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Informal Caregivers in Greek Hospitals: a Unique Phenomenon of a Health System in Financial Crisis

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ABSTRACT

Background: In Greece it is quite common for family members to provide informal unpaid care for another family member during hospitalization, alongside healthcare professionals. Understaffing and lack of nursing personnel, due to austerity measures implemented in Greece during the last eight years, force families to provide informal care during hospitalization. The aim of the research was to study the role of informal caregivers (IC) during a family's member hospitalization, factors affecting their presence and patient's needs that were met by them. **Material and methods**: This cross-sectional study was conducted in five medical wards of a tertiary general hospital in big city of Northern Greece, during 14 weeks using a questionnaire with demographics, clinical data, and type and frequency of interventions performed by ICs. Patient/nurse ratio was also recorded. **Results**: On the total, 210 ICs participated (63.42% response rate). The vast majority of ICs were females, married, close relatives and in their late forties. More than half of them (58.1%, n=122) stayed by their patient bedside for more than 17 hours per day, as it was found that 13.8 patients were allocated to each nurse. Less than one quarter of ICs reported that their patient's status was not serious at all and according to them, one third of the patients were totally dependent and one fifth were totally self-sufficient and able to take care of themselves. Nineteen out of the twenty three interventions performed by caregivers were interventions of basic nursing care. **Conclusion**: The GHS administration officials are called to consider nursing understaffing in order to provide adequate and safe care. As new personnel is very difficult to be hired, family members could be trained, through structured programs, in basic nursing skills and interventions, so that they could participate in their family member's care and provide continuity of care at home.

Keywords: caregivers, family members, hospitalization, nursing interventions.

1. INTRODUCTION

Family, a major source of social support, is closely related to self-care (1). Quite often, family plays a key role in supporting and caring for the ill member, as unpaid caregivers. The unpaid care provided by non-healthcare professionals/family members is called informal care and can be found in various cultures and civilizations where family bonds are strong. Informal caregivers provide daily care at home and, often, when hospitalization is required, alongside healthcare professionals.

In Greece, over the last seven years, in the midst of economic turmoil, literature has revealed a number of negative effects for the population as well as the healthcare system in general. Despite that, it seems that Greeks still withstand. This paradox phenomenon is attributed to the "strong traditional bonds of family and social solidarity within the Greek society that have prevented the onset of a widespread humanitarian crisis" (2).

In the beginning of the 1980s, the current Greek Healthcare System (GHS) was established, based on the UK National Health System (NHS), with some variations. It consists of a mixture of public and private hospitals/clinics and private doctors, funded by population taxes, public sickness funds and private insurance agencies, and, quite often, out-of-pocket money from healthcare consumers. During the years of austerity, dramatic reductions in salaries and pensions, unemploy-

ment and consequent extreme financial inability and social exclusion are leading people, which previously could afford to visit private clinics and doctors, back to public hospital (3).

It has been argued that understaffing and lack of nursing personnel is a phenomenon attributed to economic crisis and austerity measures. A more in depth Greek literature research, can show that even in the 1960s and 1970s there have been requests for increases in the number of employed nurses (4-6). Understaffing is causing increased patient/nurse ratio resulting in lower quality of delivered care. Over the decades, this care deficit convinced Greek population that patients, during hospitalization, must be accompanied by a family member which will support every need (7).

Meanwhile, public hospitals have to overcome under funding, reduced budgets, lack and freeze in recruitment of personnel due to the enforcement of economic measures, making difficult to meet the increased needs (8-9). Due to these financial difficulties, quite often, Greek hospitals have to cut down on equipment, consumable materials and medications or replace these with others less expensive. While public healthcare system is facing increased demands for services, inevitably it is going to offer lower quality and quantity of healthcare services. Within this context, it was decided to study the role of informal caregivers in a tertiary hospital. The aim of the present research was to study the factors affecting the coming and staying of informal caregivers during a close relative's hospitalization. Furthermore, the mapping of needs that were met by informal caregivers during their stay by the patient's bedside was researched also.

2. MATERIAL & METHODS

2.1. Setting and Sample

A cross-sectional study was conducted in five wards of the medical services of a tertiary general hospital in a big Northern Greece city. In order to participate, caregivers had to be at the bedside of his/her relative continuously, day and night, to speak Greek and give his/her written informed consent. The patient had to be hospitalized for at least five days. On the total, 210 informal caregivers, from the initial 302, agreed to participate in the study (response rate 63.42%). Anonymity of their personal data was kept. Approval of the hospital's and the health prefecture's ethics committee was obtained after providing the necessary documents.

2.2. Procedure

Data collection lasted for 14 weeks, during summertime of 2016. Data were collected in one different day per week, in order to gather holistic information. Caregivers were approached and asked to fill in the questionnaire in one hour. The researcher, keeping a record of the exact time of questionnaire administration, returned to collect it at exactly one hour. For elder participants with eye-sight problems, the researcher completed the questionnaire during an interview.

2.3. Research Instruments

A questionnaire measuring the level of informal caregiving in hospitalized patients (7) was used, after obtaining permission by the researchers. The specific questionnaire was divided into five parts with five-point Likert scale questions (1=totally disagree to 4=totally agree), including patients' and caregivers' demographics, data about hospitalization and caregivers' interventions performed. In addition, data on the patient/nurse ratio on the day of the interview and on the specific ward for each shift were recorded.

2.4. Data Analysis

Statistical analysis was performed using SPSS Version 21.0. For nominal-qualitative variables relative and absolute frequencies for each group were calculated. For continuous variables measures of central tendency and variability were estimated. Normality test, with Kolmogorov-Smirnov, was conducted and non-parametric tests were used. Statistical significant level was determined at 5% (p=0.05).

3. RESULTS

3.1. Demographic characteristics

The majority of the informal caregivers were females caring for mainly male patients (55.7%, n=117). The mean age of caregivers was almost ten years younger than the patients (Table 1). More details on caregivers' characteristics regarding family status, residence and presence by the patient's bedside are presented in Table 2. More than half of the caregivers stayed by the bedside of their patient for more than 17 hours/day for at least 9.3 (±10.4) days, even though most of them resided in the same city/town with the hospital and could easily/quickly come to the hospital if needed. Moreover, more than one third of the caregivers (35.7%, n=75) reported that their patient's clinical status was extremely serious and only 22.9% (n=48) of the patients were totally self-sufficient and able to take care themselves.

		Caregivers	Patients
Age		48.7 (±14.8)	58.6 (±18.3)
Gender	Male	25.2% (n=53)	55.7% (n=117)
	Female	74.8% (n=157)	44.3% (n=93)
Educational status	Il-literal	1.9% (n=4)	4.8% (n=10)
	Elementary school	12.9% (n=27)	24.8% (n=52)
	High School	15.2% (n=32)	15.7% (n=33)
	Lyceum	23.8% (n=50)	20.5% (n=43)
	Vocational school	15.2% (n=32)	12.9% (n=27)
	Applied University	13.8% (n=29)	3.8% (n=8)
	University	10.5% (n=22)	6.7% (n=14)
	Post-graduate	5.7% (n=12)	1.9% (n=4)
	Do not answer	1.0% (n=2)	3.8% (n=8)
Professional status	Civil servant	16.2% (n=43)	12.9% (n=27)
	Private employee	14.8% (n=31)	11.4% (n=24)
	Free-lance professional	18.1% (n=38)	16.2% (n=34)
	Farmer	7.6% (n=16)	7.1% (n=15)
	Laborer	6.7% (n=14)	7.1% (n=15)
	Pensioner	13.3% (n=28)	27.6% (n=58)
	Unemployed	21.0% (n=44)	13.8% (n=29)
	Do not answer	2.4% (n=5)	3.8% (n=8)

Table 1. Caregivers' and patients' demographic characteristics

3.2. Patient/nurse ratio per working shift

In order to determine the reasons for caregivers' active participation in care during hospitalization, the patient/nurse ratio was studied. More specifically, in the wards under investigation patients rated from 12 to 45, with a mean number of 26.9 (±10.1) patients. A mean of 13.8 (±3.2) patients in the morning shift were allocated to each nurse. The ratio was even higher during late and night shift.

	Never		1-2 Times/day		3-4 times/ week		5-6 times/ week		Daily		Do not answer	
	N	%	N	%	N	%	N	%	N	%	N	%
I help the patient to take his/her oral medication	59	28,1	9	4,3	2	1	17	8,1	120	57,1	3	1,4
I help the patient to take his/her rectal administered medication	167	79,5	11	5,2	11	5,2	-	-	16	7,6	5	2,4
Blood glucose calculation and administration of insulin	149	71	8	3,8	9	4,3	12	5,7	26	12,4	6	2,9
Take his/her temperature	109	51,9	15	7,1	6	2,9	21	10	55	26,2	4	2
Change the urine bag	177	84,3	8	3,8	5	2,4	1	0,5	15	7,1	4	2
Administer the bed-pan	115	54,8	11	5,2	6	2,9	14	6,7	58	27,6	6	2,8
Help him/her change positions in bed	50	23,8	10	4,8	16	7,6	26	12,4	106	50,5	2	1
Provide massage to him/her	49	23,3	7	3,3	19	9	21	10	111	52,9	3	1,5
Encourage him/her to perform his/her exercises provided by the physiotherapist	76	36,2	10	4,8	15	7,1	17	8,1	89	42,4	3	1,5
Watch the flow of the iv drip or blood	63	30	15	7,1	8	3,8	9	4,3	111	52,9	4	1,8
Help with his/her morning toilet (face and teeth washing, hair combing)	15	7,1	7	3,3	13	6,2	16	7,6	157	74,8	2	1
Bed-making	15	7,1	22	10,5	28	13,3	28	13,3	98	46,7	3	1,5
Help him/her to change nightgown/pyjamas	25	11,9	26	12,4	30	14,3	8	3,8	120	57,1	1	0,5
Change bed linen	63	30	47	22,4	38	18,1	10	4,8	47	22,4	5	2,4
Food preparation/help during eating/feed the patient	35	16,7	13	6,2	11	5,2	17	8,1	132	62,9	2	1
Help him/her to wash his/her hair in the bathroom	101	48,1	32	15,2	29	13,8	3	1,4	41	19,5	2	1
Provide bed hair wash	136	64,8	15	7,1	7	3,3	6	2,9	38	18,1	8	4,8
Help him/her to move with a wheelchair	106	50,5	19	9	12	5,7	9	4,3	58	27,6	5	2,9
Help other patients hospitalized in the same room with my patient	52	24,8	26	12,4	20	9,5	19	9	90	42,9	3	1,5
I get him/her water or/and food from the canteen	33	15,7	12	5,7	11	5,2	22	10,5	128	61	4	1,9
I carry the plates to the kitchen	130	61,9	15	7,1	14	6,7	9	4,3	39	18,6	3	1,5
Carry the paperwork to the hospital offices	74	35,2	20	9,5	22	10,5	10	4,8	81	38,6	3	1,5
Carry blood samples & other samples to hospital labs	131	62,4	18	8,6	18	8,6	10	4,8	31	14,8	2	1

Table 2. Frequency of interventions provided by informal caregiver.

3.3. Perceptions on caregivers' presence in hospital

When caregivers were asked about what Greek society expected from them to do for their hospitalized family member, almost all (91.4%, n=192) stated that the most important was psychological support. It is not uncommon belief in the general public (36.2%, n=76), that the care provided is not good enough, so caregivers have to provide supplementary care. Later on, almost all of the participants stated that they stayed in hospital because they wanted to provide psychological support and care for their not self-reliant and insecure family member in the new and unknown environment of the hospital. It is worth mentioning, that during data processing two different statements for both the public's perceptions as well as the caregiver's reasons for staying by the patient's bedside emerged. The most common belief was that informal caregivers could communicate better with healthcare professionals (84.5%, n=178) and that patients trust more their family to be the provider of care instead of nurses (67.1%, n=141). An important reason for caregivers to provide in-hospital care was the family tradition of caring for one another (75.7%, n=159), which is actually very common in Greece. Finally, the shortage of nursing personnel, which is more evident in the years of Greece's financial crisis, was stated as an important reason for staying by the patient for the 73.4% (n=154) of caregivers.

3.4. Interventions provided by caregivers

When studying the 23 interventions performed by caregivers, the first 19 were grouped as a scale of care delivered, based on the frequency of performance, and they accounted for interventions of basic nursing care. The mean value was 55.93 (±15.22) with a range from 19 to 95. The higher the scale, the more frequent caregivers performed the specific interventions. As caregivers reported, the most common interventions were performed from 5-6 times a week to daily (Table 2).

Furthermore, females (r=0.151, p=0.032, U=3098.00) and those caregivers that were not residing in the city that the hospital was situated (r=0.147, p=0.037, U=3531.50), were performing more frequently interventions of care. In addition, the more serious the patient's health status was perceived by caregivers (r=0.344, p=0.000) and the lower the patient's ability for self-care (r=-0.309, p<0.001), the more the frequency of the provided interventions. Furthermore, it was found that with every year age increased, the scale of care delivered by caregivers increased for 0.14 (p=.034). More than double (0.37) was the increase in the scale, for every hour and day more (0.33) spent by the patient's bedside. In addition, for every unit increase in the patient/nurse ratio, the scale of care increased by 0.18. Finally, caregivers tended to believe that without their presence the patient's needs were not going to be fulfilled, especially when their patient's health status was very serious and his/her ability for self-care as very limited.

3.5. Correlations according to age

As the patient's age increased, there was an increase in

		Patient's age
Patient's health status	Spearman's rho	.178**
	Sign.	.010
Caregiver's age	Spearman's rho	.383**
	Sign.	.000
Days of hospitalization	Spearman's rho	.289**
	Sign.	.000
Hours/day staying by the patient's bedside	Spearman's rho	.173*
	Sign.	.013
Days of staying by the patient's bedside	Spearman's rho	.160*
	Sign.	.020
Patient's ability for self-care	Spearman's rho	-.355**
	Sign.	.000
Frequency of interventions	Spearman's rho	.149*
	Sign.	.034
Help patient eat	Spearman's rho	.295**
	Sign.	.000
Help to wash his/her hair	Spearman's rho	.135
	Sign.	.052
Help patient to shower	Spearman's rho	-.212**
	Sign.	.002
Change position in bed	Spearman's rho	.244**
	Sign.	.000
Help patient to take the medication administered by nurses	Spearman's rho	.191**
	Sign.	.006
Change the urine bag	Spearman's rho	-.148*
	Sign.	.032

Table 3. Correlations regarding patient's age and various variables

hospitalization days, caregiver's age, total days and hours per day spent by the patient's bedside and frequency of interventions provided. In more details, caregivers were helping patients to eat, have his/her hair washed, change position in bed, and take the medication administered by nurses (Table 7). Furthermore, it was found that the older the patient, the more serious the patient's health status and the lower the patient's ability for self-care as perceived by caregivers. On the contrary, the older the patient, the less the frequency that the caregiver helped to shower and change his/her urine bag (Table 3).

3.6. Correlations according to gender

As it was evident from the correlations, mainly females provided care for patients, either male (84.6%, n=178) or female (62.4%, n=131) (r=0.254, p=0.000). When looking into the reasons for staying at the hospital and the frequency of interventions performed by caregivers, differentiations regarding gender were found. Female caregivers believed that they had to be there because they could communicate better with healthcare professionals, patients trusted them more than nurses and due to the fact that their patient was not self-sufficient. On the other hand, male caregivers believed that they had to be at the hospital because care provided was not enough for their patient (Table 8). In an analysis of the most common basic nursing care interventions provided by caregivers, females performed more interventions than males also. (Table 4).

	GENDER	N	Mean	SD	r/p	U, p
Caregiver communicate better with healthcare professionals	Male	53	2.9	0.9	r=0.229, p=0.001	U=2995, p=0.001
	Female	157	3.4	0.7		
Patients, sometimes, trust more their caregiver than nurses	Male	53	2.7	1.1	r=0.140, p=0.043	U=3423.5, p=0.043
	Female	157	2.9	0.9		
Patient is not able of self-care	Male	53	2.9	0.8	r=0.148, p=0.032	U=3396.5, p=0.032
	Female	157	3.3	0.9		
Not sufficient care provided by nurses	Male	53	3.1	0.9	r= - 0.136, p=0.049	U=3419.5, p=0.050
	Female	157	2.8	1.0		
Morning toilet or help for morning toilet	Male	53	4,0	1,5	r= 0.196, p=0.004	U=3341.5, p=0.005
	Female	157	4,5	1,1		
Bed-making	Male	53	3,2	1.1	r= 0.197, p=0.004	U=3135.5, p=0.004
	Female	157	3,9	1,4		
Hair washing on the bed	Male	53	1,5	1,5	r=0.147, p=0.034	U=3444.0, p=0.034
	Female	157	2,1	1,7		
Helping other patients hospitalized in the same ward	Male	53	2,9	1,7	r= 0.162, p=0.019	U=3242.5, p=0.019
	Female	157	3,5	1.7		

Table 4: Correlations according to gender regarding perceived reasons for coming and staying at the hospital and interventions performed

4. DISCUSSION

For the GHS, lack of healthcare professionals, and especially nurses, is a timeless problem and was evident even in the pre-crisis era (5-6) (10-15). Healthcare Unions have stated that GHS personnel during economic crisis have been reduced by 4000, while vacant places in public hospital reach 35000 (14). Having the appropriate amount of personnel is mandatory in order to provide high quality services and fulfill the consumers' needs and demands. Nursing personnel shortage is evident when recording the patient/nurse ratio (16) and the informal caregiver's presence during hospitalization (7). Longitudinal dysfunction of GHS is forcing family members to provide in-hospital care for their relative. In the present study, the majority of caregivers (58.1%, n=122) were practically residing in the hospital, as they were there for more than 17 hours/day. In a similar research (10) in 600 hospitalized patients, it was found that 60.5% (n=363) of the patients regarded extremely necessary the presence of an informal caregiver by their bedside. Almost half of them (49.5%, n=297) had already someone from the close family circle with him/her. Another research conducted fifteen years later, found even more informal caregivers (82%) staying at the hospital (7).

The reasons that force informal caregivers to stay in hospital are associated to the actual nursing care as it is delivered in today's economic crisis affected GHS. Six out of seven most selected statements regarding informal caregiver's interventions are associated to basic nursing interventions. Patients' psychological support and empowerment are major characteristics of nursing identity, which need face to face communication and interaction in order to be achieved (16). Nursing personnel understaffing has resulted in a high number of patients being allocated to each nurse, a situation which undermines quality and safety of nursing care delivered (16). Care deficit deterministically caused by the absence of thousands of nurses from the GHS, has convinced population that patients must be accompanied by a family member, which, with its continuous presence, will support every need (7).

In many cultures, illness, regardless how serious it is, is a

family affair. Within this concept care-giving is expected to be delivered by family members either as emotional support or actual care during hospitalization or after discharge at home (17). In various studies, it has been shown that the presence of family member is beneficiary for the patient, especially in Intensive Care Unit environment (18). Informal caregivers can be the source of valuable information and enhance communication with healthcare team (19-20), can keep the patient in touch with the "outside" world (21) and promote rehabilitation (22). Furthermore, informal caregivers can increase the patient's relaxation (23), reduce anxiety (24), and provide encouragement, psychologic and emotional support (17) (25).

Care provided by informal caregivers focuses on medication management (26), familiarization and adaptation to the demands/changes in the way of life imposed by the disease (27), and participation in recovery and rehabilitation of their patient (28). Caregivers' presence ensures continuity of care (19) as, during hospitalization, they can be trained better in order to provide care for their loved one at home after discharge (29). Since the late 2000s, worldwide policies regarding family visitation changed towards a friendlier environment; allowing informal caregivers to stay more time with their family member patients and even to provide some care for them (30).

But even though, informal caregivers are allowed to stay more in hospital wards with considerable positive outcomes, they are not involved with any actual nursing interventions, only psychologic empowerment and keeping company to the patient (19) (28) (30). On the contrary, in the present study, family members provided a considerable amount of basic nursing care interventions, such as bed-making, morning toilet and hair wash, feeding or helping with meals, but also made sure that the administered medication were actually taken by the patient. Although the results of the present study cannot be generalized, as they reflect data of a specific hospital, they agree with various studies conducted in Greece, which concluded that not only Greek families have the main responsibility for caring for their disabled member at home, but they provide in-hospital care, also (7) (31-33). Similar were the findings in a rehabilitation center in Turkey, where the majority of basic nursing care interventions were performed by family members (34). Caregivers were found to be nurses' help and perform basic care in a culturally diverse population in Australia (17).

Three out of four informal caregivers, in the present study, were females and wives, daughters or daughters in law of the patients, with a lot of them practically residing in the hospital for a lot of days facing changes in their everyday routine and employment status. In the last 30-35 years, a lot of changes have been accomplished in the Greek society social structure regarding the position of females. Greek society, although more open-minded, is still expecting from female family members to care for ill and elders, mainly due to social, religious and cultural beliefs (7) (35-37). In research conducted in Spain and Italy, the demographics of caregivers were similar (around 80% of caregivers were females) confirming the belief that southern-Mediterranean families have more strong and traditional family ties than inhabitants of northern Europe (38-39). Alas, it might come as a surprise that similar findings were reported in a Norwegian research (40) both among older and in younger generation.

Having the nurse/patient ratio in mind and the fact that caregivers regarded, equally, their patients as totally dependent and self-sufficient with a little help, the caregiver's in-hospital presence for 17.2 hours/day can be justified. Family is regarded as a type of social support and is closely connected to self-care (1), but the patient's demand to have a caregiver by his/her bedside at all times is beyond this supporting role. With the various dysfunctions of the healthcare facilities (7) and the prevailing fear that being away from the hospitalized patient results in unfulfilled needs, the sense of duty is enhanced even more, making the caregiver reluctant to leave the patient even for only few hours. All this process is causing unpleasant consequences both for the caregiver and sometimes the patient, also.

The scale of care delivered by caregivers reveals the frequency of basic nursing care interventions that are usually performed by healthcare personnel. In the present study, mean value was 55.93 (out of 95), making more evident the weakness of GHS to cover sufficiently patients' needs. Nursing staff shortage is making caregivers, and mostly females, to implement a variety of nursing interventions with greater frequency and duration (41-42). A very important part in the GHS is played by informal caregivers, as they, quite often, substitute nurses in a number of basic nursing interventions (43). Continuous and constant presence of informal caregivers during hospitalization, cause major negative effects in caregivers' personal, family and work life, especially of those with lower economic status.

5. CONCLUSIONS

The present study revealed the nursing staff shortage in the specific hospital. Unfortunately, the problem is equal in the whole GHS. The reasons that force informal caregivers to come and stay in hospital during a family member's hospitalization are the main cause of care deficit created by the significant shortage of nursing staff. Informal caregivers are trying to balance this care deficit with the long hours and extended presence in hospital. During their stay, they are, often, forced to provide basic nursing care interventions instead of providing just psychological support and company to their family member.

The GHS administration officials are called to try and find appropriate solutions. Adequate nursing staff creates a safe environment for the provision of care in which patient's needs are met. In an environment like that, caregivers could be confined to psychological support and participate only in the discharge process, where all training for home care takes place. Patient and family are trained in skills and interventions that will help them to safely continue providing care at home. It is now, more than ever, needed to plan and implement changes in Greek healthcare system. As the employment of new public servants, like nurses, is forbidden by the austerity measures implemented, another solution has to be found. Informal caregivers could be trained through structured programs to provide basic nursing care during hospitalization and at home, ensuring continuity of care. These programs could be organized by the hospital's training officer and last for one or two hours during the first days of hospitalization.

- **Author's contributions:** Aikaterini Stavrianou, Alexandra Mantoudi, Eugenia Minasidou made substantial contribution to conception, design, data collection and drafting the paper. Theodora Kafkia contributed in drafting the paper, critically revised it into English and made the final edition. Anna Konstantinidou contributed to data collection. Despoina Sapountzi-Krepia and Alexandra Dimitriadou made substantial contribution in the design and supervision of the research and critically revised the paper. All authors approved the final version submitted.
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