

**ORIGINAL PAPER****Informal Care in a Formal Setting: the Case of a Neurosurgery Clinic in Western Greece**

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**Abstract**

**Introduction:** Informal care is a common phenomenon that occurs in all hospitals around the world. Greek and International literature define informal care as an unpaid care that provided to hospitalized patients from family members, friends and in general from the close social environment. In Greece informal care has become a tradition mainly due to the shortage of nurses in hospitals.

**Aim:** The main aim of the present study is to investigate the informal caregivers' opinion about informal care in a neurosurgical clinic.

**Methodology:** The sample consisted of 39 in-hospital informal caregivers from a neurosurgical clinic of a hospital in Western Greece. The data were collected in 2012 within a period of three months. A self-reported, validated and reused questionnaire was completed. The statistical analysis was based on the statistical measure SPSS and the reliability of the scales were analyzed by using alpha-cronbach factor.

**Results:** The majority of the informal caregivers in the neurosurgical clinic were women and the main reasons that stayed by the bedside of the patient were: to support psychologically the patient, the severity of the patient's condition and fear about the patient's safety. Caregivers agree with doctor's and nursing staff's recommendation that someone should stay close to the patient and most of them agree to hire a privately paid helper. The gender of caregivers does not affect the level of services that they offer to the patient neither the educational level but age does. Finally, the study showed that caregivers want to be informed of the patient's condition and most of them prefer to get the information from nurses also, they need emotional support from health professionals, to learn how to face patients' emotional needs and to know about the financial availability from insurance companies.

**Conclusion:** In-hospital Informal caregivers play an important role by providing help to patients as well as to health professionals. The design of appropriate supportive techniques and training programs from health professionals will help caregivers to strengthen their role.

**Key words:** Informal care, caregivers, health professionals, neurosurgical patients.

## Introduction

Health provision varies around the world, every country has a different model of care. Although, informal care takes place in all countries all over the world (Sundstrom et al., 2002; AIOHaWC 2004; Decima Research INC 2004; Viitanen, 2005; Mesteneos & Triantafillou 2005; Doran et al. 2006; Vilaphana et al., 2011, Van Houtven et al., 2011). In Europe the number of countries that have developed national strategies for informal carers services is limited (García-Calvente et al., 2007).

## A selection of definitions of informal care from the international literature

Informal care is defined by Masanet and La Parra (2011) as the provision of care to dependent persons from family members, friends, neighbors, and from their close social environment, without any compensation for the care provided. In an earlier definition informal care is described as a non-market composite commodity consisting of heterogeneous parts produced by one or more members of the social environment (Van den Berg et al., 2005), another definition describes informal care as an unpaid care provided by family members, friends or other persons to people who are unable to perform successfully the activities of daily living (AIOHaWC, 2004).

## Informal caregiver burden

Informal caregivers undergo a series of challenges and consequences regarding physical, emotional, mental, social and financial well being (Dunn, 2010). Recovering from a critical illness may last a long time, increasing the risk of overburdening the caregiver (Choi et al., 2011). During the primary period caregivers report many changes in their lives. Caregivers have to adopt a new role with many problems and difficult responsibilities and to experience new feelings that were unexpected (Alspach 2009; King et al., 2010b). In addition, stress affects the caregivers' behavior and their perceived experience of the caring process (Douglas & Daly 2003; McKee et al., 2011).

## In-hospital Informal Care

The majority of the literature on patients' visitation and in-hospital informal care is focused mainly on intensive care units (Dietel et al., 1982; Ross et al., 1997; Tanner 2005; Van Pelt et al., 2010). However, there is evidence in the literature that family members stay at the bedside of their hospitalized relatives also, in other hospital wards for a considerable amount of time in order to take care of

their hospitalized relatives (Rotman-Pikielny et al. 2007; Fedor & Leysene-Ouvrard, 2007). The informal caregivers' needs are summarized in the areas of information, communication and support (Griffin et al. 2009, Davidson, 2009, Lavdaniti et al. 2011). Moreover, Tamayo et al., (2010) emphasizes that caregivers often cite deficit in skills training, related to the care of their patients, lack of help from health professionals and lack of social support. In addition, Elliott and Pezent (2008), argue that the health care services can help in adequately addressing of caregivers' needs, as these needs are subject to change associated with physical, psychological and social resources of caregiver.

## In-hospital Informal Care in Greece

Research on in-hospital informal care in Greek hospitals started from the early '90s (Sapountzi, 1992) and it is supported that is highly correlated with the nursing staff shortage and cultural influences on health care provision patterns (Sapountzi-Krepia et al., 2006; Sapountzi – Krepia et al., 2008b; Lavdaniti et al., 2011). It is also supported that the reason for the long lasting tradition of the in-hospital care is the reduction of hospital costs of covering nursing activities with fewer nurses and even with less specialized nurses (Sapountzi-Krepia et al., 2006, 2008a). Another factor that caregivers argue that influenced their decision to stay by the bedside of their patients it was the severity of patient condition; while it is also supported that the presence of a family member as an in-hospital caregiver is a course of psychological support for patients (Sapountzi- Krepia et al., 2008 a). In Greece, as in most countries, the vast majority of the informal caregivers are middle-aged women, wives or daughters of the patients (Sapountzi-Krepia et al., 2006, 2008a, 2008b; Lavdaniti et al., 2011). The Greek studies published about the in-hospital informal care have been carried out in Athens which is the capital of the country and in Thessaloniki the second major city of Greece, were conducted in surgical and pathological wards, in oncology hospitals (Sapountzi 1992; Sapountzi-Krepia et al., 2008a, 2008b) and in rehabilitation settings (Sapountzi-Krepia et al., 2006). So far, none have been conducted in a Greek Neurosurgical clinic, thus it was interesting to explore this particular topic.

## Aim of the study

The aim of the present study were to assess the in-hospital informal caregivers opinions regarding: (a) the reasons that prompted in-hospital informal

caregivers to provide care to their hospitalized relatives; (b) the kind of caregiving tasks that in-hospital informal caregivers provided to hospitalized patients; and (c) satisfaction from the number of nurses that were working in the ward in which their relative were hospitalized; (d) their health education needs, informational needs and needs for support.

## Methodology

### Sample and procedure

The present study is a pilot descriptive study that was conducted in a neurosurgical clinic of a hospital situated in a major city in Western Greece. Eligible for participation in the study were in-hospital informal caregivers who cared for a hospitalized patient in the neurosurgery clinic for at least seven days. Further inclusion criteria were the following: (a) willingness to participate in the study, (b) ability to speak and read Greek, (c) age 18 years or older (informal) and (d) in-hospital informal caregivers who cared for a hospitalized patient at least for 10 days. All informal in-hospital caregivers in the neurosurgical clinic who were eligible to participate in this study ( $n = 47$ ) were provided information about the study, including issues of confidentiality. Three of the potential subjects were excluded from the sample, because they were not capable to read and understand satisfactorily the Greek language and seven denied participation in the study for personal reasons. The remaining thirty-nine respondents agreed to participate in the study, signed an informed consent form and filled the questionnaire. Two questionnaires that were incompletely filled were excluded from further analysis. The data were collected in 2012 within three months.

### Ethical Issues

Ethical approval of the study protocol were granted by the Medical School of the University of Thessaly in Greece were also provided a permission for data collection – after approval of the research protocol – by the scientific committee of the hospital in which the research were carried out.

### Research instrument of data collection

A self-report, validated and used in prior Greek studies questionnaire was used (Sapountzi-Krepia et al 2008, 2008a; Lavdaniti et al 2011). The questionnaire consisted of 80 questions with five units. The first unit included patients' and caregivers' socio-demographic characteristics also, questions that were related to hospital

accommodation and care and finally, two questions of quantitative methodology, which depict the uniqueness of the caregivers' experience in looking after the patients. The second unit included 17 questions on a first degree scale that were related to the services of care that caregivers offer to the patients and one question in which the caregivers were asked to develop their opinion. The scoring on the five-degree scale ranges from: 1=completely disagree to 5=completely agree. The third unit consisted of 17 questions on the same five-degree scale, multiple choice questions and open format questions of developing an opinion and investigation of caregivers' need for health training. The fourth unit investigated the need to gather information through 6 five-degree scale questions, 2 multiple choice questions and one question where the caregivers were asked to present their opinion. In the fifth unit the caregivers' emotional needs were investigated, via 4 scale questions, 3 multiple choice questions and 2 questions in which the caregivers were asked to state their opinion.

### Statistical analysis

The statistical analysis of the results was conducted using the statistical measure SPSS. Before everything else, the reliability of the scales was analyzed by using Alpha-Cronbach factor. The presence of the statistically significant difference in the mean value of the scale with regard to different level factors, gender, age, educational level were checked. For that purpose, the statistical methods of T-test or the fluctuation analysis by one factor (one way Anova), were used. Through the T-test we examined the presence or not of the relationship between the dependent variable and each scale. In the case when the supposition of the steady fluctuation was not satisfied, instead of the T-test or fluctuation analysis by one factor, the Welch test was used which is checked by the Levene test. To determine statistically significant or no differences, among categories when they were more than two, the LSD multiple comparison method was used.

### Results

The mean age of the sample was  $48.76 \pm 12.58$  years and the majority of them ( $n = 30$ , 82.1%) were females and married ( $n = 31$ , 83.8%). The socio-demographic characteristics of the sample are presented in Table 1. Regarding the demographic characteristics of the patients, the majority of them ( $n=24$ , 64.9%) were male with a mean age of  $50.08 \pm 19.49$  years. The mean duration of hospitalization was  $18.9 \pm 4.7$  days.

**Table 1: Social and demographic characteristics of sample.**

<u>Sex</u>	N	%
Men	7	19
Woman	30	81
<u>Marital status</u>		
Single	3	8.1
Married	31	83.5
Widowed	1	2.7
Divorced	1	5.7
<u>Education</u>		
Illiterate	1	2.7
Primary	12	32.5
Secondary 1 <sup>st</sup> level \ (3 years)	8	21.5
Secondary 2 <sup>nd</sup> level (3 years)	7	19
Vocational Training	4	10.8
University/Polytechnic	5	13.5
<u>Relation with the Patient</u>		
Wife/Husband	13	35.14
Mother/Father	11	29.73
Sister/Brother	6	16.22
Daughter/Son	5	13.51
Daughter-in-law/Son-in-law	1	2.7
Grandchild	1	2.7

Caregivers usually stay by their patients' bedside for 24 hours, if they were unable to stay another family member substitute them or they hire a privately paid patient's helper (n=29, 78.4%) .

The sample were asked to provide the reasons that prompted them to stay by their patients' bedside, their answers varied and most of them gave more than one reason.

Escorts' opinions about why they believe that the nursing staff/ doctors recommend to family members to stay close to the patient even after visiting hours were the following:

disagree (n=2, 5.4%), neutral (n=7, 18.4%), agree (n=26, 70.3%) adding, not for all the cases, only for the critical patients strongly agree (n=2, 5.4%).

With regard to why the nursing staff/ doctors recommend to the family to hire a privately paid patient's helper, the caregivers' answers were the following: 1 strongly disagreed (2.7%), 10 disagreed (27.0%) 10 answered neutral (27.0%) and 16 agreed (43.2%).

Regarding the question, what you would like the ministry or the administration to change or do in order not to be obliged to be continually close to the patient but visit him/her during visiting hours we received the following answers:

*"to have a nurse responsible for every room, like abroad",*

*"I prefer to be close to him/her, it is better this way",*

*"for critical patients there should be no visiting hours".*

Out of the total number of interviewees, 5.4% (n=2) believe that the number of nursing staff is completely unsatisfactory, 27.0% (n=10) almost satisfactory, neutrally satisfactory 45.4% (n=17), very satisfactory 18.9% (n=7) and 1 answered totally satisfactory (2.7%).

In table 3 we can see the services that caregivers provide at the neurological clinic, the study sample and the frequency that offered.

As we can see in Table 4, 28 escorts agreed (75.7%) and 2 (5.4%) strongly agreed to be given information about where the patient can go after being discharged from hospital, where the choice of residence in their home is impossible. About the above information they believe that it is the hospital's obligation to offer it. Of these, 89.2% (n=33) agreed and 1 (2.7%) strongly agreed, while 3 (8.1%) gave a neutral answer.

The same number of interviewees agree on 3% (n=36) and 1 (2.7%) strongly agrees that it is the health professionals' obligation to offer such information. In the question "what other piece of information do you consider useful to be given?", they generally report funds, insurance companies, and employment.

With regard to the question which health professional ought to provide information to the patients' relative about the patient's care, escorts (having the option to choose more than one answer) indicated: nurses (n=35, 94.6%), doctors (n=29, 78.4) psychologists (n=6, 16.2%), physiotherapists (n=4, 10.8%) and social workers (n=2, 5.4%). Until today they have received valuable information the 67.6% (n=25) from doctors, the 83.8% (n=31) from

nurses, 2.7% (n=1) from social workers, 1 (2.7%) from psychologists and 1 (2.7%) from physiotherapists while the rest 4 answered from no one because they thought that it wasn't necessary.

**Table 2: Reasons of staying close to the patient outside visiting hours.**

Which are the reasons that a family member stayed with the patient outside visiting hours?	N	%
1. Because of the severity of the patient's condition	22	59.5
2. To support psychologically the patient	34	91.9
3. Because of family tradition	4	10.8
4. Out of fear for the patient's safety	15	40.5
5. Because of shortage in the nursing staff.	7	18.4
6. Because of unsatisfactory care (in quantity) on a part of the nursing staff.	4	10.8
7. Because of unsatisfactory care (in quality) on a part of the nursing staff.	1	2.7
8. Other	14	37.8

With reference to the additional emotional needs that they would like to be covered by the hospital staff, most caregivers answered: "I can't think of anything right now", "I don't know what else", they should talk to him/her, I'm exhausted", "I want to hear all the time that he's fine, that they are doing their best". 33 escorts (89.2%) agreed that it is the health professional's obligation to offer emotional support to the patients' relatives, 3 (8.1%) answered neutrally and 1 (2.7%) disagreed. Regarding the question which health professionals they are expected to provide emotional support, caregivers suggested nurses (n=30, 81.1%), doctors (n=30, 81.1%), psychologists (n=21, 56.8%) and social workers (n=4, 10.8%).

With regard to who provided them emotional support 5 (13.5%) answered doctors, 16 (43.2%) nurses, 4 (10.8%) psychologists while the remaining 12 answered that they did not have the chance of emotional support. The majority of the caregivers would feel more comfortable asking for help from nurses the 97.3% (n=36) and from doctors the 35.1% (n=13), while they did not select any other health professional.

In whole, caregivers do not hesitate to ask what they want, although they would prefer to be encouraged more, to listen to the escort more carefully and to have more time available for them.

## Discussion

In the neurosurgical clinic, the majority of the sample were women, primarily spouses or parents, obviously due to the patients' young age in these units. The main reasons that caregivers stayed close to the patient outside visiting hours were to support psychologically the patient, the severity of the condition and finally, due to the fear for the patient's safety. These findings correspond with earlier studies by Sapountzi-Krepia et al., 2006, Sapountzi-Krepia et al., 2008 and Lavdaniti et al., 2011.

Interviewees seem to agree to a great extent with doctors or nursing staff recommendation that a family member or a relative should stay close to the patient, possibly because of the severity of the condition, 18.4% held a neutral opinion, possibly for reasons related to lack of family environment, while 5.4% disagreed probably because staying close to the patient requires professional sacrifices. 43.2% agreed to hire a privately paid helper, possibly because of the obvious overburdening of the relative, 27.0% disagreed, probably because of financial problems and 27.0% answered neutrally, mainly because they believe it concerns only severe cases. Further research, regarding short term and long term consequences due to the professional sacrifices arising from the need for care, would

**Table 3: Frequency of care activities that performed by informal in-hospital caregivers per week.**

	Every day		5 – 6 times per Week		3 – 4 times Per Week		1 – 2 times Per Week		Never	
	n	%	n	%	n	%	n	%	n	%
Oral and facial care	35	94.6	-	-	-	-	1	2.7	1	2.7
Help getting dressed	20	54.1	5	13.5	8	21.6	4	10.8	-	-
Making patients' bed, exclusive of changing sheets	31	83.8	-	-	-	-	2	5.4	4	10.8
Changing sheets	4	10.8	3	8.1	15	40.5	7	18.4	8	21.62
Help with feeding	29	78.4	-	-	-	-	1	2.7	7	18.92
Help with taking oral medication	32	86.5	-	-	-	-	-	-	5	13.5
Help with administering medication	1	2.7	-	-	-	-	3	8.1	33	89.2
Monitoring the flow of the I.V. fluid	36	97.3	-	-	-	-	-	-	1	2.7
Providing a bedpan	20	54.1	-	-	2	5.6	8	21.6	7	18.92
Help with or hair washing in the bathroom	-	-	-	-	1	2.7	1	2.7	35	94.6
Help with or hair washing in bed	-	-	-	-	3	8.1	8	21.6	26	70.3
Help with or body washing in the bathroom	-	-	-	-	4	10.8	2	5.4	30	83.34
Help with or body washing in bed	11	29.7	11	29.7	6	16.2	2	5.4	7	18.92
Help with transfer activities (bed to wheelchair and vice-versa)	-	-	-	-	1	2.7	3	8.1	33	89.2
Transfer of patient to hospital departments (X-rays ect)	-	-	-	-	-	-	-	-	37	100.0
Help with physical therapy exercises	5	13.5	-	-	2	5.4	2	5.4	28	75.7
Errands (post, bank, shopping etc.)	1	2.7	1	2.7	7	18.9	24	64.9	4	10.8

**Table 4: Informational and Emotional needs of the patients' caregivers**

Informational needs	Strongly agree		Agree		Neutral		Disagree		Strongly disagree	
	N	%	N	%	N	%	N	%	N	%
Do you consider it useful to be given information on a regular basis about the course of rehabilitation of the patients?(n=37)	11	29.7	26	70.3	-	-	-	-	-	-
Do you consider it useful to be given information about financial benefits offered by insurance companies for rehabilitation equipment? (n=37)	5	13.5	22	59.5	7	18.9	-	-	-	-
Do you consider it useful to be given information about financial benefits offered by insurance companies for a privately paid helper? (n=37)	7	18.9	30	81.1	-	-	-	-	-	-
<b>Emotional needs</b>										
To be able to discuss my concerns and fears concerning the patient's health condition with health professionals (n=37)	7	18.9	27	73	2	5.4	1	2.7		
To be able to discuss my fears as to whether I will be able to effectively face the patient's needs for care that may arise in the future (n=37)	9	24.3	24	64.9	3	8.1	1	2.7		
To be given ample time to discuss even general issues with health professionals as a stress relief measure (n=37)	-	-	15	40.5	8	21.6	14	37.8		

provide further knowledge about the emotional burden of the patients' escorts.

According to the study, in the neurosurgical clinic, men and women offer the same level of services to the patients ( $p=0,322$ ), mainly because the patient's condition dictates what they offer, the number of offered services by caregivers is not affected by their educational level ( $p=0,099$ ) and that probably shows the perceptions about care. The results of the study also showed that young people offer more services than older ones ( $p=0,010$ ) followed by middle aged people that offer as well more services than older people ( $p=0,032$ ), which may be related to the escorts' physical condition or to the treatment of the disease, which is a challenge for younger people, while, for the older ones, it may be a burden in their already overburdened life. In addition, it is clear from the study that caregivers need to learn about care giving techniques, to obtain more knowledge about diseases, but mainly to learn about stress management and how to deal with the patients' emotional needs as well as information about available funds.

The caregivers in this study do not wish to be actively involved in the handling of emergency situations, nor to acquire specialized knowledge about care giving, possibly as an expression of weakness, fear and responsibility which may involve invasive practices on their part as well as their confidence in hospital staff as the only qualified to deal with emergency situations and to provide special care giving techniques. At this point, and this is not a limitation of our study, we would like to mention that in units of acute care, teaching about care does not involve the concept of teaching care giving techniques, but also urgent supervision and constant monitoring of the patient because of the nature of the condition and the complications that may develop. Nonetheless, the majority of the interviewees (64, 9%) answered that the hospital should provide training programs about the patients' care, indicating the nurses to a great extent (94, 6%), as those who are professionally obliged to offer care giving training. 73% agreed and strongly agreed to be given information about financial benefits given by insurance companies for rehabilitation equipment, the feelings of stress, inability, fear and worry that derived from an acute episode, along with the caregivers' need for emotional support. At this point, we should mention the empathy of nurses, which promotes the humane aspect of nursing and the professional prestige.

## Conclusions

The findings of our study could guide nurses to design appropriate supportive techniques for caregivers through effective communication and targeted interventions which would fulfill their expectations. The knowledge of the changes that taking place due to the sudden aspect of the disease will enable health professionals to adjust their intervention and support towards caregivers in order to help them cope with the difficult tasks. The concept of prediction and cognitive preparation for an upcoming event, as well as the estimate of how people handle a challenge are important aspects of intervention with the aim of delaying the appearance of the effects of overburdening because of care giving. The definition of the overburdening factors will help in the appropriate interventions to empower caregivers.

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