

An Approach to Home Care. How Does the Catalanian Public Health System Handle Home Care?

ATDOM (Home Care) Group, Catalanian Society of Family and Community Medicine^a

Objective. To describe the organizational model, resources and implementation of the home care program run by the Catalanian public health service, and to note difficulties reported by primary care professionals.

Design. Cross-sectional, descriptive study.

Setting. Autonomous Community of Catalonia.

Participants. 214 primary care centers (PCCs) operating under reformed administrative procedures were surveyed, and responses were obtained from 112 (52.3%).

Main measures. Semistructured, self-administered questionnaire sent by mail, with variables that identified the center, resources, organization and use of protocols for home care. Questionnaires were collected during July to November, 2000.

Results. Home care programs were being used at 90.2% (95% CI, 84.7%-95.7%) of the centers, and had been in effect for a mean of 5.6 years. Nursing services predominated in 64% of the case, with nurses spending a mean of 5.09 h/week on the program, twice as much time as physicians and social workers. The mean rate of computerization of the data was 31.3%, and was highest ($P<.05$) in Girona (51%) and in PCCs run privately (70%). Of all participating PCCs, 70% had social workers on the staff, 13% had a home care nurse and 50% operated in coordination with social services.

Of all PCCs, 79.5% (95% CI, 72.1%-86.9%) used specific protocols for pressure sores (69.1%), terminal illnesses (43.6%), bedridden patients (41.8%) and pain management (40.9%). Evaluations were done with the Barthel scale (73.2%), the Mini-Mental State Examination (73.2%) and the Norton scale (53.6%). Continuing education (66%) and activities for care providers (>75%) were frequent in home care programs. The main difficulties identified were the burden of care (65.2%), time constraints (51.8%), inadequate social support (43.8%) and lack of coordination with other levels of care (33%).

Conclusions. Noteworthy findings were the dedication of nursing staff to the home care programs, the low level of computerization of the data, the limitations in social service resources, the uniformity of assessment protocols and scales, and the agreement regarding current difficulties.

Key words: Home care. Health programs. Primary care.

APROXIMACIÓN A LA ATENCIÓN DOMICILIARIA. ¿CÓMO TRABAJA LA SANIDAD PÚBLICA CATALANA LA ATENCIÓN DOMICILIARIA?

Objetivo. Conocer el modelo de organización, recursos e implementación del programa de atención domiciliaria (ATDOM) en la sanidad pública catalana, y las dificultades expresadas por los profesionales de atención primaria.

Diseño. Estudio descriptivo transversal.

Emplazamiento. Comunidad Autónoma de Cataluña.

Participantes. Un total de 214 centros de atención primaria (CAP) reformados, de los que respondieron al cuestionario 112 (52,3%).

Mediciones principales. Cuestionario semiestructurado y autoadministrado enviado por correo, con variables para la identificación del centro, sus recursos, organización y protocolización de la ATDOM. La recogida de respuestas se efectuó entre julio y noviembre de 2000.

Resultados. La utilización del programa ATDOM fue del 90,2% (IC del 95%, 84,7-95,7%), con 5,6 años de aplicación media. La enfermería lidera el programa en el 64% de los casos, dedicando 5,09 h/semana, el doble que los médicos y los trabajadores sociales. La informatización de datos es un 31,3%, más elevada ($p < 0,05$) en Girona (51%) y en los CAP de gestión privada (70%). El 70% de los CAP posee un trabajador social, el 13% dispone de una enfermera de soporte y el 50% está coordinado con centros sociosanitarios. El 79,5% (IC del 95%, 72,1-86,9%) de los CAP utiliza protocolos específicos: úlceras (69,1%), terminales (43,6%), encamados (41,8%) y dolor (40,9%). La valoración se realiza con las escalas de Barthel (73,2%), Mini-Examen-Cognoscitivo (73,2%) y Norton (53,6%). Son frecuentes la formación continuada en ATDOM (66%) y las actividades para cuidadores (> 75%). Las principales dificultades son la presión asistencial (65,2%), el tiempo (51,8%), los recursos sociales insuficientes (43,8%) y la falta de coordinación con otros niveles asistenciales (33%).

Conclusiones. Se destacan el compromiso de la enfermería en ATDOM, la escasa informatización y la limitación de los recursos sociosanitarios, la uniformidad de los protocolos y escalas de valoración, y la coincidencia respecto a las dificultades actuales.

Palabras clave: Atención domiciliaria. Programa de salud. Atención primaria.

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Introduction

The growing importance of home care, as a result of the steady aging of the population along with improvements in the diagnosis and treatment of chronic diseases,^{1,2} is leading to ever-greater human and material resources being devoted to covering the demand. It is important to estimate the burden of care this type of service can involve for primary health care teams (PCTs) both in terms of the patients' individual characteristics^{3,4} and in terms of population-based prediction models.⁵

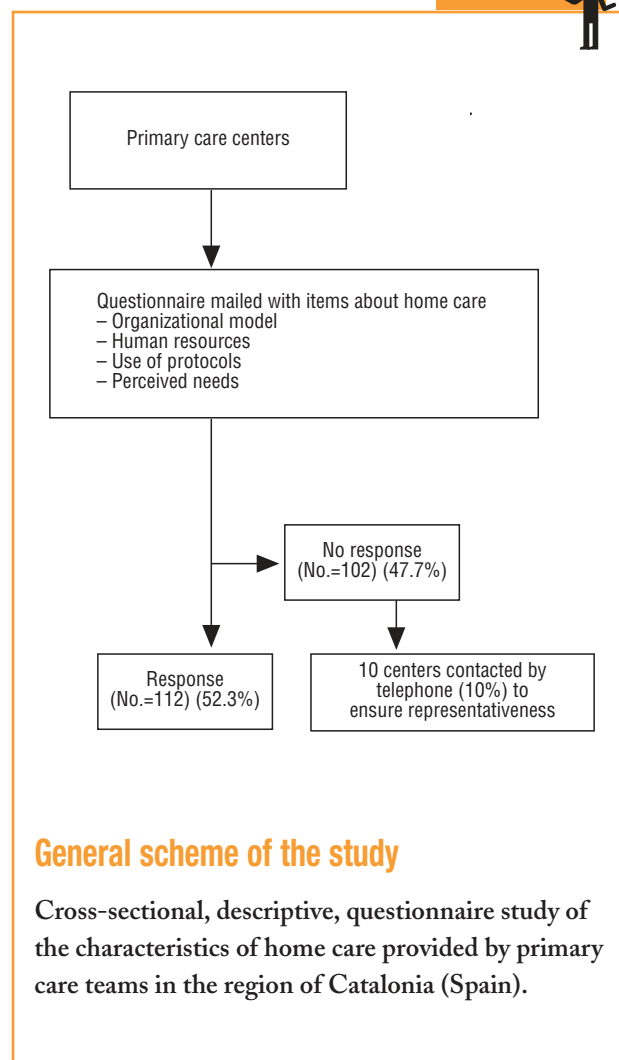
Since the recent reforms in the Spanish public health system came into effect, home care has become the responsibility of PCTs. Although other professionals have joined the support staff in some autonomous communities (as in the PADES teams, which provide home care in the region of Catalonia), most home care continues to be provided by primary care professionals.

One of the difficulties in home care is in the definition of the term itself, which is not based – as is usual among physicians – on a specific disease, but arises instead from biopsychosocial circumstances, i.e., the patient's inability to leave the home. This may be the reason why home care varies depending on the disease, social circumstances or emotional state of both the patient and the care provider.

Many studies have been done in the last 10 years to evaluate home care programs or specific protocols (for patients with dementia or pressure sores, or care for the care provider); however, fewer studies have looked at the degree of implementation of programs, the most widely used types of assessment instrument, or the difficulties professionals encounter with home care.

To characterize the current situation, the Home Care Group (ATDOM, in Spanish) of the Catalanian Society of Family and Community Medicine undertook a study aimed at updating the results of an earlier survey carried out in Catalonia in 1991, and published by Lacasa et al in 1993.⁶ The aim of the present study was to determine the degree of implementation of a home care program by different PCTs in Catalonia, in terms of the organizational model, involvement of different professionals, use of protocols for specific problems, assessment instruments, and internal and external resources. A secondary aim was to note the obstacles different professionals identified to appropriate implementation of the program. Surveys such as that reported here can help elucidate the current status of home care programs in our setting, and can provide data for different provinces, population densities and PCT characteristics.

Material and methods



Material and methods

The ATDOM Group of the Catalanian Society of Family and Community Medicine (SCMFiC, in Spanish) designed a cross-sectional, descriptive study to obtain information on the organizational model, resources and implementation of home care programs in primary care provided through the Catalanian public health service in 1999.

A semistructured, self-administered questionnaire was prepared and approved by the Communications Group of the SCMFiC. The questionnaire contained items on the center, human resources, organizational model of the program (time, responsibilities of different professionals, continuing education in home care, number of patients covered), variables related to the degree of standardization of home care (types of protocols for specific problems, instruments used to measure autonomy, cognitive status, and pressure sores), and needs perceived by health professionals for the appropriate implementation of the home care program. The questionnaire was mailed to 214 reformed primary care centers (PCCs) operating in Catalonia, which were identified from

a list maintained by the SCMFic. The questionnaire was accompanied by a cover letter that explained the aims of the study and gave basic instructions to enable the head of the home care program or the director of the PCC to complete the survey correctly. Completed questionnaires were to be returned by mail to the SCMFic offices. The results of the survey were collected during July to November, 2000. Of the 214 PCCs that received the questionnaire, replies were received from 112 (52.3%). It is important to note here that items on the questionnaire referred to the home care program that was in operation in the year 1999. The data were imported into a database and analyzed with version 9.0 of the SPSS. Chi-squared tests were used for qualitative variables. Student's *t* test and analysis of variance with Scheffe's test for comparison of the means were also used. For most cases the significance level was set at $\alpha=0.05$. To ensure that the sample was representative, 10% of the PCCs that did not return the questionnaire were contacted by telephone to obtain their responses; no significant differences in the responses were found between this group and the group of centers that returned their questionnaire spontaneously.

Results

The response rate was 52.3%, distributed by province as follows: 71.8% Barcelona, 12.7% Gerona, 9.1% Lerida, and 6.4% Tarragona. In proportional terms the province with the highest response rate among PCCs was Gerona: 73.7%. Of all PCCs that responded, 66.4% were urban and 33.6% were rural. Three-fourths (75.9%) of the centers are administered by the Catalanian Institute of Health and 24.1% by other organisms. Non-teaching centers predominated the sample (69.7% vs 30.3% teaching centers). The average number of basic care units per center was 9, and centers had been operating for an average of 8.4 years.

Most centers (90.2%; 95% CI, 84.7%-95.7%) offered home care, and mean duration of the programs was 5.6 years. The staff members responsible for the program were nurses (53.3%), physicians (20%), both (11.1%), or other professionals (15.6%). Nursing staff members devoted twice as much time to the home care program per week (5.09 h) as did physicians (2.85 h) and social workers (2.65 h). Computerization of the data from the program was 31.3%; this figure was significantly higher in Gerona (51%; $P<.05$) and in privately-run PCCs (70%; $P<.05$).

Additional resources used for the program were also studied. A social worker was included in the team at 70% of the PCCs, and a home care nurse at 13%. More than 60% of the programs were assisted by a home care support team (PADES project). Home care was coordinated with social service centers at 50% of the PCCs, and with interdisciplinary health and social service centers (UFISS, in Spanish) at 32% of the PCCs.

Most centers (79.5%; 95% CI, 72.1%-86.9%) used specific protocols. The most frequently used protocols were those to evaluate the risk of pressure sores (69.1%), termi-

TABLE 1 Protocols used most often in home care

Protocols	PCTs using the protocol (%)
Pressure sores	69.1%
Terminal illness	43.6%
Bedridden	41.8%
Pain	40.9%
Constipation	38.2%
Feeding	30.9%
Home oxygen therapy	29.4%
Dementia	23.6%
Catheter	7.2%
Grieving	2.7%
Incontinence	2.7%
Partial paralysis	0.9%

TABLE 2 Main difficulties in home care

Difficulty reported	PCTs reporting the problem (%)
Burden of care	65.2%
Insufficient time	51.8%
Lack of social support	43.8%
Lack of coordination between levels of care	33.0%
Insufficient motivation	19.6%
Geographical dispersion	18.7%
Lack of human resources	16.1%
Structure of the PCT	11.6%

nally ill patients (43.6%), bedridden patients (41.8%) and pain (40.9%) (Table 1). Protocols were used more often ($P<.05$) by teaching centers (91.2%; 95% CI, 85.3%-97%). For the overall assessment of patients, the scales used most often were the Barthel index (73.2%) for the degree of autonomy based on daily life activities, the Mini-Mental State Examination (MMSE) for mental state (73.2%), and the Norton scale (53.6%) for the risk of pressure sores. Other scales of interest were used to assess degree of autonomy (Katz instrument, 17.9%; OARS instrument, 7.2%), mental state (Pfeiffer SPMSQ, 30.4%; Set-test, 10.7%, informant's tests, 3.6%), and to assess the risk of pressure sores (Braden scale, 21.4%; Arnell scale, 2.8%).

Continuing education in home care was provided at 66% of the centers, and more than 75% offered training for care providers on topics such as risks in the home (68.6%) and caring for the care provider (59.2%).

When primary care health professionals were questioned about the main difficulties (Table 2) they saw in running a

home care program at their center, 65.2% noted the burden of care, 51.8% noted insufficient time, 43.8% mentioned inadequate social support, and 33% cited lack of coordination with other levels of care.

Discussion

This study set out to analyze the current status of home care in Catalonia. Although the number of centers that responded was only slightly over 50%, we feel this response rate to be acceptable for a questionnaire of the characteristics described here. Moreover, representativeness of the study was verified by the lack of differences in responses between PCCs that responded spontaneously and centers that did not.

The home care program is a necessary instrument to allow PCTs to provide appropriate home care in an organized manner.^{7,8} Such care requires an awareness of all available resources,^{9,10} and periodic evaluations of the objectives defined previously during analysis of integral care for homebound patients.¹¹⁻¹⁶ In this connection we emphasize the considerable increase in the implementation of the home care program⁶: currently 90% of all centers surveyed use the program in the course of the center's normal daily activities, with nursing staff responsible for the program at more than half of the centers. Nursing staff currently devote more than twice as much time to the program as other professionals (physicians or social workers). In addition, programs such as the «Health at Home» (*Salut a casa*, in Catalan)¹⁷ project, recently piloted in the city of Barcelona, should serve to further extend the home care program by enhancing the role of nursing staff. Specific protocols were used at most centers (almost 80%), and were more widespread at teaching than at non-teaching centers. Computerization of the data, now at about 30%, clearly needs to improve, especially at publicly-administered centers. Our survey findings show that although joint programs for implementing home care programs do operate, coordination between different levels of care needs to improve.

Continuing education in home care is fundamental, and although more than half of the centers we surveyed provided such training (66%), we feel it should form part of periodic training activities at all PCCs. Most continuing education efforts are aimed at preventing risks in the home,^{18,19} and at providing adequate support for the care provider.²⁰ Earlier studies²¹⁻²³ have reported physical problems such as repetitive stress back pain and lower back pain, as well as psychiatric problems such as alterations in the Goldberg anxiety and depression scales,^{24,25} especially when the care provider is a relative.^{26,27} In addition, appropriate assessment²⁸⁻³¹ of autonomy and cognitive function is important in homebound patients, as age-related physical and mental impairments have been associated

Discussion
Key points



What is known about the subject

- The most recent previous study of home care in Catalonia was done in 1991.
- The implementation of home care programs has increased steadily since then.
- There was, therefore, a need to re-assess the current status of home care.

What this study contributes

- The current importance of home care was substantiated, although certain problems persist in planning quality home care.
- There was widespread consensus on the criteria for home care among professionals at centers operating with reformed administrative procedures.
- Other findings of note were the fundamental role of nursing staff in home care, and the inadequacy of current social support.

with greater psychiatric distress of the care provider.²⁶ Invalidity in a family member is a potential source of stress within the family;²⁷ the increased anxiety can increase the use of psychotropic drugs³² by both disabled patients and their care providers.³³

The results of our survey show that the instruments used most often in Catalonia for the integral assessment of patients are the Barthel index for degree of autonomy, the MMSE to measure cognitive function, and the Norton scale for the risk of pressure sores. To assess autonomy the Barthel test (more useful in patients undergoing rehabilitation) has become more widespread than the Katz instrument, which is also a good predictor³⁴ of the frequency of visits to the doctor and patient survival and institutionalization. Also noteworthy is the use, as a second choice, of brief tests such as the SPMSQ to measure cognitive function.

As noted earlier, we consider the number of centers that participated in the survey (slightly more than 50%) to be acceptable in a study of this nature. Although the response rate probably is not a limitation in the present study, we cannot rule out selection biases. To ensure that the sample was representative, we contacted 10% of the nonresponding PCCs by telephone to obtain their responses to the questionnaire, and found no differences in the results between responding and nonresponding centers. Because the questionnaire was self-administered, this obviated the

possibility of information bias caused by low interobserver reliability.

On a final note, we emphasize that the main obstacles professionals identified here were the well-known problems of heavy burden of care (which leaves less time for home care than would be desirable), insufficient social support, and inadequate coordination between levels of care. We hope that substantial changes will come about that will allow efficient progress³⁵ in overcoming the obstacles that primary health care professionals in Catalonia have identified so clearly.

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COMMENTARY

Reflections on the Reality of Home Care

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Home care is a long-term system of integral and integrated health care provided at the home of persons who, because of illness, cannot travel to the health center. The importance of home care is growing as a result of the increase in the homebound population in the community who need this type of service. Accordingly, the results of the study by the ATDOM (home care) Group of the Catalanian Society of Family and Community Medicine deserve some thought and a few comments.

Implementation of a home care program by more than 90% of all health centers should be considered a very good result, although it cannot be ruled out that the figure might have been lower if the response rate had been higher or if more non-teaching centers had responded. Initially, the results should be interpreted as reflecting a favorable attitude by primary care professionals toward home care, and as an indication that primary care personnel do not share the opinion of detractors of the involvement of the primary care system in home care.

The results of a detailed analysis of the use of specific protocols, however, seem at odds with the widespread availability of home care programs. The low use of protocols for pressure sores in bedridden patients is surprising, as is the low use of protocols for pain management and for terminally ill patients – precisely the circumstances that account for many of the patients served by home care programs. These percentages cannot be attributed to differences in the population served, as these specific problems should themselves be considered indicators of the need for home care. Management of these problems should be guided by protocol in most primary care centers, because of their frequency and their impact on the quality of life of patients and their families. A larger study aimed at describing the profile of patients seen in home care may shed light on these apparently contradictory findings.

The study also confirms the important role of community nurses in home care, both as program directors and as the professionals who devote the most time to these programs. However, it should be considered that without meaning to downplay the role of nurses, the time other professionals in the basic health unit devote to home care is usually not

Key points

- The demand for home care is growing because of the increase in the homebound population.
- Studies that have evaluated home care programs elucidate the actual status of home care and make pertinent assessments possible.
- To ensure quality home care, close internal collaboration is needed between health services, and external collaboration is needed with social services.
- The actual contribution of support teams should be evaluated in absolute terms of improvement over existing home care programs.

great (only 8% of their working day). This might make it difficult to organize home care activities, and could lead to situations in which responsibilities are neglected.¹ Data on coverage of the programs and middle-term results (patients whose disease is well controlled, social support resources)² would make it possible to analyze whether the (relatively small) amounts of time devoted to the program are the result of low commitment by professionals, or appropriate operation of the program, which with time should require less involvement by non-nursing staff at the family medicine unit.

The problems with home care that professionals identified were those usually reported as handicaps for such programs.¹ Time constraints make it necessary to choose priorities when responding to needs; logically, highest priority is given to dealing with the burden of care at the health center, to the detriment of home care efforts. However, there are no data that indicate an «actual situation of negligence in providing care» affecting patients in home care programs. A factor that needs to be considered here is whether deficiencies in these programs are the result of inadequacy in social as opposed to medical resources – a

situation that might, moreover, undermine health practitioners' motivation to cope continuously with situations that cannot be resolved by health care professionals alone. Further progress in enabling primary care efforts to provide an exclusively medical solution to all the needs of the homebound population is unlikely. Clearly, quality home care can be ensured only if there is close internal cooperation between different health services, and good external cooperation between health and social services.^{1,3}

The study also identifies problems, reported in one-third of all centers, with coordination between different levels of care. These difficulties were noted regardless of the involvement or absence of a support team. The presence of such teams at a large percentage of centers might explain why the lack of coordination between levels of care, although recorded in a non-negligible proportion of cases, was not identified as a problem in the majority of the centers. Despite many attempts, it has not been possible to establish a health care system that operates as a seamless whole, with no gaps in the links between different levels of care. It would be interesting to explore whether the availability of support teams helps to remedy this lack of continuity. If it does not, reflection will be needed on the possible benefits of the creation of a network of care operating in tandem with a primary care system that does not have the capacity

to resolve problems in ensuring collaboration between health care and social services.

It remains to be seen whether publication of the findings of this study will inspire health care managers to provide real support for home care programs as models of shared care involving different levels of health and social services. This would undoubtedly require better standardization of care programs and appropriate increases in primary health and social care resources. On the other hand, there is a danger that the findings reported by the ATDOM Group may have no effect, or may skew the interpretation of the results, thus prejudicing most primary care professionals in favor of investing resources in other models of care.

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