

ORIGINAL PAPER**Informal Care Provision by the Family to Hospitalized Patients in a Rehabilitation Clinic of Western Greece**

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Abstract

Introduction: Recognizing the burden imposed on families and society by long-term care of chronically ill patients, there is a need to empower caregivers and take measures for slowing the deterioration of the quality of life for the caregiver and the patient.

Aim: The main aim of the present study was to investigate the caregivers' views regarding the services provided by them for their hospitalized relatives and their opinions about the their health education needs, informational needs and needs for support in a rehabilitation clinic of Western Greece.

Methodology: The sample consisted of 75 caregivers of hospitalized patients who provided unpaid services and they wanted after informed consent to participate in the study. Data were collected in 2012 within a period of 6 months. A self-reported questionnaire was completed and the statistical analysis was performed by the use of SPSS.

Results: This study shows the need for caregivers' health education on technical care and general knowledge about the disease, on how to handle an emergency situation at home. Obvious were also the need for information about the benefits to disabled people from public and non-profit organizations, but also the need for learning how to support emotionally patient. Information about the transition from hospital to home, emerged as necessary through this study. Caregivers felt that it is the obligation of the hospital to provide training and health education and indicated nurses as appropriate health professionals for the role. Also the need for emotional support for caregivers by health professionals was highlighted and caregivers believe that adequate staffing of rehabilitation units will allow health professionals to provide time for emotional support of caregivers, but also time for casual conversation on general subjects, in a civilized environment, aiming to empower caregivers for better care of patients.

Conclusion: The health education needs of the caregiver must be sufficient, after careful assessment of training needs, information and emotional support and by strengthening the concept of self-care of the caregiver. To address these needs, specific training plan is required, preparing the caregiver in his new role and adjustment to the new lifestyle.

Key words: Rehabilitation, informal care, caregivers, patients, health professionals.

Introduction

The physical - motor rehabilitation is increasingly recognized as an important area for health services and social rehabilitation of persons with disabilities. This emphasis is due to the significant increase in the number of people with chronic conditions and the survivors of neurological diseases or injuries of the nervous system, with the most representative ones being Stroke, Spinal Cord and Spinal, traumatic brain injuries and other neurological diseases, which leave residual disability. The recovery process takes place mainly in specialized rehabilitation centers, which feature an interdisciplinary working group for the care of these patients requiring complex and diverse rehabilitation procedures (de Andrade et al., 2010). International bibliography substantiates the necessity of specialized rehabilitation units which deliver Restoration maximally reducing costs (Illis, 2004) and maximizing the operating result, social activity and life satisfaction, ultimately, of the person with disabilities (Smith, 2002).

Rehabilitation includes multiple phases that occur over a period of weeks, months or even years. For many patients, primary objectives are to maximize independence, with the acquisition of basic skills, gait improvement, caregivers training, equipment provision (Taylor-Schroeder et al., 2011), and as noted by Caplan (1987) to reach a compromise among patients, families, friends and therapists regarding what constitutes the end of the treatment, rehabilitation and acceptable quality of life, is one of the most painful issues rehabilitation scientists face (Gilles & Clark-Wilson, 2000). The disease management promises significant benefits as a means for the improvement of chronic care and result optimization, given the comorbidity observed in chronic diseases, as well as in common risk factors. Terms such as care coordination, interdisciplinary team, case management, have been used interchangeably for disease management and patient education is the cornerstone of all disease management, which include daily activities training and evaluation of patient education (Krumholz et al., 2006).

In chronic disease and care, families have taken a supportive role in the maintenance and completion of daily activities of the patient and according to Miller et al. (2010) family and

caregivers should be active members of interdisciplinary teams and participate in decision making for the care of survivors after cerebrovascular event. Populations with physical and mental disabilities suffer from chronic diseases and exhibit varied and constant needs, which demand a combination of provided services sequentially or simultaneously from many providers, in the hospital, home or community (Kodner, 2002) and in accordance with Wilhelmson et al. (2011) usually relatives are for the chronically ill, the only common link between the different levels of care and to achieve a continuum of care, relatives should be involved in planning, decision making and efficiency of care. In Sweden "health care chains" have become an important part of complete health care. A chain of health care can be defined as coordinated activities in the health system that link together to achieve a final good quality result for the patient. A properly functioning chain care means that care is a continuous interaction between different standards of health care provision and caregivers.

In this study, defined as informal care is the provision of health care to dependent individuals, from family, friends, neighbors or others from the immediate social network who receive no financial compensation for the assistance they offer (Masanet & La Parra, 2011). Informal care is common worldwide and remains the most common form of long-term care (Van Houtven et al., 2011), while informal hospital care in international bibliography is primarily found in patients after leaving the Intensive Care Unit and inpatient units in critical condition (Van Pelt et al., 2010; Lee et al., 2009). The latest tendencies for prolonging survival and enhancement of ambulatory care has increased the number of informal caregivers in most cases husband/wife becomes the informal caregiver (Braun et al., 2007).

Informal care in hospital in Greece

The informal home care is a common phenomenon in many countries. In Greece informal care occurs in most hospitals, a phenomenon that has attracted the interest of nurse researchers from early '90 (Sapountzi - Krepia et al., 2008b). Relatives of patients stay next to their bed for hours and help. This phenomenon is highly correlated with the lack of nursing staff (Sapountzi-Krepia et al., 2008a) and

the root of the phenomenon, the same researchers found it is associated with low wages, poor image of nursing, lack of satisfaction nurses have from their work, insufficient number of qualified nurses, the aging nursing workforce industry, the riskiness of the job (Sapountzi-Krepia et al., 2008a). Participants provide informal care, which reflects specific nursing tasks. It is worrying that usually someone from the hospital staff proposes to relatives to stay close to the patient, even after visiting hours or even hire hired assistant (Sapountzi-Krepia et al., 2008 b). This implies that the staff deems it necessary.

The central role of the family in maintaining the state of health and the provision of informal care, vital to its members to manage diseases and provide assistance for the recovery and rehabilitation process, also emerges in the study of Lavdaniti et al., (2011). In reality the hospital informal care happens due to lack of staff and cultural influences on care standards. Another factor that affects the family visit is the health status of patients particularly when it is in a severe state. The presence of family members next to the bed of the patient during hospitalization can be an important source of emotional security and support for patients (Sapountzi-Krepia et al., 2008 a).

The distinct role of caregivers

In all care units nurses usually interact with family members who accompany patients during treatment and provide support to them. Most studies concerning care provision are based on important theoretical work on the state of stress (Lazarus and Folkman, 1984) and the theory of roles (Burr, 1979). These two dominant theoretical approaches in the care department, work, provided that the offering and taking care structures are different (Lingler et al., 2008). As part of the study in stress process, behaviors exhibited by those who accepted care, composed of environmental requirements, referred to as stress factors, which threaten or surpass the limits of adaptive capacity of caregivers. Similarly, caregivers are the focus on the approach of roles for studying the dynamic informal care. The applications of the theory of roles within the care department are common between nurse researchers, with some nurses bridging the prevailing theories, for use in their research data from both the treatment of anxiety, and the theory of roles (Lingler et al., 2008).

Studies show that providing care to a family member, can reduce anxiety and depression, increase sense of fulfilling their debt, a self-worth and bring greater closeness in relationships. It is also recognized that the burdens and benefits of offering care can coexist (McPherson, et al, 2011).

However, throughout the bibliography it is noted that because of the tremendous demands of care, the lives of caregivers often revolve solely around the needs of the loved one. The caregiver often sacrifices family relationships, friendships and participation in other activities, which leads to isolation and degradation of their social life, appearance of emotional symptoms or burnout signs. Caregivers may experience changes in sleeping patterns, appetite and energy and can describe the feeling of losing control of the situation or perception that their contribution has not a significant and lasting impact. Moreover grief usually accompanies any significant loss, including a relationship or role and the confusion and difficulty in troubleshooting or adaptation may be evident (Kasuya et al., 2000), while preserving themselves and their family is a common risk source for appearance of anxiety in almost all studies and the economic problems due to the loss of income is also a source of stress (King et al., 2010).

Coping with anxiety and depression because of their role, caregivers are often users themselves of the healthcare system (Siemens & Hazelton, 2011). In a study of Cornac and Tihanyi (2006) the needs of carers minimally recognized by professionals even from the recipients of care are noted and support that health professionals should focus more on the health needs of carers to ensure that they are able to maintain mental and physical health, to cope with the duties of care. Elliott and Pezent argue that caregivers need a coordinated, comprehensive and sustainable care plan, crafted by a trusted partnership between the involved professional care providers, which recognizes and accommodates variations in the needs of the caregiver and the one cared for over time. He stresses that although educational programs for caregivers are relatively common practice in rehabilitation programs they usually do not prepare caregivers adequately for issues and roles that they will face at home. For this reason it is recommended for the rehabilitation staff to develop a working partnership with the caregiver

during patient care in hospital (Elliot & Pezent, 2008). According to Hervey and Rumsay (2004) in their study in the UK for caregivers of the mentally ill, there is a need to shift the prevailing culture towards one in which caregivers are considered by professionals as partners in promoting patient care, partners with real knowledge and a unique perspective to contribute. Caregivers need information and knowledge to treat and support mechanisms; they also want recognition of their work. They often feel trapped in a lonely struggle, in which they feel belittled and isolated.

Throughout national bibliography the content of interventions for caregivers is encoded into three broad categories: information on professional skills, to assist them in carrying out their functions, family assistance to help caregivers - mates manage family concerns, and facilitating access to available resources (Northouse et al., 2010; Tamayo et al., 2010; Peeters et al., 2010; Griffin et al., 2009; Schubard et al., 2008). Secondary, as they are called, caregivers, assistants of the main carer, can contribute to improving care, thus constituting a more extensive network of care to avoid exhaustion.

Aim of the study

Exploring the views of caregivers on the services provided by the same care services and the assessment of their needs for health education and support, in a rehabilitation clinic in western Greece.

Methodology

Sample and procedure

This research was carried out through the Graduate Program " Primary Care " in School of Medicine, University of Thessaly. It was conducted in clinical Rehabilitation Hospital of Western Greece based on people with acquired motor - mainly - disabilities. The sample consisted of 75 caregivers of patients who provided unpaid services, willing to answer. A key criterion for exclusion from the study was salaried caregivers.

Research instrument of data collection

Respondents answered a self-administered questionnaire or in the form of a personal interview. The purpose of the study was orally analyzed and the caregivers signed a consent

form, that he agreed to take part in the research. The anonymity of caregivers who participated in the survey was respected. The survey was conducted from March 2012 to September 2012.

We used a questionnaire specifically designed to investigate the care provided to hospitalized patients, which was developed by Sapountzi - Krepia et al., (2008a) which has also been used in previous studies. A prerequisite of this survey was the hospitalization of the patient for at least two weeks after admission, under restriction of researchers to achieve the adjustment. So we called the caregiver to respond to the last week of the services he offered. The questionnaire consists of 80 questions, which are structured in five sections. The first section includes socio-demographic characteristics of patients and their caregivers, questions related to their stay in the hospital for care issues and two questions of qualitative methodology which illustrate the uniqueness of the caring experience caregivers have.

The second section includes 17 questions in a five-point scale, related to the care services they provide to their relative and a question to which we invited the caregiver to develop his view. The rating of the five-point scale ranging from 1 = strongly disagree to 5 = strongly agree. The third section includes 17 questions of the same five-point scale, selective questions and development of views that explore the need for health education of caregivers. The fourth section explores the need for information, through 6 questions on five-point scale, 2 questions of choice and a question to which we invite the caregiver to give his opinion. The fifth section explores the emotional needs of the caregiver, with 4 scale questions, 3 questions of choice and 2 questions which we invite the caregiver to give his opinion.

Statistical analysis

The statistical analysis of the results was performed using the statistical package SPSS. Using the coefficient Alpha-Cronbach the reliability of the scales was analyzed. Control check was made whether or not a statistically significant difference in the mean value of the scales was to be found, on the different levels of factors, gender, age, educational level of caregivers. For this purpose we used statistical methods t-test or analysis of variance with one factor (one way Anova). Through the F-test we

examined whether or not there is relationship between the dependent variable and each scale. In the case which the assumption of constant variance was not satisfied, instead of the t-test or analysis of variance with one factor, the test Welch was used which will be controlled by the test Levene. For the purpose of determining whether or not there are significant statistical differences between categories when they were more than two, we used the method of multiple comparisons LSD.

Ethical Issues

Permission approval of the study by the Scientific Council of the hospital was secured. Anonymity of participants was respected and the participants signed the consent form.

Results

The socio-demographic characteristics of the patients are shown in Table 1 and the socio-demographic characteristics of the patients' caregivers are shown in Table 2.

The study was conducted in a Rehabilitation Clinic of a Hospital of Western Greece and the sample consisted of 75 caregivers who were providing unpaid care and lived near their patients 24 hours a day, according to the import regulation, which requires mandatory stay caregiver in order to train them in providing care to these fully or partially incapacitated patients, even after leaving the hospital to be able to care for the patient in the community. They offered full time employment for a period of 14 days minimum to 90 days maximum. Patients were categorized according to their disease in those who had had a stroke (thrombotic or hemorrhagic) (n = 28, 37.3%), head injuries (including brain tumor surgical resection) (n = 10, 13.3%), with spinal cord injury or / and Spine (including remedial interventions Spine as kyphoscoliosis), but other disease entities such as spinal cord infarction (n = 22, 29.3%) and those suffering from neurological diseases such as Guillen Barré syndrome, multiple sclerosis, myopathy, brain hypoxia, (n = 15, 20.0%) and who were hospitalized for 14 days minimum and 90 days maximum, with an average of 20 days of hospitalization and standard deviation for 9 days

For the majority of caregivers of the sample (n = 55, 73.3%) it was not necessary to change their employment because of their relative's illness. Specifically, six caregivers (8.0 %) have

used normal leave, two (2.7 %) unpaid leave, one (1.3 %) turned full time to part time, 4 caregivers (5.3 %) received some facilitations from the employer, while 7 (9.3 %) had to discontinue their work. The 69.3 % of the caregivers (n = 52), hire a private nurse when they can't stay close to their sick relative or another relative replaces them in their absence.

The reasons why a caregiver is constantly near the patient are mainly for psychological support (n = 65, 86.7%), due to the severity of the disease (n = 50, 66.7%), fear for the safety of the patient (n=36, 48.0%) details are shown in Table 3. Of those who remain close to the patient for reasons of patient safety (n = 36) believe that the number of nursing staff is almost or completely unsatisfactory in a percentage of 43.2 %. Due to the severity of the patient's condition, 51 caregivers (out of 75) remain close to him. The caregivers in our sample strongly agreed at a rate 10.7% (n = 8), agreed by 37 (49.3 %) that usually one of the nurses or doctors recommend the family to remain close to a hospitalized relative even after the visiting hours or to hire a private nurse for the patient.

Services offered to the patient

The services offered to the patient's daily care or assistance are for grooming, fow wearing nightwear, changing sheets, feeding assistance, help for getting oral medications, transportation to various wing, transfer from wheelchair to bed and vice versa, physiotherapy exercises application, psychological support. Details for all services provided are presented in Table 4. The results on the effect of caregiver gender factor at the scale: services offered, show that women caregivers offer higher quantity of services to patients than men (p = 0.017) and the quantity of services is not affected by the level of study (p = 0.462). The sample was divided into three age groups, younger than 50 years, 50-60 years and older than 60 years and was not found any statistically significant difference between the first and the third age group (p = 0.08) to the services provided. However, the first age group (< 50) offers services of a higher quantity (3.3768) to patients than the caregivers of the third age group (3.0667).

Health education needs of the patient's caregiver

The health education needs of the caregivers

concern teaching of care techniques, knowledge about the disease, knowledge about treatment after discharge from the hospital, teaching for fundraising from family or nonprofit organizations, knowledge to support the emotional needs of patient and teaching for dealing with stress and the question on how health professionals should provide education to patient's relatives for the care of patients, the majority of caregivers (n = 71, 94.7%) stated that this should be done by nurses. 49 caregivers had the opportunity to be trained in a subject about patient care and 26 not. What they learned was intermittent bladder catheterization, feeding by mouth or gastrostomy, apply and remove stockings, splints, guardians, moving from bed to wheelchair, physiotherapy and occupational therapy exercises and general care. The teaching was done by a doctor, nurse, physiotherapist, occupational therapist, by showing the processes mostly, while two caregivers watched a video in English showing the manner in which intermittent catheterization is performed (Tables 5,6,7,8).

Needs of caregivers for information

The informational needs of the caregivers concentrate on the progress of the patient's rehabilitatio, information on cash benefits that give the pension funds for the purchase of various types of rehabilitation machines (wheelchair, sticks etc.), but also for the employment of a private nurse (Table 9). Sixty two caregivers (82.7 %) agreed and 10 (13.3 %) strongly agreed that they should be given information on where their patient has to go, after leaving the hospital, when a stay at home is impossible. Regarding the question, who in their opinion should provide information on patient care, the majority of the caregivers indicated (n = 68, 90.7%) nurses. To the question, what other

information you think would be useful to be provided to you, the following were reported: "More for the tests done" , "if I can also get compensation for caring for them," "more about special pensions provided to disabled people, or any other benefits," "we do not know what to ask, the staff should give us what we need to know", "what will happen tomorrow, we live in a remote village".

Emotional needs of the attendant

The emotional needs of the caregiver are mostly expressed by the desire to be able to discuss their concerns and fears about the state of the health status of the patient, and the degree of effective response to care needs that will arise in the future. Asked if it's a professional obligation of health professionals to provide emotional support to relatives of patients five strongly agreed (6.7 %), 51 agreed (68 %), by adding "we also need support" (Table 10).

Regarding health professionals from whom they would expect to provide emotional support, they answered by nurses at a rate 69.3% (n = 52), by doctors at a rate 68% (n = 51), by psychologists at a rate 50.7% (n = 38), social workers at a rate 8% (n = 6), the Physical Therapists at a rate 4% (n = 3), while another 7 (9.2 %) answered "all, each on his own field". ealth professionals by whom they had the opportunity to accept some kind of emotional support were mainly nurses (n = 38, 50.7%), adding it was because they meet them more often, physicians (n = 27, 36.0%), psychologists (n = 13 , 17.3 %), physiotherapists (n =3, 4.0%), while 26 caregivers (34.7 %) responded that by all employees and their majority, caregivers would address with greater ease asking for help nurses (n = 65, 86.7 %).

Table 1: Socio-demographic patient data of Clinical Rehabilitation

Age	Average	Standard deviation
16 - 85 years	55 - 21 years	15 - 22 years
Sex	N	%
Male	47	62.7
Female	28	37.3
Professional Status		
Freelance	24	32
Public - Private Employee	12	16
Worker - Farmer	8	10,7
Retired	17	22.7
Household	10	13.3
Student	1	1.3
Unemployed	3	4
Studies		
Illiterate	3	4
Primary School	24	23.0
Few primary school classes	3	4.0
Few middle school classes	6	8
Middle school	11	14.7
High school	11	14.7
Graduate IEK - KEK	2	2.7
University graduate	14	18.7

Table 2: Socio-demographic characteristics of caregivers of patients

Carers Age 30 - 79 years	Average 52.3 years	Standard Deviation 10.24 years
Sex	N	%
Male	20	26.7
Female	55	73.3
Occupation		
Freelance	9	12
Public - Private Employee	16	21.3
Worker - Farmer	4	5.3
Retired	15	20
Household	31	41.3
Marital status		
Married	68	90.7
Single	2	2.7
Widowed	3	4
Divorced	2	2.7
Studies		
Illiterate	2	2.7
Few classes of Primary School	1	1.3
Primary School	25	33.3
Few middle school classes	4	5.3
Middle School	13	17.3
Few High School classes	1	1.3
High School	15	20
Graduates IEK - KEK	2	2.7
University Graduates	11	14.7
Masters	1	1.3
Affinity with the patient		
Wife	48	64.0
Mother - father	13	17.3
Sister - brother	6	8.0
Daughter - son	5	6.7
Daughter in law - son in law	1	1.3
Other relation-friend	2	2.7

Table 3: Reasons why someone from the family or an exclusive nurse is near the patient on and outside visiting hours

Why is someone from the family or the exclusive nurse near the patient on and outside visiting hours?	N	%
1. Because of the seriousness of the patient's situation	50	66.7
2. Psychological support for the patient	65	86.7
3. From family tradition of support	15	20
4. Fearing for the safety of the patient	36	48
5. Due to lack of nursing staff	23	30.7
6. Due to unsatisfactory care providers (in quantity) in terms of nursing staff	4	5.3
7. Due to unsatisfactory care providers (in quality) in terms of nursing staff	1	1.3

Table 4: Services Offered

	Daily		4-5 times / Week		3-4 times / Week		1-2 times / week		Never	
	N	%	N	%	N	%	N	%	N	%
Morning care or assistance for morning care n = 75	68	90.7	-	-	1	1.3	2	2.7	4	5.3
Change or help change nightwear / pajamas n = 75	39	52.0	13	17.3	18	24.0	4	5.3	1	1.3
Grooming bed n = 75	67	89.3	1	1.3	1	1.3	4	5.3	2	2.7
Change of linen n = 65	7	9.3	6	8.0	30	40.0	21	27.8	11	14.7
Preparation / assistance for food or feeding the patient n = 75	67	89.3	-	-	-	-	3	4.0	5	6.7
Help getting oral medication Orally n = 75	68	90.7	1	1.3	-	-	1	1.3	5	6.7
Help getting other medication (supposituaries) n = 75	2	2.7	-	-	1	1.3	20	26.7	52	69.3
Monitoring the flow of IV serum n = 75	5	6.7	-	-	-	-	1	1.3	69	92.0
Granting bedpans n = 21	-	-	2	2.7	5	6.7	1	1.3	13	17.3
Washing the patient's hair in bath n = 75	1	1.3	-	-	3	4.0	31	41.3	40	53.3
Changing site of the patient's body on bed n = 75	-	-	-	-	4	5.3	30	40.0	41	54.0
Bathing patient in bathroom n = 75	6	8.0	10	13.3	16	21.3	5	6.7	38	50.7
Bathing patient on bed n = 75	20	26.7	7	9.3	11	14.7	6	8.0	31	41.3
Transferring patient from wheelchair to bed and vice versa n = 75	42	56.0	1	1.3	-	-	9	12.0	23	30.7
Transferring patient to various laboratories n = 75	45	60.0	-	-	2	2.7	4	5.3	24	32.0
Physiotherapy exercises application n = 75	61	81.3	1	1.3	4	5.3	2	2.7	7	9.3
Patient errands. Services n = 75	2	2.7	1	1.3	8	10.7	52	69.3	12	16.0

Table 5: Effect of caregiver gender factor at mid scale: services offer

Scale 1				test equality fluctuations	
Sex	N	Average	Standard deviation	Levene	ANOVA
Male	20	3.1167	0.47971	P=0.195	P=0.017
Female	55	3.3806	0.39035		
Total	75	3.3102	0.42905		

Table 6: Educational level of caregiver and services offered

	N	Average	Standard deviation	test equality fluctuations Levene	ANOVA
A degree	28	3.2595	0.51363	P=0.094	P=0.462
B degree	35	3.3048	0.37374		
C degree	12	3.4444	0.36441		
Total	75	3.3102	0.42905		

Table 7: Correlation between age groups and the services they offer

Age Groups					
	N	Average	Standard deviation	test equality fluctuations Levene	ANOVA
<50	23	3.3768	0.42097	P=0.092	P=0.001
50-60	27	3.4790	0.30720		
>60	25	3.0667	0.45256		
Total	75	3.3102	0.42905		

Table 8: Health education requirements of the patient's attendant

	I agree strongly		Agree		Neutral		Disagree		Disagree strongly	
	n	%	n	%	n	%	n	%	n	%
Need for learning care techniques n = 75	14	18.7	46	61.3	9 12.0		6	8.0	-	-
Knowledge about the disease n = 75	20	26.7	53	70.7	2	2.7	-	-	-	-
Learning about the prevention of pressure sores n = 75	11	14.7	31 41.3		19	25.3	14	18.7	-	-
Addressing complications n = 75	9 12.0		29	36.7	10	13.3	27	36.0	-	-
Knowledge for treatment after discharge from hospital n = 75	15	20.0	55	73.3	4	5.3	1	1.3	-	-
Diet and fluid intake n = 75	6	8.0	38	50.7	28	37.3	3	4.0	-	-
Learning techniques for asking for help from public and non- profit organizations n = 75	18	24.0	50	66.7	4	5.3	3	4.0	-	-
Learning to seek help from family n = 75	1	1.3	38	50.7	27	36.0	9	12.0	-	-
Knowledge about the emotional needs of the patient n = 75	8	10.7	54	72.0	10	13.4	3	4.0	-	-
Learning to treat anxiety / stress n = 75	14	18.7	49	65.3	10	13.3	2	2.7	-	-
Learning to avoid dispersing infections n = 75	2	2.7	17	22.7	40	53.3	16	21.3	-	-
Is hospital obliged for providing the above mentioned education? n = 75	1	1.3	43	57.3	19	25.3	12	16.0	-	-
Are health care professionals obliged for providing the above mentioned education? n = 75	6	8.0	57	76.0	7	9.3	5	6.7	-	-

Table 9: Needs of caregivers for information

Do you think it useful to be given regular information about the progress of the rehabilitation of the patient ?		
	N	%
Agree strongly	27	36.0
Agree	47	62.7
Neutral	1	1.3
You think it useful to be given information about the cash benefits that give the pension funds for the purchase of various types of objects for rehabilitation (wheelchair, crutches, prosthetics , etc.)		
	N	%
Agree strongly	32	42.7
Agree	42	56
You think it useful to be given information about the cash benefits given by the insurance funds for the employment of an exclusive nurse?		
	N	%
Agree strongly	27	36.0
Agree	41	54.7
Neutral	5	6.7

Table 10: Emotional needs of the attendant

To be able to discuss my concerns and my fears about the course of the health status of the patient with health professionals		
	N	%
Agree strongly	13	17.34
Agree	49	65.3
Neutral	10	13.3
Disagree	3	4
Disagree strongly	-	-
To be able to discuss my fears, if I will be able to respond effectively to the care needs of the patient that may occur in the future		
	N	%
Agree strongly	26	34.7
Agree	42	56
Neutral	5	6.7
Disagree	-	-
Disagree strongly	-	-

Discussion

In this study women caregivers outweigh men (55 women, 20 men), as in other studies, those of Allen (2012), Wolff & Kasper (2006), Szinovacz & Davey (2007). Also a significant time commitment to meet the many needs of the patient is seen, such as feeding, personal hygiene, changing clothes, and other services included in the treatment program and are consistent with previous studies, as Sapountzi-Krepia et al., 2006; Sapountzi -Krepia et al., 2008 (a,b); Lavdaniti et al., 2011.

In the rehabilitation clinic, according to this study, the majority of relatives of patients (69.3 %) hire an exclusive nurse when they can't be near the patient or are replaced by another relative in their absence, while at 30,7% they don't hire an exclusive nurse, but it wasn't also necessary for them to be absent. Moreover, the majority of caregivers are spouses/husbands, while we cannot

conclude to what extent the first-level caregivers are part of the "care chain" that other members of the family or social environment are. These results are consistent with an earlier study that of Sapountzi-Krepia et al. (2006). The reason for remaining close to the patient outside visiting hours for rehabilitation clinic for caregivers is mainly for psychological support of the patient due to the severity of the patient's condition, fearing for the safety of the patient, for lack of nursing staff and family support tradition. These responses may be associated with the traditional structure of Greek society that highlights the value of family environment for the patient to recovery, also revealing additional needs arising from staff shortages. Similar results were encountered in a study of Sapountzi-Krepia et al. (2008b).

A large percentage of the clinic rehabilitation, agree that usually one of the

nurses or doctors recommend the family to remain close to a relative hospitalized outside visiting hours, probably due to the recognition of the various needs of these patients as a result of the situation dependency they have. Similarly, one of the nurses or doctors usually recommend the family to hire a private nurse, according to this study, women offer services to a greater extent than men do and this is probably associated with the women generation "who did not have to leave the house" or previous experiences of care they may have or because of an "intrinsic" tendency for proper care. In the same sample of caregivers it was found that the services they offer are not affected by the educational level and we could say that shows the beliefs about the meaning of caring. In addition, younger caregivers provide more care services than the older ones and that is probably explained due to the better fitness the younger have.

This study highlights the need for caregivers of clinical rehabilitation, of education and health education, who appreciate as very important learning care techniques and gaining general knowledge about the disease, but also their involvement in addressing emergency situations, revealing the anxiety about the possibility of such an event, because they recognize the importance of proper conduct until the arrival of a doctor or nurse, but also the acquisition of valuable knowledge that will serve after leaving the hospital. Obvious is also the need for information about the benefits of public and non-profit organizations, but also the need to learn how to emotionally support the patient and our results are consistent with the study of Lavdaniti et al. (2011).

Information about the transition from hospital to home, emerge as necessary through this study. For many caregivers additional support is needed in their transition to other care facilities, as well as more information on all available resources in the community and benefits from public

non-profit organizations.

The same respondents felt it's the obligation of the hospital to provide education and health education and they indicate the nurses as the more appropriate from all health professionals for fitting to this role, probably because of the identity of nurses as main care providers, and thus as appropriate trainers. Caregivers think as suitable for providing information for patient care mainly the nurses.

According to the study sample, a need for emotional support for caregivers by health professionals exists.

It is estimated that adequate staffing of rehabilitation units will enable healthcare professionals to give from their working time for the emotional support of caregivers, but also time for conversation on general subjects, in a civilized environment, for relieving the stress and empowering caregivers in their struggle to provide better care for their hospitalized relatives. Nurses in their daily contact with patients and patients' relatives use counseling techniques and incorporate elements of counseling in clinical practice, with guidance, information, psychological support, encourage the expression of feelings of the patient and of the caregiver. It is the therapeutic relationship between nurse in Rehabilitation with the patient and his environment in order to promote health that strengthens the validity and effectiveness of the profession.

An organized and structured framework for information and support of caregivers may possibly reduce caregiver and nursing staff burden phenomena. In our study other locations of emotional needs were identified such as the need of proximity of staff, the need of staff to encourage caregivers and helping them to deal with their feelings of uncertainty about the future.

Conclusions

Recognizing the burden brought by long-term care on families and society, there is a

need for empowering the caregivers of chronically ill patients, in order to slow the deterioration of the quality of life of the caregiver and of the patient. This study shows that the way in which the health education needs of the caregiver are defined must be sufficient, after a careful assessment of educational needs.

Moreover, the expression of personal perceptions of the caregivers regarding informational needs and needs for emotional support have to be encouraged for strengthening the concept of self-care of the caregiver. To address these needs specific training plan is required towards the preparation of the caregiver in his new role and adaptation to the new lifestyle. The findings of our study could guide nurses in the design of appropriate methods for caregivers' support, through effective communication and through targeted interventions which will fulfill the caregivers' expectations. Effective communication between the nurse and the caregiver, will allow the development of effective patient care plan.

The training of caregivers with individualized programs based on the characteristics and personality of the caregiver, the discussion of needs, the severity of the patient's disease, the choice of the appropriate method of learning techniques, with constant repetition, rephrasing, with reference to the use of intervention and enhancing feedback, we believe that will alleviate in some way the caregiver burden, with considerable benefits for the patient. These may take the form initially of an organized teaching program and as well by the distribution of printed material regarding specific health care techniques. So by helping the caregivers to overcome stress, health professionals can help them to adapt, in their caring role that is going to continue in the future.

The impact of chronic disease is not limited only to the person who suffers, but also is extended to the family. Patients and their

families should be educated to make solid decisions and to become good co-helpers. In Greece, family and other forms of informal care is a vital link that enables people with chronic disease to remain in the community and reduce readmissions to the hospital. For this reason, the role of caregivers must be supported and strengthened.

References

- Braun M, Mikulincer M, Rydall A, Walsh A, Rodin G. (2007) .Hidden morbidity in cancer: spouse caregivers. *J Clin Oncol*, 25(30):4829-34.
- Cormac I, Tihanyi P. (2006) . Meeting the mental and physical health care needs of carers. *Advances in Psychiatric Treatment*, 12:162-172.
- de Andrade LT, de Araújo WG, Andrade Kda R, Soares DM, Chianca T. (2010). Role of nursing in physical rehabilitation. *Rev Bras Enferm*, 63 (6) :1056-60.
- Elliott TR, Pezent GD. (2008). Family caregivers of older persons in rehabilitation. *Neuro Rehabilitation*, 23(5):439-46.
- Giles GM., Clark-Wilson J. (2000). Ethical issues in Rehabilitation. In *brain injury. Rehabilitation. A neurological function approach (scientific I. Karpathiou Ch)*. Ed. Ellin, Athens,14.
- Griffin JM, Friedemann - Sánchez G, Hall K, Phelans, Van Ryn M.(2009) . Families of patients with polytrauma: Understanding the evidence and charting a new research agenda. *J Rehabil Res*, 46 (6) :879-892.
- Illis LS. (2004). The case for specialist units. *Spinal cord*, 42 (8): 443-446.
- Harvey N, Ramsay R. (2004) . Carers as partners in care. *Advances in Psychiatric Treatment*, 10:81-84.
- Kasuya RT, Polgar-Baley P, Takeuchi R. (2000). Caregiver burden and burnout. *Aguide for primary care physicians. Postgrad Med*, 108 (7) :119-23.
- King RB, Ainsworth CR, Ronen M, Hartke RJ. (2010). Stroke caregivers: pressing problems reported during the first months of caregiving. *J Neurosci Nurs*, 42 (6) :302-11.
- Krumholz HM, Currie PM, Riegel B, Phillips CO, Peterson ED, Smith R, Yancy CW, Faxon DP: American Heart Association Disease Management Taxonomy Writing Group. (2006). A Taxonomy for Disease management: a scientific statement from the American Association Disease Management Taxonomy Writing Group. *Yale University, USA*, 114 (13) :1432-45.
- Kodner DL, Spreeuwenberg C. (2002). Integrated care: meaning, logic, applications, and implications - a discussion paper. *Int J Integr Care*, 2: e12.

- Lavdaniti M, Raftopoulos V, Sgantsos M, Psychogiou N, Tsaloglidou A, Georgiadou C, Serpanou I, and Sapountzi-Krepia D. (2011). In-hospital informal caregivers' needs as perceived by themselves and by the nursing staff in Northern Greece: A descriptive study. *BMC Nursing* 10:19.
- Lingler LH, Sherwood PR, Crighton MH, Song MK, Happ MB. (2008). Conceptual challenges in the study of caregiver Care Recipient Relationships. *Nurs Res*, 57(5) :367-372.
- Masanet E, La Parra D. (2011). Relationship between the Number of Hours of informal care and the Mental Health Status of caregivers. *Rev Esp Salud Publica*, 85 (3); 257-66.
- McPherson CL, Wilson KG, Chyurlia L, Leclerc C. (2011). The caregiving relationship and quality of life among partners of stroke survivors: A cross-sectional study. *Health Qual Life Outcomes*, 9:29.
- Peeters J, Van Beek A, Meerveld J, Spreeuwenberg P, Franke A. (2010). Informal caregivers of persons with dementia their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nursing*, 9 (1):9
- Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P, Billinger SA: American Health Association Council on Cardiovascular Nursing and the stroke. Council. (2010). Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association *Stroke*, 41 (10) :2402-48
- Northouse LL, Katapodiri MC, Song L, Zhang L, Mood DW. (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *Cancer J Clin*, 60 (5) :317-39.
- Sapountzi-Krepia D, Raftopoulos V, Sgantsos M, Dimitriadou A, Ntourou I, Sapakas G. (2006). Informal in-hospital care in a rehabilitation setting in Greece: An estimation of the nursing staff required for substituting this care. *Disability and Rehabilitation*, 28(1):3-11.
- Sapountzi-Krepia D, Lavdaniti M, Psychogiou M, Arsenos P, Paralikas T, Triantafylidou P, Georgiadou C. (2008). Nursing staff shortage and hospital informal care in an oncology hospital in Greece: The nursing staff's perceptions. *International Journal of Nursing Practice*, 14:256-263 (a).
- Sapountzi-Krepia D, Raftopoulos V, Psychogiou M, Sakellari E, Toris A, Vrettos A and Arsenos P. (2008) . Dimensions of informal care in Greece: the family's contribution to the care of patients hospitalized in a oncology hospital. *Journal of clinical Nursing* 17, 1287-1294 (b).
- Schubart JR, Kinzie MB, Farace E. (2008). Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol*, 10 (1) :61-72.
- Siemens I, Hazelton L. (2011). Communicating with families of dementia patients: practical guide to relieving caregiver stress. *Can Fam Physician*, 57 (7) 801-2.
- Smith M. (2002). Efficacy of specialist versus non-specialist management of spinal cord injury within the UK. *Spinal Cord*, 40:11-16.
- Tamayo GL, Broxson A, Munsell M, Cohen MZ. (2010). Caring for the caregiver. *Oncol Nurs Forum*, 37(1): E50-7.
- Van Hooftven DH, Voils CI, Weinberger M. (2011). An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatr*, 11:77
- Wolstenholme, Fenn D, Gray A, Keene J, Jacoby R, Hope TM .(2002). Estimating the relationship between disease progression and cost of care in dementia. *Br J Psychiatry*, 181:36-42.
- Taylor-Schroeder S, LaBarbera J, McDowell S, Zanca JM, Natale A, Mumma S, Gassaway J, Backus D. (2011). The SCIREhab project: treatment time spent in SCI rehabilitation. Physical therapy treatment time during in patient spinal cord injury Rehabilitation. *J Spinal Cord Med*, 34 (2):149-61.