 5% recibía ayuda formal. El 72,5% presentaba sobrecarga al inicio de la intervención, la cual era más elevada cuanto mayor era la edad del cuidador. No se detectaron diferencias en relación con el parentesco, el estado civil o la actividad laboral del cuidador. Los participantes valoraron muy positivamente el programa y destacaron la posibilidad de compartir experiencias con otros cuidadores, así como el aprendizaje de conocimientos y habilidades para mejorar los cuidados. En 68 cuidadores se comparó la carga antes (54,76 ± 15,16 puntos) y después de la intervención (53,02 ± 12,55), sin que la diferencia fuera estadísticamente significativa.

Conclusiones. Existe una elevada sobrecarga entre los cuidadores que es mayor a medida que aumenta la edad. Los cuidadores valoraron muy positivamente su participación en el programa. La asistencia al cuidador debería integrarse en la atención al paciente.

Palabras clave: Cuidador. Demencia. Educación para la salud.

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A commentary follow this article (pág. 67)

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The design of the ALOIS program, results of the pilot study, and partial results of the educational intervention were presented at the IX Congress of the SMMFYC in Madrid in 1999, the II National Alzheimer Conference in Bilbao in 1999, and the III National Alzheimer Conference-18th International Conference of Alzheimer's Disease in Barcelona in 2002.

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Introduction

Family support is the main predictor of whether older persons remain in the community and whether admission to a permanent care facility or other center is delayed or avoided. Studies of patients with dementia have shown that caregiver characteristics (relation to the patient, age, employment status, persons in the household, symptoms of anxiety or depression, and quality of life) are much more accurate predictors of severity or symptoms of dementia.^{1,2}

Many studies have documented the negative repercussions of caregiving on health. Although all such studies note that the most important consequences are psychological (particularly, an increased frequency of anxiety and depression³⁻⁵), other effects are the substantial repercussions on physical health,⁶ a considerable increase in social isolation,^{3,7} and a worsening economic status.⁷ In addition, caregivers do not appear to seek medical help often, and most of their problems go undiagnosed.⁴

Attempts to measure the impact of caregiving have used nonspecific instruments that analyze quality of life or the presence of psychopathological symptoms such as anxiety or depression. Attempts to create instruments to measure the impact of caregiving more directly have led to the use of the term "burden." The burden of care depends on the repercussions of caregiving, the coping strategies used, and the support available. A number of scales have been developed to measure this burden objectively. Among them, the best known are the Screen for Caregiver Burden⁸ and the Caregiver Burden Interview.⁹ Their usefulness lies in their ability to identify persons at greater risk or with greater needs, and to serve as a predictor of institutionalization. Although quality of life and burden of care are clearly related, burden of care is a better predictor of institutionalization.¹⁰

Many types of intervention have been described for caregivers of patients with dementia, with the aim of improving patient care and the caregiver's self-care.¹¹ Some studies have shown these interventions to be effective.¹²⁻¹⁵ Measurements of effectiveness in these studies were based on the delay in institutionalization,¹³ decreased prevalence of anxiety or depression in caregivers^{14,15} and reduced burden of care.¹⁵ However, a recent meta-analysis,¹⁶ while noting the beneficial effects of psychosocial interventions, failed to find specific benefits in terms of burden of care. Another review of these interventions concluded that no recommendations could be established in view of the lack of adequate studies.¹⁷

The ALOIS program is an educational program aimed at principal caregivers of patients with dementia. The intervention is based on group health education led by primary care professionals at health centers. The program

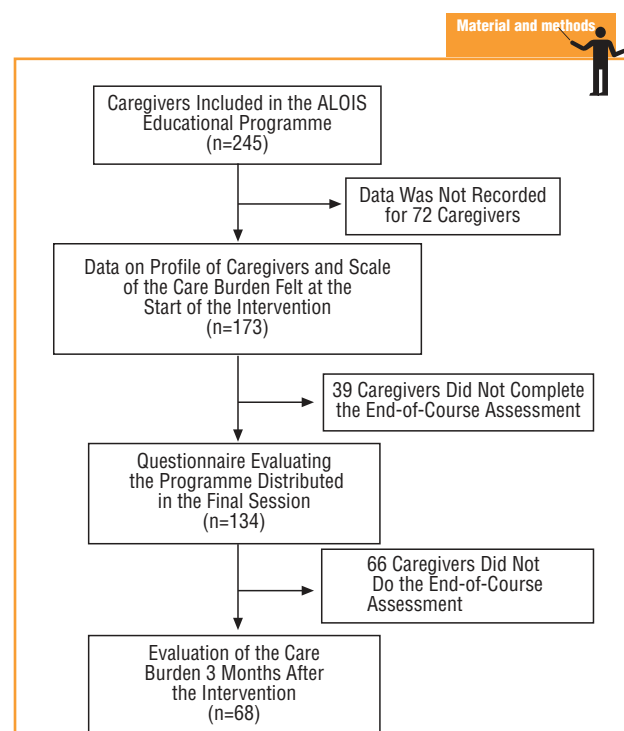
intends to provide caregivers with knowledge about dementia, and to give them an opportunity to exchange ideas among themselves, and to learn different skills for caregiving and self-care.

Our aim in the present study was to evaluate the profile and burden of care in caregivers who participated in the ALOIS program. We also attempted to evaluate the usefulness of the program from a subjective (caregivers' perceived usefulness) and an objective point of view (possible influence on burden of care).

Material and Methods

The program was begun in 1998 in a Health Area in the Community of Madrid (central Spain). A total of 24 primary care professionals were invited to take part. A 20-hour workshop was held to train the trainers, and six teams were then created. Each team consisted of at least one physician, a nurse and a social worker.

The educational program took place in 8 weekly sessions of 2 hours each. The key points to be communicated in each session were selected in advance to ensure similarity across sessions led by different teams.



General Scheme of the Study

Descriptive study of an uncontrolled intervention to investigate the profile and burden of care in caregivers of patients with dementia enrolled in the ALOIS program.

Caregivers were recruited by members of the ALOIS program teams and by other staff members at participating primary care centers, who were informed about the program and asked to recruit caregivers from their own patient list. Caregivers of patients with any type of dementia were allowed to participate. In general, only the main care provider for any given patient took part. The instruments we used to evaluate the results of the program were caretaker's profile, Zarit's Caregiver Burden Interview, and a specially-designed questionnaire developed for participants to evaluate the program.

Results

Between 1998 and 2000 we included in the program 227 principal caregivers, distributed in 16 groups of 8 to 20 participants each. Data were available for 12 groups (in 3 groups no evaluation tests were used, and in 1 group the results were lost).

Data for the caretaker profile and Caretaker Burden Interview were obtained at the start of the program for 173 caregivers. The most common characteristics were female sex (83.9%), mean age 54.6 years (range, 26-83 years), married (82.5%), no formal education or primary school education only (70.2%), housewife (54.3%), and patient's daughter (58.5%). Table 1 shows the distribution of the participants according to educational level, employment status, and relation to the patient. About one-fourth (24%) of the caregivers did not live in the same household as the patient, although they were considered the main care provider. The informal help received with care (mostly from other relatives of the patient) was considered substantial by 60.3% of the caregivers, and 4.7% received formal help from a public institution. The data for the patients' functional status are shown in Figure 1.

At the start of the program, the burden perceived by the caregiver and scored with the Caregiver Burden Interview was 57.6 ± 15.48 ($n=173$). Tables 2 and 3 show the percentages of respondents who scored highly on each item, and the distribution of the levels of burden of care.

About three-fourths (78.9%) of the caregivers who did not feel burdened according to the Caregiver Burden Interview were younger than 55 years, in comparison to 5.8% between 55 and 65 years, and 15.8% more than 65 years old. The differences were statistically significant at $P < .05$. No differences were found for relation to the patient, marital status or employment status of the main caregiver.

The evaluation questionnaires distributed at the final session of the program were completed by 134 caregivers, who considered the program to be valuable (mean overall score of 4.63 points out of a possible 5). Figure 2 summarizes the responses to the question "What was the best thing about the course?" According to participants, the aims that were achieved most effectively were contact with other persons with similar problems, and obtaining new knowledge and skills to improve the quality of care. Al-

TABLE 1 Caregiver Profile: Sociofamilial Characteristics

Educational level	
Primary school	48.6%
Technical school	20.3%
Secondary school	6.8%
University level	2.7%
No or incomplete formal education	21.6%
Employment status	
Housewife	54.3%
Employed	31%
Retired	12%
Seeking employment	2.6%
Relation to the patient	
Son/Daughter	58.5%
Spouse	19.6%
Son-/Daughter-in-law	12.7%
Sibling	2.8%
Grandchild	0.7%
Other	5.7%

most all caregivers (96%) were glad they had taken part in the program.

The effectiveness of the program in reducing the burden of care in the middle term could be studied for only 68 caregivers who completed the Caregiver Burden Interview before the intervention and again 3 months after the program. Mean score at the start of the program was

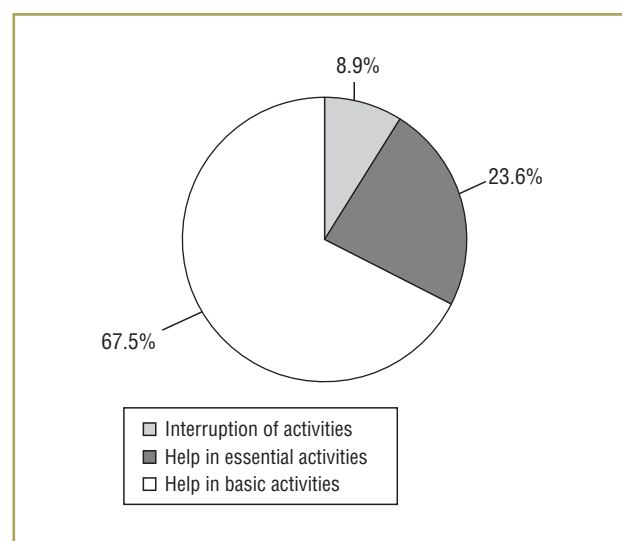


FIGURE 1 Patient's functional status (degree of dependence) according to information provided by the caregiver.

TABLE 2
Results of the Zarit Caregiver Burden Interview

Question	% of Caregivers Who Scored ≥ 3
1. Do you feel that your relative asks for more help than he/she needs?	48.9%
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	70.4%
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	67.6%
4. Do you feel embarrassed over your relative's behavior?	19.5%
5. Do you feel angry when you are around your relative?	38.1%
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	38.1%
7. Are you afraid of what the future holds for your relative?	67.6%
8. Do you feel your relative is dependent upon you?	84.1%
9. Do you feel strained when you are around your relative?	46.6%
10. Do you feel your health has suffered because of your involvement with your relative?	51.7%
11. Do you feel that you don't have as much privacy as you would like because of your relative?	45.4%
12. Do you feel that your social life has suffered because you are caring for your relative?	61.4%
13. Do you feel uncomfortable about having friends over because you are caring for your relative?	27.8%
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	66%
15. Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?	36.9%
16. Do you feel that you will be unable to take care of your relative much longer?	38.6%
17. Do you feel you have lost control of your life since your relative's illness?	39.8%
18. Do you wish you could just leave the care of your relative to someone else?	48.9%
19. Do you feel uncertain about what to do about your relative?	40.3%
20. Do you feel you should be doing more for your relative?	36.4%
21. Do you feel you could do a better job in caring for your relative?	32.9%
22. Overall, do you feel burdened caring for your relative?	67.1%

Possible responses: 0, never; 1, rarely; 2, sometimes; 3, quite frequently; 4, nearly always.

54.76 $\pm$ 15.16, and mean score after the program was 53.02 $\pm$ 12.55; this difference was not statistically significant. According to levels of burden of care, the percentage of caregivers with a heavy burden decreased from 37% at the start of the study to 34.8%, but the proportion of caregivers with a slight burden increased somewhat from 18.8% to 28.3%. The most significant difference, when we compared this subgroup of 68 caregivers with the whole sample of participants in the program, was found in the lo-

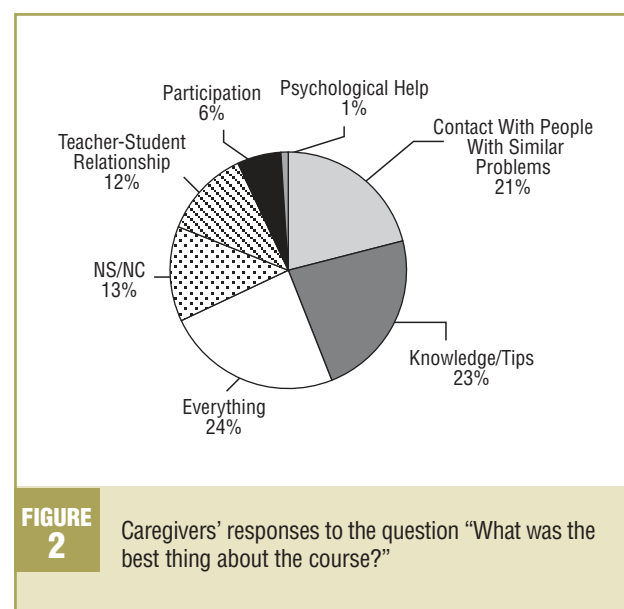
TABLE 3
Results on the Caregiver Burden Interview at the Start of the ALOIS Program

Burden of Care (Cut-Off Points 46-47/55-56)	
No burden	27.7%
Slight burden	16.8%
Heavy burden	55.5%

wer degree of dependence of patients (49.2% needed help with basic activities, versus 65.8% for the whole sample). All health care professionals who participated in the intervention teams were satisfied with the group education experience, according to the results of the evaluation by these participants. The most frequent problems identified were in training the trainers and in managing groups of caregivers whose patients were in widely different stages of dementia. Problems related with training were identified in recruiting caregivers, generally because of suboptimal cooperation by other staff members at the health center, and in finding a convenient place to meet when caregivers were assigned to different health centers. Intervention groups set up in rural areas were particularly problematic in this respect.

Discussion

The ALOIS program was created initially to provide caregivers with an opportunity for training and to exchange ideas on the care of patient with dementia. A second aim was to support primary care professionals in the development of group education programs aimed at carers of persons with dementia. The objectives of the program were

**FIGURE 2**

Caregivers' responses to the question "What was the best thing about the course?"

therefore less aimed at evaluating the effectiveness of this type of intervention, and more oriented toward the wider dissemination of such programs to provide professionals and caregivers with a reference instrument for similar activities. The considerable amounts of data from the evaluation that were lost reflected the less than optimal supervision of different teaching teams.

Another important limitation of the study is the heterogeneity among the caregivers we recruited, and who looked after patients with different types of dementia in widely differing stages. These factors made the training groups' work difficult at times, and made certain biases more likely. In addition, our study evaluated the burden of care only at the beginning and 3 months after the end of the program. We have no data on the subsequent course of the burden on caregivers, the demand for social services, or the appearance of specific disorders such as anxiety or depression.

The caregiver profile we obtained is very similar to that of other Spanish studies of caregivers of patients with dementia,¹⁸ neurodegenerative disease,⁷ or patients with different types of dependence.^{5,6} Evidently, this profile is slowly disappearing in Spain, and the enormous volume of work it represents does not seem to be absorbed by the currently inadequate social services system. This reinforces the need for interventions designed to facilitate the work of caregivers of patients with dementia.

It is noteworthy that more than 20% of the caregivers who described themselves as the principal carer did not live in the same household as the patient. In general, it is the daughters of patients who must look after their relatives, including one or both parents who live in a separate household. However, the burden of care was no greater in this subgroup of caregivers than in other relatives.

More than 60% of the caregivers received substantial help from other family members, but fewer than 5% received any type of institutional help. The EURO CARE¹⁹ study, which analyzed factors associated with the burden of care in different countries of the European Union, noted that the low level of formal help in Spain was one of the greatest sources of stress for caregivers of patients with dementia. In contrast, the high degree of informal help (compared to other countries) was a protective factor. Some studies of interventions for caregivers also considered the most appropriate social resources for each patient. It seems clear that in Spain, such individualized counseling might improve the results of these programs. It is true that social resources are scarce; however, what is no less true is that patients and caregivers are not referred as often as is desirable to available social resources.

Although studies of the burden of care are relatively common in the international literature, the Caregiver Burden Interview was validated in Spain only recently, by Martín Carrasco et al.⁹ The findings in the present study showed the burden to be heavier in our patients than in the afore-

Discussion
Key points



What is Known About the Subject

- Caregiver characteristics are the best predictors of institutionalization of patients with dementia.
- The impact of patient care on the caregiver affects all elements of health care. Instruments designed to measure the burden of care attempt to measure this impact objectively.
- Studies of psychosocial interventions for caregivers of patients with dementia have reported significant benefits. The most appropriate interventions for each caregiver should be identified, as should the most suitable evaluation instruments.

What This Study Contributes

- The ALOIS program is a structured group education experience for caregivers of patients with dementia followed in primary care.
- The profile of an "average" caregiver in our setting was that of a 55-year-old married woman with formal education (if any) only to the primary school level, not employed outside the home, and who was the patient's daughter. Fewer than 5% of the caregivers received formal help from public institutions.
- Most caregivers who participated in the program had a heavy burden of care that suggested some (probably underdiagnosed) disorder.
- The burden of care was greater in older caregivers. Although the program was considered valuable by caregivers and professionals who took part, we were not able to demonstrate a significant reduction in the burden of care in caregivers after the intervention.

mentioned validation study. The study population used in Pamplona included caregivers of older patients with different psychiatric disorders, whereas our study population was more homogeneous, consisting mainly of caregivers of patients with dementia. When we compared the results for specific items, we found a much higher incidence in our caregivers of problems related to insufficient time, deterioration of social relationships, and stress produced by caregiving. Several studies have shown greater burdens of care in caregivers of patients with dementia as compared to caregivers of patients with other problems.^{20,21} Similarly, the total score and percentage value for burden of care were higher than in the EURO CARE study,¹⁹ both in general and for the subgroup of Spanish caregivers. This may be

related with the fact that the caregivers recruited for our study were responsible for patients with recently diagnosed dementia, a factor that generally involves a lower burden of care.

In the present study we found differences between caregivers only in connection with age: the older the caregiver, the greater the burden of care. This difference was not found in other studies,^{22,23} although one study did find differences between men and women (with greater burdens being reported for the latter).²³ In the present study the number of male caregivers was too small to detect differences between the sexes, if any differences exist. The EURO CARE study¹⁹ found the opposite association, i.e., a greater burden of care in younger caregivers. However, this study included only the patient's spouse as caregiver, and in this subgroup the nature of the association may be different.

We found no differences between the results of the Caregiver Burden Interview at the beginning and the end of the program. However, a curious finding was that the subgroup of caregivers who completed both interviews had a lower initial burden of care, and the patients they cared for were in lower stages of dependence than the group as a whole. This may have skewed the results, as the caregivers who were likely to benefit most from this type of intervention may have been those with the greatest burdens of care. Even caregivers with a lighter burden of care responsible for patients in the initial stages of illness may suffer from increased anxiety because of contact with caregivers subjected to greater burdens, who describe problems that are more complex and which less experienced caregivers have not yet faced. This hypothesis is supported by the finding that in the subgroup who responded to both the preintervention and the postintervention interview, the percentage of caregivers with a heavy burden of care decreased, while the percentage of caregivers with a slight burden increased.

Although some studies have reported significant reductions in the burden of care after individual^{13,14} and group psychological and educational interventions,^{15,24-26} Brodaty et al,¹⁶ in their recent meta-analysis, found no benefits in terms of burden of care. The problem with judging these findings lies in the variety of methods used in different studies, which involved different tests of the burden of care, different observation periods, and naturally different types of interventions. Some authors have proposed quality of life scales^{27,28} as the most sensitive instruments for measuring changes caregivers experience after this type of intervention. Future studies under the ALOIS program will use the SF-36 questionnaire as one of the evaluation instruments.

Despite the limitations noted above, the group education experience was judged useful by both caregivers and health professionals. The large number of caregivers and professionals currently involved in the program is a clear sign of

the interest in this problem. The high levels of burden of care we detected should raise our awareness of the need to find more appropriate types of support for caregivers. The support they receive has direct repercussions on their own health as well as on the health of the persons they care for, and probably also on the health care system in Spain. Defining the best strategies for each type of patient and caregiver is a complex task. We believe our program will allow us to determine whether caregivers responsible for patients with more advanced stages of dementia are more likely to benefit from this type of intervention, as some authors have suggested.²⁹

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COMMENTARY

How Effective Are Support Interventions for Caregivers of Patients With Dementia?

J. Argimón Pallas

A number of studies have described the problems of caregivers of persons with dementia. Among these problems are loss of support from a life partner, social isolation, and difficulties in making complicated financial, legal and social decisions. The burden of care is considerable in economic, emotional and physical terms, and translates in many cases as increased physical and psychological morbidity.¹

In the interesting study by Alonso Babarro et al, no significant reductions were found in the burden of care in caregivers who participated in the ALOIS program. These results are consistent with the findings of two recent systematic reviews that found no conclusive evidence to sup-

port the use of interventions based on technologies such as the telephone or personal computer, caretaker education or training, or highly specialized multidimensional strategies for training caregivers.^{2,3}

Should these results be interpreted to mean that the interventions we might use for caregivers of patients with dementia have no effect? Although the reviews suggest this interpretation, the questionable methodological quality of the clinical trials carried out to date makes it impossible to state categorically that support interventions for caregivers of patients with Alzheimer's disease and other dementias are not effective. Most studies included small numbers of patients, did not ensure that the groups were comparable

Key Points

- Systematic reviews of clinical trials that evaluated support interventions for caregivers of patients with dementia have provided no conclusive results that support the effectiveness of these interventions.
- The results of many of these clinical trials should be interpreted with caution given their poor methodological quality.
- Studies with longer follow-up periods and that include greater numbers of patient-caregiver pairs would make it possible to determine whether interventions aimed at supporting caregivers are effective.

for all co-interventions, and recorded different outcome variables. On the other hand, some well-designed studies⁴⁻⁶ obtained favorable results for caregivers.

Studies now under way or whose results are now being analyzed may be of great help in clarifying the effectiveness of interventions aimed at caregivers of patients with dementia. Notable among these studies is the REACH project (Resources for Enhancing Alzheimer's Caregiver Health), a multicenter trial that will evaluate different psychosocial interventions and their impact on health and well-being in 1222 caregivers residing in six cities in the USA.⁷

Patients with Alzheimer's disease have a mean live expectancy of 7 to 10 years from the time of diagnosis. Given that the care needs change in persons with a disease of this nature, future research should attempt to evaluate the impact of the disease on the caregiver in the long term, even after the patient has died. In this connection one recent article observed that more than 40% of the caregivers had clinical symptoms of depression during the final months of the patient's life, and 30% had questionnaire scores that were suggestive of risk of depression one year after the patient had died.⁸ These figures are higher than those found for caregivers of patients with other terminal illnesses. A multitude of factors may account for this, but the main factors are that the caregivers face a long-term illness, and that the illness is associated with behavioral

disorders which, in the final stages of the disease, create a high degree of dependence in the patient.

Future clinical trials should examine interventions that have been evaluated and published previously, and should incorporate outcome variables that are common to other studies and which are easy to interpret by all interested parties, especially caregivers themselves.⁹ Caregivers occupy a very important place in a community's health and social policies,¹⁰ and future research should concentrate on identifying those interventions able to prevent or minimize deterioration in mental health and loss of quality of life in caregivers.

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