

Modalities and Costs of Familiar and Social Support to Chronically Ill Patients: A Pilot Investigation in the Udine Health District

Michele Petrinco¹, Silvia Snidero², Miriam Totis³, Mario Casini³, Anuška Ferligoj⁴, Patrizia Rozbowsky⁵, Dario Gregori¹, and the SNAC Study Group⁶

Abstract

The main objective of this study was to quantify the characteristics of social networks in a sample of elderly ill patients. These patients who had chronic illness were receiving home based care, in an Italian district during 2001. Both patients and caregivers were interviewed. The analysis of the caregivers' questionnaire was conducted to avoid missing answers when gathered from the patients. This method also enabled a better understanding of the impact of social support on chronic illness pathologies. Further more, it allowed the investigation of the patients' network, the caregivers' point of view, the costs, the quality of care and the assessment of socio-demographical data of both. Results highlighted the particular situation of patients, characterized by high dependence from other persons especially

¹ Department of Public Health and Microbiology, University of Torino, Italy

² Dept. of Mathematics and Statistics Applied to Human Sciences, University of Torino, Italy

³ ASS no 4 "Medio Friuli", Udine, Italy

⁴ Faculty of Social Sciences, University of Ljubljana, Slovenia

⁵ Department of Human Sciences, University of Trieste, Italy

⁶ The SNAC Study Group (in alphabetical order)

Maria Cecilia Albanese, MD "Santa Maria della Misericordia" Hospital, Udine; Mario Casini, MD Head of Udine District - ASS n°4 "Medio Friuli"; Paola Di Nicola, "Department of Education", University of Verona, Italy; Anuska Ferligoj, PhD "Faculty of Social Sciences", University of Ljubljana, Slovenia; Paolo Maria Fioretti, MD "Santa Maria della Misericordia" Hospital, Udine; Marco Ghidina, IRCAB Foundation, Udine; Dario Gregori, PhD "Department of Public Health and Microbiology", University of Torino, Italy; Tina Kogovsek, PhD "Faculty of Social Sciences", University of Ljubljana, Slovenia; Miriam Isola, Department of Medical and Morphological Research, University of Udine, Italy; Simona Liguori, MD Oncologist Udine District - ASS n°4 "Medio Friuli"; Niel Oldridge, PhD Regenstrief "Institute for Health Care", Indiana University Center for Aging Research, Schools of Allied Health Sciences and Medicine Indiana University; Patrizio Prati MD, Neurologist IMRF Gervasutta - ASS n°4 "Medio Friuli"; Patrizia Rozbowsky, PhD, "Department of Human Sciences", University of Trieste, Italy; Franca Soldano, Department of Medical and Morphological Research, University of Udine, Italy; Miriam Totis Social Worker - ASS n°4 "Medio Friuli"; Agostino Zampa MD, Fisiatria IMFR Gervasutta - ASS n°4 "Medio Friuli".

for every day activities. Most of the caregivers were family members for the number of persons involved and for the time spent for the care. The network support maintenance and mobilization costs evaluation was faced suggesting three different strategies, according to three different ways of time-opportunity calculation, of the informal caregivers.

1 Introduction

The growing emphasis in the Western world on transferring at least part of the in-hospital care of some patients to primary, community based care, is targeted to specific goals: (i) to increase the efficiency of care leaving the patients as close as possible to their home, (ii) to increase the independence of the patients, and their quality of life, and (iii) to contain the overall costs of care, particularly for long term chronic illnesses. The main reasons for this fast growing interest in replacing hospital care with home care are: (i) the growth in the number of elderly and chronically ill people, (ii) the lack of availability and accessibility of acute and sub-acute inpatient service, (iii) the technological innovation, (iv) the patients' choice, as they often prefer to stay in their home environment, thus improving quite substantially their standards of living (Bentur, 2001). In this respect, it is possible to divide the patients who receive medical home care in two categories: (i) chronically ill patients who often are at high risk of hospitalization with relative long durations, and (ii) patients who, owing to an acute event, need short-term, intensive medical treatments but they don't need long-term nursing and maintenance care. In general, medical home care is an alternative to long-term care for elderly and chronically ill patients, who require living along with the limitations imposed by their clinical conditions. The most prevalent illnesses of these patients are usually congestive hearth failure, chronic pulmonary disease and the final stages of a terminal illness (Bentur, 2001). The impact of such diseases and treatments should be measured not only in terms of survival (quantity of life) but also in terms of well being (O'Boyle, 1992), in particular for chronic illnesses with poor prognosis. In 1996 the World Health Organization Quality of Life Group defined the Quality of Life as "an individual's perception of their position in life in the context of culture and values system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in complex way by the person physical health, psychological state, level of independence, social relationship and their relationship to salient features of the environment" (World Health Organization Quality of Life Group, 1996). Certainly, a home assistance for such patients has the potential to improve their Quality of Life as chronic ill subjects, because it can increase their independence and their possibility of getting more social support. Eventually, the social support influences also health outcomes and reduces mortality, as it is known that stressful social relationship increases health problems (Kaplan and Toshima, 1990).

The term “social support” refers to different aspects of social relationships and may be defined in terms of quantity of social relationships (integration versus isolation), in terms of structure of a person’s social relationships (in this case the expression “social network” is often used) or as qualitative content of relationships, meaning the degree to which the social relationships provide emotional concerns, understanding, caring, instrumental and practical aid (House and Khan, 1985). Moreover, social support has to be split in two different parts: actual support and perceived support. In most of the studies perceived support is the most powerful predictor of health (Turner, 1983). Lately many researches have been conducted in order to understand the impact of social support on different chronic illnesses (Newsom *et al.*, 2005, Simoni *et al.*, 2006). These researches have led to a general acceptance that social support has a beneficial effect on daily life and it helps people to remain healthy.

In this study, particular attention has been given to heart disease, cancer and dementia, which represent a major part of the burden of chronic diseases (Joyce *et al.* 2005). Currently, psychosocial factors and social relationships are known to play a crucial role as predictors of mortality in congestive heart failure patients (Murbreg and Bru, 2001); whereas a lack of social support and social isolation are associated with increased risk of mortality (Case *et al.*, 1992). As regards patients affected by dementia, there is a little evidence of the effect of social support on the occurrence of dementia (Henderson *et al.*, 1996); the results of a study on different degrees of social connections showed that being single and living alone are strong determinants of dementia, almost doubling the disease risk (Frantiglioni *et al.*, 2000). The social support for cancer patients is important for psychological adjustment and survival (Carlsson and Hamrin, 1994); other studies underline the differences between patients who receive treatment away from or at home (Payne *et al.*, 2001).

Home based care assistance can decrease the readmission rate and its associated costs. It improves the overall quality of life of chronically ill patients and their perception of independence. It is very difficult to compare the costs of medical home care with hospitalization costs. The reduction of the days of hospitalization, as a consequence of early discharges, can lead to medical home services with long duration, raising the total costs for the system (Vaux, 1988). Moreover, the National Health System saving could become an expense for patients and their families.

The goal of this study was to investigate the social and medical care support given to chronic patients in a northern Italian Health District, using the methodology of social network analysis. Finally, an attempt to provide preliminary estimates of the cost of an “at home” care was performed, with the aim of including both direct and indirect costs represented by the family activities in taking care of patients.

2 The health system in Udine

Social support was assessed in a sample of elderly patients (over 75 years old) with chronic illness (cancer, heart failure, dementia), who requested the National Health Service (NHS) for a “Home Based Care” during 2001, in the Udine Health District.

Udine Health District is an Italian health community district, situated in the North-East of Italy, in the Friuli Venezia Giulia Region. The Region counts 1.200.000 inhabitants and shows both agricultural and industrial economy and high social and economical levels.

In Italy home care services are provided by two different organizations:

- Home care health service provided by N.H.S. consists in nurse and/or rehabilitation therapist’s home visits and interventions for people who need to be treated at home (medications, physiotherapy, monitoring chronic disease,...). These services are free;
- Home care social service provided by municipalities consists in caring for aged people (personal hygiene, house cleaning, meal preparation, telemedicine). These services have to be paid according to the patients’ incomes. Home care social services may also be provided by several kinds of private agencies.

The district of Udine is the smallest administrative entity of the NHS (supporting from 60 to 150 thousand inhabitants) and it is the reference point for social services and primary cares. The local epidemiological situation is similar to the national one: chronic diseases are prevalent with a high pressure for hospitalization.

As the health and social services come from two different organizations, the district decided to constitute a single unit, integrating the overall activities: *(i)* the social and health request organization, *(ii)* the improvement of cooperation between hospital and district for the early discharges, *(iii)* the development and implementation of the services, *(iv)* the social and health workers’ training, *(v)* the establishment of a home service network information point.

The final purposes of this kind of service were: *(i)* to avoid early hospitalization of aged people, *(ii)* to hold up loss of autonomy, *(iii)* to reduce hospitalization rates and promote early discharges, *(iv)* to facilitate the decision of aged people to stay at home.

During the first year activity 2433 people were cared by integrated home care service.

3 Study design and sample

The sample consisted of 50 patients affected by cancer, heart failure and dementia older than 75 receiving Home Based Care from the Health District of Udine during 2001. The sample was randomly selected from a list of consecutive patients in charge of the District having these characteristics. Presentation letters were sent to selected patients; then they were contacted by phone to fix two appointments: one for a face-to-face interview with them and the other for a face-to-face interview with one of their caregivers.

Since the objectives of this study were the identification of the patients' networks⁷ and the final costs for the families, the network was centered on the patient. Social networks of the patients were measured using structured interviews for both patients (when possible) and caregivers, using ad hoc questionnaires.

The caregivers' questionnaire was an extension of the patients' one, containing a number of additional questions about his/her activities. The answers of the caregivers were used both to clarify uncertain situations given by the patients' partial or doubtful answers and to complete missing answers. Caregivers were classified as "relative caregivers" if they were strict relatives of the patient, "extra-relative caregivers" if they were friends or neighbours, "volunteer caregivers" if they were people coming from no-profit organizations, "private" if they were people without specific education, being paid for giving assistance from the patient's family, "professional" if they were people with specific education paid from the family and finally "non-private" if they were people provided by the local Health System.

The patient's questionnaire included questions about: the social network, the quality of care, the costs supported for the care, and socio-demographical data. The caregiver's questionnaire consisted of different groups of questions about: the social network of the patient, the quality of care (in his/her opinion), the total costs for the care, the activities involved in caring the patient, and socio-demographical data.

One of the main objectives of the study was the evaluation of the total costs of the care, considering both the direct costs (including the price -if paid- to receive the home care services from the NHS and the compensation of other private caregivers), and the indirect costs (including the time-opportunity of volunteer caregivers spent to care for the patient).

Direct costs were calculated on the basis of the hours of the professional caregiver's work in assisting the patient, the salary and the price of the "NHS Home Care". The subjects were asked about the price of the home care service provided by the district (in case they had paid it) during the interview.

⁷ Patients' networks include professional and non professional assistance (volunteers or family) helping the patients in their daily activities.

Indirect costs, expressed in terms of the cost of the time–opportunity of the volunteer caregivers, were harder to evaluate. We proposed three strategies for the evaluation of the indirect costs, on the basis of the volunteer caregiver’s profession and multiplying the time of care for: (i) the average regional salary of the profession in 2001 (case 1), (ii) the average salary of a professional caregiver (case 2), (iii) the mean net Italian income per capita in 2001 (case 3). As regards the other caregivers (15 persons), because of the heterogeneity of their professional lives (mostly retired or dedicated to home care), it wasn’t possible to think of a given salary for their time, and thus we decided to assign: the average salary of the interviewed caregivers (case 1), the average salary of a professional caregiver (case 2), and the mean net Italian income per capita for 2001 (case 3).

For the statistical analysis we used the following measures: mean, median, absolute numbers, percentages, first and third quartile, confidence intervals. All analysis were done using SPSS ver 13.

3 Results

Most of the sample (50 pts) is living with another person (Table 1). The majority, 61%, is living with one or more relatives and the 19.5% with his/her partner.

Table 2 presents the patients’ activities and their autonomy in managing them. A patient was classified as “independent” in an activity if she/he can manage at least 70% of his/her activities alone, with or without difficulty; she/he was classified as “less independent” if she/he can manage less than 70% of the activities with the help of someone else; she/he was classified as “totally dependent” if she/he is completely unable to manage it without the help of someone else. According to these criteria forty-nine patients (98%) resulted dependent in their home activities and 42 (84%) resulted dependent in their daily activities (Table 1).

Table 1: Characteristics of the patients. Percentages refer to the number of people matching the specific condition (rows) among those (N) for which the information is available. Health and social assistance are not mutually exclusive categories.

| | | N | N (%) |
|--------------|----------------------------------|----|-----------|
| Independence | At least 70% of daily activities | 50 | 8 (16%) |
| | At least 70% of home activities | 50 | 1 (2%) |
| Living | Alone | 46 | 2 (4.3%) |
| | With the partner | 46 | 9 (19.5%) |
| | With one or more relatives | 46 | 28 (61%) |
| | With a private assistant | 46 | 6 (13%) |
| | With another patient | 46 | 1 (2.2%) |
| Assistance | Health workers’ assistance | 45 | 43 (96%) |
| | Social workers’ assistance | 45 | 4 (8.9%) |

Table 2: Usual activities and autonomy of the patients. Percentages refer to the number of people being in a condition of (i) independence, (ii) partial dependence and (iii) complete dependence for each given activity (row).

| Activities | N | Independent patients | Less independent patients | Totally dependent patients |
|-------------------------------------|----|----------------------|---------------------------|----------------------------|
| <i>Home activities</i> | | | | |
| shopping | 50 | | 36 (72%) | 14 (28%) |
| cleaning | 50 | 4 (8%) | 32 (64%) | 14 (28%) |
| cooking | 50 | 5 (10%) | 31 (62%) | 14 (28%) |
| washing laundry | 50 | 3 (6%) | 33 (66%) | 14 (28%) |
| ironing | 50 | 2 (4%) | 34 (68%) | 14 (28%) |
| gardening | 50 | 4 (8%) | 20 (40%) | 26 (52%) |
| giving injections and bandaging | 50 | 1 (2%) | 43 (86%) | 6 (12%) |
| housework | 50 | 2 (4%) | 35 (70%) | 13 (26%) |
| <i>Daily activities</i> | | | | |
| washing body and bathing | 50 | 4 (8%) | 46 (92%) | |
| washing hands and face | 50 | 22 (44%) | 28 (56%) | |
| putting on shoes and socks | 50 | 11 (22%) | 35 (70%) | 4 (8%) |
| (un)buttoning and (un)doing zippers | 50 | 14 (28%) | 33 (66%) | 3 (6%) |
| putting on clothes | 50 | 14 (28%) | 33 (66%) | 3 (6%) |
| using the WC also going there | 50 | 15 (30%) | 26 (52%) | 9 (18%) |
| rising from and going to bed | 50 | 13 (26%) | 33 (66%) | 4 (8%) |
| feeding | 50 | 27 (54%) | 22 (44%) | 1 (2%) |
| washing and combing hairs | 50 | 3 (6%) | 47 (94%) | |
| cut nails and toes | 50 | 8 (16%) | 42 (84%) | |
| going up and down stairs | 50 | 9 (18%) | 13 (26%) | 28 (56%) |
| walking around the house | 50 | 14 (28%) | 15 (30%) | 21 (42%) |
| walking outside the house | 50 | 8 (16%) | 14 (28%) | 28 (56%) |
| taking medications | 50 | 12 (24%) | 38 (76%) | |

Table 3 shows who is helping these “less independent” patients in their home and daily activities. Relative caregivers are clearly playing the major role in assisting the patients in their life habits (walking, rising from bed, washing), but impressively, they also take care of more sophisticated activities, like injections, which usually require a level of training, in the same percentage as professional caregivers.

As for the utilization of the services of the “NHS Home Based Care” and the corresponding level of satisfaction, 91.5% of the sample was satisfied with the health workers’ assistance (73.9% of these consider the health care received useful), whereas only 8.9% were satisfied with social workers’ assistance. For the 76.5% of the patients the timing of the interventions are good for their needs, the 79.3% doesn’t feel limited by the workers’ presence and 58.6% said that the interventions were fast in case of urgent need.

The utilization of the structures during the last 6 months is particularly homogeneous for the different structures; on average, patients required one General Practitioner’s visits, one Specialists’ visit, one hospitalization and one corresponding ambulance call. The average number of medicines per day for patient is 4. The 27.7% of the patients called the social assistance in the 6 months

of the study, mainly requesting for information, whereas the 11.1% contacted voluntary organizations for Tele-Emergency related services.

Table 3: Who is helping the less independent patients in their activities. Percentages refer to the number of caregivers, according to their classification as “relatives” or “professional”, giving their assistance in each given activity (row).

| Activities | N of | |
|--------------------------------------|------------|---|
| | caregivers | Relative caregivers Professional caregivers |
| <i>Home activities</i> | | |
| shopping | 38 | 32 (84%) 6 (16%) |
| cleaning | 30 | 19 (63%) 11 (37%) |
| cooking | 30 | 22 (73%) 8 (27%) |
| washing laundry | 33 | 23 (70%) 10 (30%) |
| ironing | 31 | 23 (74%) 8 (26%) |
| gardening | 18 | 17 (94%) 1 (6%) |
| giving injections and bandaging | 38 | 21 (55%) 17 (45%) |
| housework | 32 | 21 (66%) 11 (34%) |
| <i>Daily activities</i> | | |
| washing body and bathing | 53 | 39 (74%) 14 (26%) |
| washing hands and face | 33 | 23 (70%) 10 (30%) |
| putting on shoes and socks | 41 | 30 (73%) 11 (27%) |
| (un) buttoning and (un)doing zippers | 40 | 28 (70%) 12 (30%) |
| putting on clothes | 39 | 28 (72%) 11 (28%) |
| using the WC also going there | 27 | 23 (85%) 4 (15%) |
| rising from and going to bed | 39 | 30 (77%) 9 (23%) |
| feeding | 20 | 14 (70%) 6 (30%) |
| washing and combing hairs | 44 | 34 (77%) 10 (23%) |
| cut nails and toes | 45 | 33 (73%) 12 (27%) |
| going up and down stairs | 12 | 11 (92%) 1 (8%) |
| walking around the house | 11 | 11 (100%) |
| walking outside the house | 10 | 10 (100%) |
| taking medications | 46 | 36 (78%) 10 (22%) |

Only the “less independent” patients were considered. “Other caregivers” (not private and not relative) not considered.

3.1 Caregivers

In correspondence with the 50 patients of the sample, 110 caregivers were interviewed (on average 2.2 caregivers for patient). The 110 caregivers included both professional and volunteer caregivers. Sixty-five caregivers (59%) were patients’ relatives and 45 (41%) were not relatives: out of these 45, 30 (27%) were professional caregivers. The 45% of the total number of the caregivers lived with the patient.

Tables 4 and 5 present the total number of caregivers classified by relation (relatives/extra-relatives) and by residence (cohabiting/not cohabiting with the patient). The 12% of the caregivers were of the same generation of the patient

(partner, sister), whereas the 88% were from upper generation (sons, daughters, nephews). The caregivers were 79% female and this percentage increases up to 96% if we consider only the professional caregivers. Both among professional and volunteer caregivers there is a clear preponderance of female. Caregivers were on average 59 year old, the 64% with a lower education and they have assisted the patient since 8.6 years on average.

Caregivers, half of which are relatives, are thus providing a long-term assistance for such patients.

Table 4: Number of relative caregivers.

| N=110 | Partner | Son | Daughter | Sister | Daughter in law | Sister in law | Son in law | Grandchild |
|-------------------|------------|-----------|-------------|-----------|--------------------|------------------|---------------|------------|
| Cohabiting | 10 (9%) | 6 (5%) | 13 (12%) | 2 (2%) | 6 (5%) | 2 (2%) | 1 (1%) | 3 (3%) |
| Not cohabiting | | 6 (5%) | 12 (11%) | | 1 (1%) | | 2 (2%) | 1 (1%) |

Table 5: Number of extra-relative caregivers.

| N=110 | <i>Private</i> | | | | | <i>Not private</i> | |
|-------------------|-----------------|-----------|-----------|-----------------------------|-----------------|--------------------|-------------|
| | Physiotherapist | Home Care | Nurse | Extra- community Care | Private Care | Neighbour | Other |
| Cohabiting | | | | 5 (4%) | 2 (2%) | | |
| Not cohabiting | 1 (1%) | 3 (3%) | 6 (5%) | 10 (9%) | 3 (3%) | 4 (4%) | 11 (10%) |

3.2 Type and times of the developed activities

The time the caregivers devote to the care of the patient were calculated on the basis of the activities of Table 1. These activities were classified according to the importance given by the patient to his/her normal life. Particular attention was given to daily activities, such as body care and home activities, considered important for the living environment.

The average daily time of care requested by a patient consists of 6 hours and 10 minutes; the average daily time of care spent by each of the 110 caregivers to care for the patient is 2 hours and 48 minutes (Table 6 and 7). The average time of care a patient receives daily is 6 h and 10 min, divided into (on average) 4 h and 34 min in case of relative caregivers, in 1 h and 29 min in case of private caregivers and in 7 min in case of other caregivers (neighbours and friends). On average the time that each caregiver spend daily for helping the patient 2 h and 48

min: on average each relative spend 3 h and 31 min, each private caregiver spend 2 h and 29 min and each other type of caregiver spend 23 min.

Table 6: Average daily time of care for patient.

| | Relative caregivers | Private caregivers | Other caregivers | Total |
|--|--|---------------------------------------|-------------------------------|--|
| Average daily time for patient (hours and minutes) | 4 h 34 m [3h 38m; 5h 32m] C.I. 95% | 1 h 29 m [40m; 2h 19m] C.I. 95% | 7 m [0 m; 29m] C.I. 95% | 6 h 10 m [5h 5m;7h 16m] C.I. 95% |

Table 7: Average daily time of care for caregiver.

| | Relative caregiver | Private caregiver | Other caregiver | Weighed average |
|--|---|--|--------------------------------|---|
| Average daily time for caregiver (hours and minutes) | 3 h 31 m [2h 42m; 4h 21 m] C.I. 95% | 2 h 29 m [1h26m;3h 32m] C.I. 95% | 23 m [0; 1h 1m] C.I. 95% | 2 h 48 m [2h 4m; 3h 34m] C.I. 95% |

3.3 Estimates of the direct and indirect cost of home care

The total cost per month was estimated on the basis of the price of the service (paid by the patient or by an assistant), the cost of other professional assistants and the cost of the time-opportunity of the volunteer assistants (Table 8). The average costs for the patient's family is thus estimated to range between 1500 and 2100 euro per month, according to the various definition for the time-opportunity adopted.

Table 8: Estimate of direct and indirect costs (direct public costs estimated on 28 patients: 939 €).

| | Real salary | Professional assistant salary | Average italian salary |
|---|-------------|-------------------------------|------------------------|
| Patients paying private care | 291 | 291 | 291 |
| Assistants paying private care | 314 | 314 | 314 |
| Cost of private assistants | 334 | 334 | 334 |
| <i>Time-opportunity of volunteer assistants</i> | 983 | 1134 | 605 |
| Total euros per patient per month | 1922 | 2073 | 1544 |

It appears that the relatives represent the 74% (in terms of time) of the patient's care, the private caregivers represent the 24% and the other caregivers represent only the 2%.

If we take as a reference a 40-hours working time per week, assistance of patients represents half of the their relatives' working time.

4 Discussion

The data show how the informal care to patients represents the major part of the overall care, both for the number of people involved and for the time spent.

The information about the time spent for the care by the various categories of caregivers underline the great engagement of the members of the family, especially females, on the patient's care. The other caregivers help the patient daily for a very short time. This is in agreement with other researches (Roberto *et al.*, 2005), where the main importance of the family in the care of chronic illness is evident. It is to notice that the interviewed caregivers have assisted the patient on average since 8.6 years.

Several studies indicated that the experience of care giving is different for males and females: more often female patients receive assistance from both spousal and non spousal sources, but male patients tend to rely solely on their wives (Northouse *et al.*, 1999). Moreover in literature it appears that female caregivers report more stress and burden (Blood *et al.*, 1994), more demands associated with the illness (Stetz, 1987) and more unmet needs for help with household tasks (Allen, 1994) with male caregivers. After the person is identified as the one who is the main reference for the patient, it should be useful to provide her with social support. This could be addressed to both the health care professional assistance (50% of the relatives are forced to administer injections to the patients) and to less qualified, daily activities, in particular to those related to the personal care of the patient (77% of the caregiver's activity is somehow related to washing and cleaning).

The total cost for the family is quite high, about 1500-2000€ per month, which represents not much less than the average family income in Italy. Of course, this is much less than the cost for a full-time hospitalization, which should roughly account for about 4500€ per month. Nevertheless, it has to be recognized that most of the home care costs are indirectly (and hidden) imputed to families as the assistance is intense and continued.

This study has the important limitation of not considering indirect costs (loss of productivity due to assistance, social and relational impact of assistance for the closest relatives) in the computation of the overall burden of the home care assistance, thus making these estimates somehow conservative. These points constitute perhaps the pattern for future research in this field.

The small sample and the high number of missing values, and the specific regional environment where the investigation was conducted are surely limiting the generalization of this study results. The Friuli Venezia Giulia region is actually characterized by a sort of "rural" relationships, with the children being close to the

parents up to the end of their life. This model can hardly be exported to other situations (like metropolitan areas), limiting therefore the interpretation of the study results. Nevertheless, the indication that at least “some” costs are in charge of the families (perhaps inappropriately) is clearly emerging from this research.

References

- [1] Allen, S.M. (1994): Gender differences in spousal care giving and unmet need for care. *Journal of Gerontology*, **49**, 187-195.
- [2] Bentur, N. (2001): Hospital at home: what is its place in the health system? *Health Policy*, **55**, 71-79.
- [3] Blood, G.W., Simpson, K.C., Dineen, M., Kauffman, S., and Raimondi, S.C. (1994): Spouses of individual with laryngeal cancer: caregiver strain and burden. *Journal of Communication Disorders*, **27**, 19-35.
- [4] Carlsson, M. and Hamrin, E. (1994): Psychological and psychosocial aspects of breast cancer treatment. *Cancer Nursing*, **17**, 418-428.
- [5] Case, R.B., Moss, A.J., Case, N., McDermott, M., and Eberly, S. (1992): Living alone after myocardial infarction. Impact on prognosis. *JAMA*, **267**, 515-519.
- [6] De Vaus, D.A. (1991): *Surveys in Social Research*. London: University College London Press.
- [7] Frantiglioni, L., Wang, H., Ericsson, K., Maytan, M., and Winblad, B. (2000): Influence of social network on occurrence of dementia: a community based-longitudinal study. *Lancet*, **335**, 1315-1319.
- [8] Henderson, A.S., Graison, D.A., Scott, R., Wilson, J., Rickwood, D., and Kay, D.W.K. (1996): Social support, dementia, and depression among the elderly living in the Horbat community. *Psychol Med*, **16**, 379-390.
- [9] House, J.S. and Khan, L. (1985): *Social Support and Health*. Cohen s. c. and syme, s. l. edn. Orlando, FL: Academic Press. Chap. Measures and concepts of social support.
- [10] Kaplan, R.M. and Toshima, N. (1990): *The Functional Effects of Social Relationships on Chronic Illness and Disability*. Sarason, b.r. and sarason, i. b. and pierce, g. n. edn. New York: John Wiley. Chap. In Social Support: an Interactional View, pag.427-453.
- [11] Joyce, G.F., Keeler, E.B., Shang, B., and Goldman, D.P. (2005): The lifetime burden of chronic disease among the elderly. *Health Aff (Millwood)*, **24** Suppl 2:W5R18-29.
- [12] Murberg, T.A. and Bru, E. (2001): Social relationships and mortality in patients with congestive hearth failure. *Journal of Psychosomatic Research*, **51**, 521-527.

- [13] Newsom, J.T., Rook, K.S., Nishishiba, M., Sorkin, D.H., and Mahan, T.L. (2005): Understanding the relative importance of positive and negative social exchanges: examining specific domains and appraisals. *J Gerontol B Psychol Sci Soc Sci.*, **60**, 304-312.
- [14] Northouse, L.L., Mood, D., Templin, T., Mellon, S., and George T. (1999): Couple's patterns of adjustment to colon cancer. *Elsevier, Social Science & Medicine*, **50**, 271-284.
- [15] O'Boyle, C.A. (1992): Assesment of qualità of life in surgery. *British Journal of Surgery*, **79**, 395-398.
- [16] Payne, S., Jarrett, N., Jeffs, L., and Brown, L. (2001): Implications of social isolation during cancer treatment. The implications of residence away from home during cancer treatment on patients experiences: a comparative study. *Health and Place*, **7**, 273-282.
- [17] Pecoraro, R.E., Inui, T.S., Chen, M.S., Plorde, D.K., and Heller, J.L. (1979): Validità and reliability of a self-administered health history questionnaire. *Public Health Report*, **9**, 231-238.
- [18] Roberto, K.A., Gigliotti, C.M., and Husser, E.K. (2005): Older women's experiences with multiple health conditions: daily challenges and care practices. *Health Care Women Int.*, **26**, 672-92.
- [19] Simoni, J.M., Frick, P.A., and Huang, B.A. (2006): Longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychol.*, **25**, 74-81.
- [20] Stetz, K. (1987): Caregiving demands during advanced cancer: the spouse's needs. *Cancer Nursing*, **10**, 260-268.
- [21] Turner, R.J. (1983): *Psychosocial stress: trends in theory and research*. Kaplan h. b. edn. New York: Academic Press. Chap. Direct, indirect and moderating effects of social support on psychological distress and associated conditions.
- [22] Vaux, A. (1988): *Social Support Theory, research, and intervention*. New York: Praeger.
- [23] World Health Organization Quality of Life Group (ed). (1996): What Quality of Life? World Health Organization Quality of Life Assesment. Vol. 17 World Health Organization Quality of Life Group, for World Health Organization Quality of Life Group.