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Care available to severely disabled older persons living at home in Florence, Italy

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Abstract

Aims—To characterize the epidemiology of disability in, and the level of care available to, older community-dwellers in an Italian urban sample.

Methods—In a 2-phase survey, persons aged 65+ years, randomly selected from the patients lists of 98 primary care physicians (PCP), were screened (phase I) by their PCP with a structured questionnaire to detect the presence of: 1) need of help in performing Basic and 2) Instrumental Activities of Daily Living (BADL, IADL); 3) poor vision or 4) hearing; 5) weight loss; 6) use of homecare services; 7) self-perceived inadequacy of income. Subjects reporting 2+ problems were further evaluated in face-to-face structured interviews (phase II).

Results—Of 5445 participants, 597 (11%) screened positive in phase I and 416 were interviewed in phase II. Of these, 4, 29, 19 and 49% were disabled in 1-2 IADL, 3+ IADL, 1-2 BADL, and 3+ BADL. The extent of the support network increased with disability severity ($p < 0.01$). The 274 participants with BADL disability received most of their help from close relatives ($58.3 \pm 2.5\%$), followed by salaried assistants ($20.5 \pm 2.1\%$), other relatives ($19.5 \pm 1.9\%$), and public healthcare services ($0.6 \pm 0.36\%$). Of the 397 care-givers interviewed, one-third were willing to institutionalize the older participants in case of further functional deterioration. This propensity was predicted only by a self-reported poor attitude towards caring.

Conclusion—Many severely disabled older Italians receive care in their home by highly supportive family members. The level of assistance provided to them by public healthcare services is minimal.

Keywords

Disability; healthcare; home-bound elderly; ASSI survey

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Introduction

With the progressive aging of the population, the healthcare systems of industrialized countries are facing the burden of increasing expenditure to care for the most severely disabled older persons.

More than 19% of the Italian population is aged 65+ years: thus, according to United Nations data, Italy is the oldest world country (1). Basic healthcare needs (primary care, drugs, hospital services for acute diseases, and most rehabilitation services) of older Italians are covered by the National Health System, free of charge or with a small co-payment. The National Health System and either social assistance funds, provided by local government, or out-of-pocket resources are jointly used to finance residential or home-based long-term care for disabled individuals. However, the total amount of resources available is limited, and access to long-term care, either residential or home-based, is difficult. At the same time, there is an unbalance toward residential care: only 3.0% of Italians older than 65 years receive home-based assistance, a proportion almost identical to that (2.7%) of elders residing in long-term facilities, compared with median values of 7.9 and 5.8%, respectively, in 18 European countries (2). Thus, unlike the situation in many other countries, in Italy most older disabled persons remain in their homes and are cared for by family members (3). Moreover, it is unclear whether homecare services are correctly delivered to the disabled persons who deserve most, as the relationship between the epidemiology of disability in older Italians and the allocation of homecare services has not been seriously investigated. National statistics are in fact limited and potentially inaccurate, in that they are mainly based on telephone interviews and do not offer detailed descriptions of the older disabled persons and their care-givers.

To better characterize services available to disabled older persons in various care settings, the Italian Agency for Regional Healthcare Services sponsored the project “Assistenza Socio-Sanitaria in Italia” (ASSI; “Social and Healthcare Services in Italy”). Within this overall purpose, the specific aim of the research unit at the University of Florence was to conduct an epidemiologic assessment of disabled older community-dwellers and their care-givers. The main findings of this study are reported in this article.

Methods

Study protocol and population

The study was conducted in two phases. In phase I, older community-dwellers living within the Local Health Unit of Florence, Italy, were screened for the presence of disability by their primary care physician (PCP). Subjects living in nursing-homes were excluded, and those who screened positive were subsequently interviewed in their homes (phase II). Data on age-specific prevalence of disability from previous surveys in the same catchment area (4) was used to estimate a sample size of approximately 6000 individuals, in order to obtain an adequate number (at least 30) of disabled individuals over the age of 90. The initial sample was a random selection of 20% of those aged ≥ 65 years, registered as of October 2002 with 94 PCP practising in the Local Health Unit, which includes the urban area of Florence and several small towns in the surrounding area. A total number of 5927 subjects was selected for screening.

The study protocol was approved by the ethics committee of the Careggi university hospital, where the research unit is based.

Data collection

Phase I—The screening questionnaire, filled in by the PCP, included seven index items, briefly exploring: 1) disability in Basic and 2) Instrumental Activities of Daily Living (BADL, IADL); 3) severe visual or 4) hearing impairment; 5) self-perceived inadequacy of income; 6)

use of homecare services; 7) involuntary weight loss >3 kg in 12 months. We had previously demonstrated that responses to this questionnaire, compared with direct examination, correctly identified most older persons with BADL and IADL disability; the risk of disability increased with the number of positive answers, and the best compromise between sensitivity and specificity in the detection of disabled persons was at a cut-off value of two (4). Based on this previous experience, persons with two or more problems were considered as suitable for phase II.

Phase II—The persons who had screened positive in phase I were further assessed in their home with face-to-face structured interview, based on the principles of comprehensive geriatric assessment (5) and conducted by trained nurses. The questionnaire was modeled on previous instruments used in studies conducted in the participating institutions (6,7), with the inclusion of new sections on the involvement of family members and other persons providing care.

BADL and IADL disability was defined as need for help in at least one of seven (moving in the house, getting in and out of bed, dressing and undressing, washing face and hands, eating, toileting, continence) and 14 activities (getting out of the house, climbing stairs, walking 400 m, shopping, bathing or showering, cooking, doing light housework, doing heavy housework, washing clothes, cutting toe-nails, using the telephone, using public transportation, managing drug therapy, managing finances), respectively. Functional activities involving upper extremities (raising arms, grasping objects, carrying a bag) were also considered. For analytic purposes, participants were stratified according to the severity of disability, i.e. need for help in 1-2 IADL (including activities involving upper extremities), 3+ IADL, 1-2 BADL, and 3+ BADL.

Cognitive status was assessed with the Mini Mental State Examination (MMSE). Education was evaluated as the highest school grade completed, and was subsequently categorized into elementary, middle, and high school or above. Socio-economic level was defined objectively (home property) and subjectively (self-perceived economic status, categorized as very poor/poor, fair, good/excellent).

The support network was explored in terms of number of household and non household members, type of family relationship, and frequency of contacts. In non-proxy interviews, participants were also asked to describe, for each member of the network, the level of skill in care of the elderly (scored as progressively decreasing from one to five) and qualitative aspects of their personal relationship, such as the intensity of their emotional bond (decreasing with a score from one to four) and their availability to increase the amount of care provided if necessary (decreasing with a score from one to three) (8).

A global measure of help received was obtained by adding the percent help received in each BADL (with the only exception of continence), referring to each caring person, with a maximum of four. Caring persons were grouped into categories as follows: 1) close relatives (spouse or children), 2) other relatives, friends or volunteers, 3) paid assistants, and 4) public services. The help provided by persons in the same category was summed, to obtain the share of help borne by each category. For example, if participants received 30% of the help required for dressing/undressing from their spouses, 20% from one child, and the remainder from a paid assistant, the shared help for this task was classified as 50% close relatives and 50% salaried personnel.

Primary care-givers were interviewed by means of a structured instrument, apart from the participant, to define their demographic, social and occupational status, the amount and type of care provided, as well as the economic, social, emotional and health difficulties that care implied. Lastly, the quality of the personal relationship between care-giver and participant, and

the willingness or otherwise of the care-giver to provide additional care (“breaking-point”) in case of further functional decline were also studied.

Analytic procedures

Statistical analysis was performed with SPSS for Windows 12.0 (SPSS Inc., Chicago, Illinois, USA). Continuous variables were reported as mean $\pm$ standard error of the mean. Relative frequencies were compared with the chi-square test, considering the significance of the trend when appropriate.

Differences in continuous variables were analyzed in ANOVA (or ANCOVA, when continuous variables were entered as covariates) models, with polynomial contrasts to examine the significance of a trend, as appropriate.

Multivariable logistic regression was used to estimate the risk [odds ratio with 95% confidence interval (OR, 95% CI)] of the care-giver being close to breaking-point. To this purpose, care-giver characteristics (age, gender, kinship with participant) were entered first in the model, followed stepwise by age, gender, and functional, emotional, and cognitive status of participants. In a third level of analysis, years of care, perceived burden of care-giver (in terms of economic, social, emotional and health consequences), extent of network, and level of personal satisfaction reported by the care-giver were entered as further explanatory variables, stepwise or in different combinations, in separate logistic models.

A two-tailed *p*-value of less than 0.05 was considered statistically significant.

Results

As detailed in the flow-chart (Fig. 1), of the initial 5927 sampled subjects 482 were unavailable for screening for a variety of reasons. Of the remaining 5445 subjects (mean age 75 ± 0.1 yrs; 42% men), 597 (11.0%) were considered as positive to the phase I questionnaire by their PCP. The prevalence of positive screening increased markedly with age, from 3.3% at age 65-69 yrs, up to 78.6% at age 95+ yrs, and was lower in men (8.5%) than in women (12.7%; $p < 0.001$). The association between female gender and a positive screening remained significant also in an age-adjusted logistic model (OR 1.2, 95% CI 1.01-1.49; $p = 0.043$).

Of the 597 phase I positive participants, 431 were later interviewed in phase II; Figure 1 shows the reasons for unavailability for phase II evaluation. Fifteen subjects were excluded after the interview because they reported no disability (i.e., false positives of screening). Thus, 416 participants (131 men, 285 women; mean age 82 ± 0.4 yrs, range 65-99) were included in the final study sample. Of these, 160 (38.5%) were 75 to 84 years old and 188 (45.2%) were 85+. Only 4.1% had a high school or higher education level; 32.5% had a spouse or a partner. Because of severe sensory or cognitive impairment, interviews were conducted with a proxy informant in 46.9% of cases.

Grading of disability

A high percentage of participants who screened positive in phase I were disabled in three or more BADL (Table 1) or scored less than 21 on the MMSE (58.9%). One hundred and twenty-eight participants (30.8%) had only mild disability (less than 3 BADL impaired) with severe cognitive impairment (MMSE < 21), 43 (10.3%) were severely disabled but had no evidence of severe cognitive impairment (MMSE ≥ 21), 86 (20.7%) had severe cognitive impairment with relatively well preserved physical function, and as many as 159 (38.2%) had both severe disability and cognitive impairment.

The severity of disability increased significantly with advancing age and was comparable between men and women (Table 1). As shown in Figure 2, in gender-stratified comparisons the age-related increase in disability severity was confirmed in women, but not in men: more than half the women aged 85+ years were severely disabled (3+ BADL impaired) and none of them was only minimally disabled (1-2 IADL impaired). Education and socio-economic status were not associated with the severity of disability which, conversely, was greater in participants with poorer cognitive status, as indicated by an MMSE score of <21 ($p<0.001$; data not shown).

Extent, composition, and involvement of the support network

The support network included 3.0 ± 0.07 persons per participant, and was comparable in men (3.0 ± 0.12) and women (3.0 ± 0.08 ; $p=0.848$) and across age groups (Fig. 3). Only two participants (0.5%) reported that they had no contacts, whereas 36 (8.7%) had only one contact. Spouses were present in the network in 29.6% of cases, children in 75.2%, other relatives in 55.5%, volunteers in 8.4%, paid assistants in 43.3%, and institutional services in only 7.0%. As expected, the presence of a spouse was significantly more frequent in men (60.3%) than in women (15.4%; $p<0.001$) and decreased significantly with advancing age (65 to 74 yrs: 63.2%, 75 to 84 yrs: 34.4, 85+ yrs: 13.3%; $p<0.001$).

The total number of members in the support network and its composition (children, other relatives, other persons including volunteers, paid assistants, institutional services) were similar in men and women, with the only exception of the number of other relatives, which was slightly but significantly lower in men (0.7 ± 0.08) than in women (1.0 ± 0.07 ; $p<0.001$). Conversely, the extent of the network increased significantly with the severity of disability (1-2 IADL: 1.7 ± 0.33 , 3+ IADL: 2.9 ± 0.13 , 1-2 BADL: 3.1 ± 0.16 , 3+ BADL: 3.2 ± 0.11 ; $p<0.001$; least square means with polynomial linear contrasts), independent of age, gender, and MMSE score. Substantial differences in network composition were observed across age groups: the number of relatives involved increased significantly, and that of children and salaried assistants showed a non-significant increment with advancing age, whereas the opposite trend was detected for volunteers and, even more significantly, for institutional services which, overall, played a negligible role (Fig. 3).

Only 155 participants (37.3%) had at least one person in the network who reportedly had a good or excellent level of training or expertise in the care of older disabled persons. The proportion of qualified assistants increased with the severity of disability (1-2 IADL: 17.6%, 3+ IADL: 29.9%, 1-2 BADL 33.8%, 3+ BADL 44.6%; $p=0.001$).

The qualitative characteristics of the relationship (intensity of the bond and availability to help) with network members were comparable by gender, age, and severity of disability (data not shown). In the 274 participants disabled in BADL, only $1.1\pm0.34\%$ of needs were reported to be unsatisfied. Most of the help in daily activities was given by close relatives ($58.3\pm2.5\%$), followed by paid assistants ($20.5\pm2.1\%$) and other relatives ($19.5\pm1.9\%$). The share of help provided by institutional services was only $0.6\pm0.36\%$. Close relatives provided greater ($71.9\pm4.2\%$) and, reciprocally, paid assistants lower ($12.4\pm3.0\%$) contributions for men than for women (52.6 ± 2.9 and $23.8\pm2.7\%$; $p<0.001$ and $p=0.014$, respectively). The share of help provided by close relatives was progressively lower, whereas that provided by other relatives, volunteers, and salaried assistants progressively higher, with advancing age (Fig. 4).

Characteristics and role of the primary care-giver

Three hundred and ninety-seven (men: 122, 30.7%) primary care-givers were interviewed, whose ages ranged between 22 and 91 years. Of these, 63.0% and 13.2% were aged 65 to 74 and 75+ years, respectively. In 70% of cases, the primary care-givers lived with the disabled

participant; in 18.5%, they cared for more than one older person and in another 27% for somebody else in the family (usually, young children).

Primary care-givers provided financial, personal, housekeeping, and general support care in, respectively, 41.1, 66.5, 76.3 and 88.7% of cases; the vast majority of them (97.7%) also emphasized their roles as affective or emotional supporters. On average, they had been providing care for 8.2 ± 0.4 years, and for five years or more in 62.5% of cases.

Admittedly, care was a fairly and very demanding task for 31 and 48% of primary care-givers, respectively. Difficulties in finances, health status, social relationships and emotional balance caused by caring were reported by 21, 34, 35, and 47% of care-givers, respectively. Nevertheless, most of them felt satisfied with their role: when asked “*How do you feel about your role as a care-giver?*”, 59.7% stated that they provided care willingly and 20.2% with gratitude toward a person who deserved it, whereas only 14.6% reported that their only motivation was a sense of duty, and 5.5% that care-giving was an effort they would have happily avoided. One-third of the primary care-givers stated they were willing to institutionalize their relatives in case of further decline in their health status. Ranking of participants' condition, considered by care-givers as sufficient reasons for institutionalization, included: being bed-ridden (72.7%), having behavioral symptoms (70.5%), being unable to feed oneself (42.4%), being incontinent (34.8%), and having communication difficulties (30.3%).

In a logistic regression model, multivariable predictors of care-givers' propensity to institutionalize disabled participants were only their family relationship and care-givers' perception of their role, as assessed from the answer to the question “*How do you feel about your role as a care-giver?*” (Table 2). Neither the demographics of care-givers and participants, the presence/severity of disability, nor the years of care provided, all entered in a stepwise logistic regression model, significantly contributed toward predicting this outcome. Other variables (reported presence of cognitive impairment or behavioral symptoms, care-givers' financial, health-related, social, and emotional burden, extent of support network, presence and amount of care provided by paid assistants) entered in the logistic model in various combinations, all proved similarly not to be independent predictors.

Discussion

A simple screening questionnaire, administered by PCP, identified older persons with a severe level of functional and/or cognitive impairment, most of whom were totally dependent on somebody's help in their basic needs. Around the older disabled person, a close support network was usually found, including two or more persons (in most cases, female members of the family), whereas the role of public health services was marginal. The primary care-giver, who was responsible for the overall organization of care, and for a large share of its direct provision, was generally a family member. In spite of the substantial burden of care provided on a continuous basis, most primary care-givers appeared unwilling to waive their role and to institutionalize the elderly, even in cases of further functional, cognitive or behavioral deterioration. A positive psychological attitude was the almost exclusive determinant of the ability of the care-giver to continue caring.

Although international comparisons are difficult, because of differences in samples and methods of ascertainment, it is useful to compare our findings with those reported from other countries. A study conducted in Japan described the use of welfare and healthcare services by older community-dwellers who had applied for long-term care insurance, most of whom required personal assistance in daily activities. Of 237 participants with care-givers, only 22% did not use any kind of service, and more than one-third used two or more services (9). In Europe, the proportion of older disabled persons who received home-care services ranged from

24% in Denmark to less than 4% in Italy, Spain and Portugal (2,10). Thus, the results of the present study confirm that, in Italy, the amount of care provided by institutional services to older disabled persons is definitely lower than in most industrialized countries and, paradoxically, declines with advancing age (Fig. 3). Moreover, as reported by other authors (11), recipients of community care in Italy are characterized by very high physical and cognitive impairment.

Our results are in agreement with previous Italian reports, as summarized in a recent publication by the Eurofamcare project (12), showing that in Italy the family continues to support the direct burden of the care for the elderly almost entirely. Although Italian women appear to be increasingly more engaged in the job market (12) and, conversely, are less available for caring activities, they maintain their central role in the care of disabled seniors. As our data show, the network is able to adapt dynamically - in both the extent and level of training of its members - to the severity of disability and, when necessary, the family compensates for the lower personal involvement of its members with a shifting of care to paid assistants.

The data collected in this study indicate that the system may be unable to tolerate future scenarios of increased care-giver burden. As our data show, most of the care-givers are themselves quite old, have been caring for many years, and do so for several dependent members of the family. If traditional family bonds should become weaker, or a dramatic decrease in financial resources limit the possibility of maintaining paid assistants, many more older Italians with severe disability would remain unsupported by their relatives and exert an unbearable pressure on institutions for residential care. The Italian health and social support system is completely unprepared to cope with this possible shift, which may therefore have dramatic consequences. To prevent this hazard, it would be wise to enhance home-based caring services for elderly Italians, to a level closer to that found in other industrialized countries. Achievement of this goal would be greatly facilitated by the implementation of a standardized, validated assessment system, as done in previous studies (11), to collect information on care needs and provision, and make it available to other providers in the service network. Clearly, this would require an initial investment of huge resources, which would be probably compensated by a reduction in healthcare costs afterwards. A recent randomized clinical trial conducted in Canada demonstrates the sustainability of a community-based program of integrated care for vulnerable older persons, centered on alternative and assisted housing instead of hospital and institutional care: in this program, the number of patients who had been hospitalized for acute conditions and remained in hospital awaiting nursing-home placement ("bed-blockers") was reduced by 50%, without either increasing total costs or compromising overall health outcomes (13).

There is a strong consensus that caring for older disabled persons may produce physical and psychological stress. Providing care may seriously limit care-givers' freedom, impair their financial viability, health, and social relationships (14-16), and eventually increase the risk of death (17). Moreover, stressed care-givers are more prone to abandon, or institutionalize, disabled older persons (18). A complete dependence of older disabled persons on a family care-giver, who may eventually become overloaded by the burden of caring, is also possibly associated with abuse. A recent cross-national survey of nearly 4000 older community-dwellers receiving health or social community services in 11 European countries, reported a 4.6% prevalence of abuse. The proportion screening positive increased with the severity of cognitive impairment, presence of depression, delusions, pressure ulcers, active resistance to care, less informal care, expressed conflict with family or friends, or living in Italy or Germany. The authors suggested that this last finding may be related to higher levels of dependency in the participants looked after at home in these countries, as a result of cultural and service provision differences (19). It is therefore important to identify factors which may predict - and eventually prevent - the care-givers' burden. Interestingly, in our sample neither the objective burden, nor

the reported negative consequences of care predicted the care-givers' propensity to seek residential care. This may suggest that the care-givers we interviewed were still able to compensate for their stress because of their strong attitude and motivation to caring, which would to some extent prevent them from abdicating their role. If this interpretation is correct, it further emphasizes the need for adequate support to these persons. According to a recent randomized clinical trial, depressive symptoms diminished in care-givers of patients with Alzheimer's disease, if they received collaborative care in their homes, compared to a regimen of augmented usual care (20). We would argue that similar benefits are not restricted to care-givers of patients with dementia, who would benefit extensively from home-based care provided to their disabled older relatives. Instead, such strongly motivated persons would probably not profit from wider availability of residential care services.

Limitations of the study should be recognized. The functional status of participants who had been declared as impaired by their PCP was subsequently verified with appropriate instruments, yet procedures in phase II did not include any evaluation of a representative sample of participants who had screened negative in phase I. Thus, although the proportion of positive screeners who were eventually confirmed as disabled in direct interviews in this study was very high, we might have lost some false negatives. However, the screening instrument used had been proven, in a previous study, to have excellent concurrent validity, and in another ASSI report (4) it was also shown to have very high predictive validity. We could not assess whether the reported breaking-point truly corresponded to real behaviors by care-givers, because the study cohort was not followed-up until institutionalization. This may be the aim of a future study. Lastly, our results, obtained in a random community-based sample in the area of Florence, may not be entirely generalizable to other samples of older persons in Italy.

When these potential limitations are discounted, we believe that our findings have important implications in the public health field in Italy. They describe thoroughly the burden of disability in older persons living in their homes, their needs, and the paucity of help available to them and to their families, who sustain their caring role with an extraordinary sense of responsibility.

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Fig. 1. Study flow-chart

Fig. 2. Level of disability in basic and instrumental activities of daily living (BADL, IADL) of 416 participants, stratified by age and gender

Fig. 3. Extent and composition of support network, by age

Fig. 4. Shares of help provided to 274 participants disabled in BADL by different components of support network, by age

Table 1

Severity of disability in 416 participants, in whole sample and by age and gender.

	Severity of disability			
	1-2 IADL	3+ IADL	1-2 BADL	3+ BADL
Total, n (%)	14 (4.1)	117 (28.1)	80 (19.2)	202 (48.6)
Age (years)				
65-74 (n=68), %	8.8	35.3	23.5	32.4
75-84 (n=160), %	5.6	31.9	18.1	44.4
85+ (n=188), %	1.1	22.3	18.6	58.0
Gender				
Men (n=131), %	5.3	30.5	16.8	47.3
Women (n=285), %	3.5	27.0	20.4	49.1

IADL, BADL: Instrumental, Basic Activities of Daily Living.

Table 2

Multivariable predictors of propensity of care-givers to institutionalize disabled older persons. Logistic regression model, initially also including the following variables, which were later stepwise removed: age and gender of both primary care-givers and older participants, level of disability, and years of care provided.

	OR	95% CI	<i>p</i>
Family relationship			0.030[*]
Spouse	1	—	
Brother/sister	1.55	0.45-5.37	0.488
Child	1.24	0.69-2.24	0.466
Son/daughter in law	2.21	0.92-5.34	0.075
Other	3.52	1.49-8.33	0.004
Answer to the question			0.001[*]
“How do you feel about your role as a care-giver?”			
I do it willingly	1	—	
I do it only because of gratitude	2.03	1.16-3.54	0.012
I do it only as a duty	2.02	1.10-3.72	0.024
I find it difficult	5.09	2.02-12.81	0.001

* Trend value.