

# Homecare for patients with heart failure in Italy

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**Key words:**  
Heart failure;  
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**Background.** Heart failure (HF) represents an important health issue in western countries, especially for the elderly, frail population. A number of HF patients must usually be assisted at home. No information is available about the usual care of HF patients in Italy. The aim of this study was to describe the characteristics of HF patients receiving homecare in the Italian general practice.

**Methods.** A questionnaire was sent to 320 general practitioners (GPs) involved in the Health Search project. Among these, 148 (46.2%) answered and 376 home-ridden HF patients (60.3% women, median age 85 years) were identified.

**Results.** 257 (57%) patients were in NYHA class III or IV. Multiple relevant concomitant diseases occurred in 326 (86.7%) subjects. Only 140 (37.2%) patients were able to take their pills without any help; caregivers, mainly family members, were required 24 hours a day in 78.7% of cases. The length of homecare was > 1 year in 84.5% of cases.

**Conclusions.** According to our data, thousands of HF patients are usually assisted at home for long periods in Italy. This is a very old group of subjects with heavy co-morbidity and a high need for continuous, prolonged assistance. Studies specifically aimed at the care of HF patients are needed.

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## Background

Heart failure (HF) represents a major problem for all the western health services and the burden of assistance to the patients affected by this disease is increasing and will keep increasing in the future<sup>1</sup>. As far as Europe is concerned, the mean age of the HF population is 74 years<sup>2</sup> and the median age at presentation is 76 years<sup>3</sup>. Therefore, it is highly probable that frailty, concomitant diseases, physical and cognitive impairment, typical situations in the elderly, make access to medical services difficult or impossible for a high number of HF patients. Several studies about homecare are focused on the problem of hospitalization, hospital readmission and follow-up after discharge, usually managed by specialized nurses<sup>2</sup>. To our knowledge, few data are available about home-ridden patients. Furthermore, most studies were conducted in countries where the role of out-of-hospital nurses is well established and the organization of the health service substantially differs from Italy, where the general practitioners (GPs) mainly guarantee homecare, and the number of specialized and non-specialized nurses working outside the hospi-

tal is largely insufficient. The aim of this study was therefore to describe the main characteristics of the HF patients who are unable to leave home.

## Methods

Usual homecare was considered to be present if > 90% of cares outside the hospital was delivered at home. The diagnostic criteria reported by the European guidelines<sup>2</sup> were used to identify HF patients; no attempt was made to verify the GP's diagnosis.

A questionnaire was prepared with the purpose of collecting in an anonymous way the following information among an Italian GP's HF population: demographic data (age, gender) and clinical data (HF NYHA classification, concomitant diseases other than cardiac disease, pharmacological anamnesis, last cardiologic visit, length and kind of homecare).

In September 2003 we sent a simple questionnaire to 320 GPs who regularly forward data to the database of the Italian College of GPs (SIMG), selected according to a range of quality check. These physi-

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cians are a representative sample of the Italian GPs, and their data have already been used for research purposes<sup>4-6</sup>. Only 148 GPs answered (46.3%) and among these 27 reported no patients affected by HF who usually required homecare, whilst 121 sent questionnaires about 376 HF patients (on average 3.1 per GP, range 1-13). The demographic characteristics of the subjects assisted by these 148 GPs (205 451 patients, 47.5% males) were compared to those of the whole Italian population as reported by the Italian Institute of Statistics in order to check possible differences between age groups and geographical area (Table I).

Age-specific HF prevalence in the study sample was calculated by dividing detected cases with the total number of individuals in each age group.

**Results**

According to the questionnaire sent by the 148 GPs enrolled into the study, 376 HF patients unable to leave home were identified. Among these subjects, 127 (33.7%) were men, 227 (60.3%) women, and in 22 (6.0%) cases gender was not reported. The mean age was 83.8 years (range 59-101 years, median 85 years), being lower for men (81.8 years) than for women (84.8 years). HF prevalence in the population (Table II) registered by the participant GPs was 0.18% (confidence interval 0.16-0.20) and it raised to 0.62% when taking into account only the sample population > 60 years (confidence interval 0.55-0.68). According to the NYHA classification, 117 (31.1%) patients were in NYHA class II, 173 (46.0%) in NYHA class III, and 84 (22.3%) in NYHA class IV (2 missing values). Diuretics were used in 324 (86.2%) patients, digoxin in 217 (57.7%), angiotensin-converting enzyme inhibitors/angiotensin receptor blockers in 84 (22.3%), and beta-blockers in 17 (4.5%). Concomitant diseases other than HF, representing for these individuals an important obstacle to leave home, were reported in 326 patients, most of them having more than one co-morbidity (Table III). In particular, the most frequently reported pathologies were osteoarthritis (52.8%) and respiratory diseases (34.7%). General clinical conditions influenced HF patients autonomy in their daily medical care. In fact, only 140 (37.2%) patients were able to take their drugs without any help and 32 (8.5%) maintained autonomy with the use of a drug dispenser. Complete help was needed in 177 (47.1%) patients and partial help in 21 (5.6%) whilst this information was unknown to the GP in 6 (1.6%) cases. The majority of the patients' caregivers were family members or other relatives (75.8%), the remaining being represented by unskilled personnel. About homecare assistance we have collected the following data: a caregiver was present at home 24 hours a day in 78.7% of cases, 12 hours a day in 6.4%, and 4 hours a day in 3.7% of patients. In 40 (10.6%) patients the caregiver presence was reported as

**Table I.** Geographical distribution for the observed population.

Age group (years)	HS			ISTAT		
	North	Center	South and Islands	North	Center	South and Islands
< 10	1340 (1.3%)	189 (0.5%)	860 (1.4%)	2 157 950 (8.4%)	954 908 (8.6%)	2 365 593 (11.3%)
10-19	6529 (6.4%)	2417 (6.1%)	5925 (9.34%)	2 194 847 (8.5%)	1 026 180 (9.3%)	2 721 820 (13.0%)
20-29	12 252 (12.0%)	4938 (12.4%)	10 252 (16.2%)	3 474 565 (13.5%)	1 489 737 (13.4%)	3 195 971 (15.3%)
30-39	18 016 (17.6%)	6726 (16.9%)	11 782 (18.6%)	4 275 847 (16.6%)	1 785 946 (16.1%)	3 229 082 (15.5%)
40-49	16 456 (16.1%)	6426 (16.1%)	10 670 (16.8%)	3 545 909 (13.8%)	1 517 870 (13.7%)	2 710 770 (13.0%)
50-59	15 080 (14.8%)	5830 (14.6%)	8635 (13.6%)	3 453 347 (13.4%)	1 453 573 (13.1%)	2 340 659 (11.2%)
60-69	14 032 (13.7%)	5427 (13.6%)	6749 (10.6%)	3 122 040 (12.1%)	1 338 139 (12.1%)	2 086 021 (10.0%)
70-79	11 013 (10.8%)	4690 (11.8%)	5443 (8.6%)	2 365 602 (9.2%)	1 054 329 (9.5%)	1 559 325 (7.5%)
80-89	5816 (5.7%)	2571 (6.5%)	2554 (4.0%)	939 827 (3.7%)	402 501 (3.6%)	563 315 (2.7%)
≥ 90	1615 (1.6%)	665 (1.7%)	553 (0.9%)	183 472 (0.7%)	73 763 (0.7%)	96 987 (0.5%)
Total	102 149 (100.0%)	39 879 (100.0%)	63 423 (100.0%)	25 713 406 (100.0%)	11 096 946 (100.0%)	20 869 543 (100.0%)

HS = Health Search population; ISTAT = Italian population according to the Italian Institute of Statistics.

**Table II.** Prevalence of home-ridden patients with heart failure in the study sample.

Age group (years)	Males	Females	Total
60-69	9 (0.07%)	10 (0.07%)	19 (0.07%)
70-79	43 (0.48%)	40 (0.33%)	83 (0.39%)
80-89	50 (1.28%)	109 (1.55%)	159 (1.45%)
≥ 90	25 (3.02%)	68 (3.39%)	93 (3.28%)
Total	127 (0.13%)	227 (0.21%)	354 (0.18%)

**Table III.** Concomitant diseases other than cardiac disease in patients with heart failure.

Concomitant disease	Males	Females	Total
Osteoarthritis	49 (38.6%)	138 (60.8%)	187 (52.8%)
Respiratory	56 (44.1%)	67 (29.5%)	123 (34.7%)
Other neurologic/ sensorial	19 (15.0%)	28 (12.3%)	47 (13.3%)
Dementia	15 (11.8%)	30 (13.2%)	45 (12.7%)
Stroke	17 (13.4%)	20 (8.8%)	37 (10.5%)
Severe obesity	1 (0.8%)	25 (11.0%)	26 (7.3%)
Cancer	11 (8.7%)	13 (5.7%)	24 (6.8%)
Other	31 (24.4%)	48 (21.1%)	79 (22.3%)

“variable” and in 2 cases this information was missing. Free nurse assistance was possible for 164 (43.8%) subjects and nurses visited 92 (24.5%) patients on a regular basis; cardiologic home visits were regularly scheduled in 15 (3.9%) patients. The length of homecare and the time from the last cardiologic visit/hospitalization are reported in table IV. The results highlight that homecare for these patients started from 5 to 1 year before the survey in 84.5% of cases and about one third of HF patients did not receive a cardiologic visit since 1 year.

## Discussion

The prevalence of HF is increasing in the developed countries<sup>1</sup>. This disease affects mainly the elderly, the mean age of the HF population being 74 years<sup>2</sup> with a median age at presentation of 76 years<sup>3</sup>. Therefore it is

**Table IV.** Time from the last cardiologic visit/hospitalization and beginning of homecare.

Time	Last cardiologic visit	Length of homecare
> 5 years	17 (4.5%)	123 (32.7%)
> 2 years	42 (11.2%)	137 (36.4%)
> 1 year	57 (15.2%)	58 (15.4%)
> 6 months	66 (17.6%)	29 (7.7%)
< 6 months	184 (48.9%)	27 (7.2%)
Missing value	10 (2.7%)	2 (0.5%)
Total	376 (100%)	376 (100%)

highly probable that frailty, concomitant diseases, physical and cognitive impairment make access to medical services difficult or impossible for a number of HF patients. According to the European guidelines<sup>2</sup> “the organization of care should be closely adapted to the need of the patients’ group and the resources of the organization”. A current challenge for the health service is represented by those HF patients who are not able to leave home, since they frequently require a specially designed model of care. As far as we know, no specific information is available about this group of patients, consequently it is difficult to plan adequate intervention strategy targeted to improve the quality of care and reduce the need of hospitalization. For this reason our study aimed to provide basic data about homecare in Italian HF patients.

**Prevalence and severity of heart failure.** The prevalence of home-ridden patients with HF is 0.18% (confidence interval 0.16-0.20) and most of them (68.4%) are in NYHA class III or IV. If we extrapolate these results to the whole Italian population, almost 100 000 patients, mainly with advanced HF, would be usually assisted at home. In the Health Search Database (unpublished data), to which our participant GPs periodically send their data, the prevalence of codified diagnosis of HF in a population of almost 420 000 subjects > 20 years is 0.91%. According to these data, the HF patients assisted at home represent approximately 20.0% of the whole population of HF subjects in primary care. The range of HF patients reported by each GP is very large (0-13). Such information can be probably explained by the variability among the main factors which determine the need of home assistance: a) obstacles to leave home and/or difficulties for the doctor to reach the patient at home, b) the GPs’ personal approach to homecare, c) the local expectation about homecare standards. Furthermore, a non-homogeneous approach to the diagnosis of HF, obstacles to evidence-based diagnosis<sup>7</sup> and/or under/over-diagnosis could have played a role. Over-diagnosis is probably not important, since most of the patients have been hospitalized or visited by a cardiologist; on the other hand it is possible that the diagnosis of HF has been overlooked in very old subjects, affected by important co-morbidity.

**Age and gender.** Our group of patients was very old (mean age 83.8 years, median 85 years) and most of them were female (60.4%). Other previous investigations were performed in different settings reporting a mean age of 64 years (73% men)<sup>8</sup> among patients followed up by cardiologic outpatient clinics in Italy and a mean age of 76 years (52% men)<sup>9</sup> regarding patients hospitalized for HF. Moreover in a recent survey of the European general practice the mean age of subjects affected by HF resulted of 70 years (55% men)<sup>10</sup>. In a Southern Italian region, the mean age of HF patients in general practice was 70 years<sup>11</sup>. Therefore demograph-

ic characteristics of HF patients who are usually assisted at home by Italian GPs seem to be different not only from those of the subjects usually visited in cardiologic outpatient clinics, but also from HF inpatients and from the patients usually assisted by GPs. These results could be attributable to a different selection of HF patient subgroups in such studies. Italian HF patients unable to leave home to receive health care represent a burden totally on the shoulders of the GPs differently from the rest of Europe where there is the presence of specific health care structures.

**Relevant co-morbidity.** As expected, co-morbidity was frequently reported within the HF population, contributing to the difficulty in leaving home for over 86.7% subjects (Table III). The presence of other important diseases makes treatment of HF more difficult in the elderly population and, in some cases, such as advanced dementia or cancer, may also reduce the relevance of HF in the context of global patient management. Co-morbidity may also influence the choice of the human resources needed for appropriate homecare and it damages the effectiveness of home assistance in case of clinical deterioration of HF.

**Need of support and length of home assistance.** No patient was completely alone at home because the vast majority of them was assisted by their families. More than a half needs help to take the usual therapy and supportive care at home was available 24 hours a day in the majority of cases. Nurse care was available in 43.8% of cases and actually provided in about 24.5%; this apparent under-use of an available, free service has probably many reasons: a) generic rather than professional help was needed, b) general support was already provided by relatives and other caregivers, c) the shortage of nurses can limit the service to the most severe cases. We do not know if the nurses were specialized in HF care, but this is highly unlikely, because specialized nurses working outside hospital are extremely rare in Italy. Overall, it is clear that the burden of assistance is very high and long-lasting, in fact we observed from the questionnaire that home assistance was needed for more than 5 years in 32.7% and 2 years in 36.4% of these patients. These figures apparently contrast with the short-term prognosis of NYHA class III and IV<sup>2</sup>, representing the majority of our patients. Since other important diseases are present in almost 90% of the cases, it is likely that they were the main determinant of the need of home assistance, at least at the beginning. Advanced HF has probably developed only in the last period of time. Unfortunately our survey cannot explore this hypothesis that can be tested only by a prospective follow-up study.

**Hospitalization and cardiologic care.** The rate of hospitalization and/or specialized care was really elevated during the last year (68.3%) and higher with respect to

that reported in Europe (41%) for the whole HF population cared for by GPs<sup>10</sup>. This result is not unexpected since age represents a risk factor for hospitalization and the mean age of the HF population was advanced. Furthermore, as previously discussed, the presence of relevant co-morbidity, frequently in elderly people, could increase the need of hospitalization.

Although > 84% of patients were hospitalized and/or referred in the last 2 years, drug prescription differed from that recommended by guidelines<sup>2</sup>. There are probably many reasons for this apparent under-treatment: a) our population differs from those enrolled in clinical trials, b) co-morbidity may contraindicate some drugs, c) co-morbidity may need a compromise in polytherapy, d) deteriorated quality of life and/or short life expectancy may make intensive HF therapy futile. Furthermore, the efficacy of complex polytherapy in elderly, chronic patients has not been adequately studied, as well as the relevance of adverse effects of multiple drug regimens<sup>12</sup>.

**Study limitations.** The main limitations of our study are the selection of the participant GPs and the relatively low number of patients. Even if it is possible that the participant GPs share a particular homogeneous attitude toward HF homecare assistance, this seems to be very unlikely, given the wide range of prevalent patients cared for at home. Only 376 subjects are included in our survey and this small number could make difficult a direct extrapolation of the data to the whole Italian population. Another important limit is the use of a very simple questionnaire, which restricted the number and quality of available data. However, we think that the information provided could be very useful for a basic understanding of this important health issue and for planning future studies.

In conclusion, in Italy thousands of HF patients are usually assisted at home for long periods. This is a very elderly group of subjects with heavy co-morbidity and high need of continuous or prolonged assistance, the burden of which is almost exclusively on the families. Most of these patients are in NYHA class III or IV and hospitalization and/or cardiologic care are very frequent. Further studies aimed at improving the quality of care in elderly HF patients are urgently needed.

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