

Original Article

Informal Caregivers' Perceived Needs for Health Education Information and Emotional Support: A Comparison between Acute and Sub-Acute Rehabilitation Settings

Vassiliki Stavrou, BSc, MSc, RN
University General Hospital of Ioannina, Greece

Avraam Ploumis, MD, PhD
Orthopaedic Spine Surgeon, Assoc. Professor and Chief Division of Physical Medicine and Rehabilitation
Department of Surgery, University of Ioannina Medical School, University Campus, Ioannina Greece

Spiridon Voulgaris, MD, PhD
Professor of Neurosurgery, Medical School, University of Ioannina, Greece

Markos Sgantzos, MD, PhD
Physiatrist, Assistant Professor of Anatomy, Medical School, University of Thessaly, Larissa, Greece

Maria Malliarou BSc, MSc, PhD, RN
Major, 404 Military Hospital, Larisa, Greece, Scientific Collaborator Technological Educational
Institution of Thessaly, Larisa, Greece

Despina Sapountzi-Krepia, BSc, MSc, PhD, RN, RHV
Professor, President of the Nursing Department, Frederick University, Nicosia, Cyprus

Correspondence: Vassiliki Stavrou, University General Hospital of Ioannina, Greece
E-mail: vstavroy2000@gmail.com

Abstract

Introduction: In-hospital informal care is a common phenomenon in Greece. Health education, information and emotional support needs are important elements for informal caregivers' care. Informal caregiver is defined as a spouse, adult child, other relative, partner or friend who is close to the patient and provides care or help within a wide range of needs.

Aim : To conduct a comparative study on health education, information and emotional support needs between informal caregivers of hospitalized patients in two University Hospital Clinics.

Methodology: Seventy five informal caregivers of hospitalized patients of the Department of Physical Medicine and Rehabilitation and 37 informal caregivers of the Neurosurgery Division participated in this study. The family care for hospitalized patients questionnaire distributed to all participants and data were collected and analyzed using the statistical software SPSS (Version 15.0).

Results: The analysis showed that there is a higher need for health education (0.006) and information (0,019) in the caregivers of the Department of Physical Medicine and Rehabilitation compared to their counterparts of the Neurosurgery Department, while no differences were observed regarding the needs for emotional support.

Conclusions: During rehabilitation, hospitalized patients' caregivers should be well trained by nurses on fulfilling patients' needs, on detecting signs of disease progression, on expected complications and they need also to be emotionally supported. The need for health education and provision of information was more pronounced at the Rehabilitation clinic. Providing information and training on nursing techniques to inpatients' caregivers can make them more capable on fulfilling patient's needs, while the provision of emotional support may be beneficial for minimizing their burden.

Key words: informal caregivers, health education needs, information, emotional support needs

Introduction

Care is a worldwide phenomenon and care is provided in all cultures while in certain ones care is a moral duty for any family member who is in need. Colliere (1989), has identified that care is not a professional characteristic but it refers to support given by any person to another in order to continue living (Gonzaga & Arruda, 1998). The number of informal caregivers, mainly family member, is rising due to the higher life expectancy and the increasing numbers of disabled and long-term ill patients. In addition, the provision of ambulatory care to those patients contributes to the above (Braun et al., 2007). In-hospital informal care is a common phenomenon in Greece since the early 1980s due to the nursing staff shortage, but mainly due to cultural beliefs on family bonding. The cultural belief is that family has an obligation and responsibility to provide care to its family members in illness and disability (Sapountzi – Krepia et al., 2008a, Sapountzi – Krepia et al., 2008b).

Within the context of the present study informal caregiver is defined as a spouse, adult child, other relative, partner or friend who is close to the patient and provides care or help within a wide range of needs (Bevans & Sternberg, 2012, Grand et al., 2013).

Informal in-hospital care

In recent years a better understanding of family's role in periods of chronic illness and disability started to develop in Greece helping experts to consider that diagnosis of chronic illness is an important period for health professional to start developing a family-oriented approach of the patients' care. The term "family" is used in a broader concept including family members and whoever the patient himself feels as his family. It can be a spouse, children, parents, relatives and friends from the social or professional field. All the above usually provide care to the patient, share his concerns and problems associated with the disease (Karkanias, 2010).

Informal Caregiving exists in almost all cultures and informal caregivers can be found in patients' homes, in rehabilitation centers and in other long term care facilities where chronically ill and disabled patients are hospitalized after their discharge from hospitals (Davidson, 2009; Lee et al, 2009; Van Pelt et al, 2010).

Informal caregiving is a common phenomenon in hospital wards in Greece, and has been researched since the early 90's (Sapountzi, 1992). The rise of in-hospital informal caregivers is related to the understaffing, to severity of the disease, but also to the cross-cultural caregiving standards (Sapountzi – Krepia et al, 2006; Sapountzi – Krepia et al., 2008a, Sapountzi – Krepia et al., 2008b; Lavdaniti et al, 2011). Informal caregivers provide in-hospital care that reflects specific nursing tasks such as bathing, cutting toe nails, dressing patients, positioning /moving patients, providing general patient comfort, dietary control, medication and symptom management (Sapountzi et al, 2006; Bee et al, 2009). As it is stressed by Sapountzi-Krepia et al (2008b) the ward staff, usually doctors and Nurses, suggest that a relative should stay at the patient's bed-side even after visiting hours.

Nursing staff shortage in the hospitals of the Greek National Health System is the main reason for such a high patient/nurse ratio. Although there have been periods, in Greece, when economics were good, allowing a solution to the problem of nursing shortage, nothing was done, manifesting that it has been more of a political and administrative decision than a decision related to economics (Sapountzi et al, 2006; Skroumpelos et al, 2012).

Health Education needs, information and emotional support of the caregivers.

Although caregivers are often characterized as "latent patients" because of the organic, emotional, psychological, social and financial burden they experience (Dunn, 2010), nurses tend to overlook their needs (Schubart et al, 2008). The caregivers' needs are related, mainly, to health education, information and emotional support (Northouse et al, 2010; Parks & Novielli, 2000; Choi et al, 2011). It is often reported that informal caregivers lack the necessary skills related to caregiving (Sapountzi et al, 2006) and they do not have any assistance from healthcare professionals or any kind of social support (Tamayo et al, 2010). It is also reported that nursing staff usually underestimates the need to inform the patients' relatives and their need to be close to their patient (Davidson, 2009). Earlier studies in Greek population argue that the informational and educational needs of informal caregivers are focusing on patient's conditions,

treatment and dexterities of care (Kosco & Warren, 2000).

In order to support caregivers it is important to embrace their social and psychological needs (Tamayo et al, 2010). Help provided by a supportive context can substantially decrease the feelings of loneliness and helplessness. Providing caregivers with appropriate information is an effective way of reducing stress and uncertainty. The information needed concerns diagnosis, treatment and prognosis of the disease and it has to be adjusted to each health condition and suitable and comprehensible by the caregiver, so it can be properly understood (Papadatou & Anagnostopoulos, 1995; Griffin et al, 2009). A thorough understanding of how people search for information could be vital for healthcare professionals in order to be more effective in providing care (Papadatou & Anagnostopoulos, 1995; Schubart et al, 2009). One reason that most of healthcare professionals have to focus on \ is maintaining the caregivers' good health status, in order to be able to cope with their tasks (Cormac & Tihanyi, 2006). Developing a functional relation, during patients' hospitalization, between Rehabilitation units' staff and caregivers is strongly recommended (Elliott & Pezent, 2008).

The aim of the present study was to compare outcomes related to health education needs, informational and emotional support needs between the informal caregivers of the Neurosurgery Department (acute rehabilitation phase) and the Department of Physical Medicine and Rehabilitation (sub-acute rehabilitation phase).

A comparison of the two groups of patients' caregivers -at acute rehabilitation phase and sub-acute rehabilitation phase was done in order to assess their needs on health education and support of patients, because it was hypothesized that acute state of the disease and urgent condition may trigger emotions and needs not possibly observed in rehabilitation phase, where patient is more stable or improved or he/she has already accepted his permanent disability.

Methods

Setting and sample

The study carried out in the Neurosurgery and the Rehabilitation Clinic of a University hospital of Western Greece. The wards included in the study, accepted patients who were mainly

inhabitants of western Greece. Eligible for participation in the study were informal caregivers who provided care for hospitalized patients in the Neurosurgery and Rehabilitation Clinic for seven days at least. This limitation was set because the questionnaire asked the subjects to recall and report on the educational, informational and emotional support needs that they realized they had during the previous week. All eligible for participation in-hospital informal caregivers were approached by a member of the research team, they were informed about the study and were asked to participate. Seventy five (75) informal caregivers from the Department of Physical Medicine and Rehabilitation and 37 informal caregivers from the Neurosurgery clinic agreed to participate in the study, they were provided with a copy of the questionnaire and asked to complete it and put it in special collection boxes.

Procedure

Permission for the study was granted by the hospital's research committee and administration permissions were granted by the head of the Department of Physical Medicine and Rehabilitation and the Neurosurgery Department of a University Hospital of Western Greece.

The purpose of the study was explained to the caregivers, who also signed a written consent form. The questionnaire was anonymous, it was administered in the Greek language and the principles of the Declaration of Helsinki were followed in all the stages of the research.

The instrument

A specially designed, self-reported questionnaire, the In-Hospital Informal Care Questionnaire (IHICQ) developed and validated by Sapountzi-Krepia et al (2006) and it was used as a research tool in previews studies (Sapountzi – Krepia et al, 2006; Sapountzi – Krepia et al., 2008a, Sapountzi – Krepia et al., 2008b; Lavdaniti et al, 2011). The questionnaire included questions on the demographic and social characteristics, both for caregivers and patients, as well as information about cause and duration of hospitalization. Moreover, in the questionnaire there were included three specific subscales: a) health education needs, b)information needs and c) needs for emotional support needs, with a 5-point Likert type format questions (1 Strongly Disagree, 2 Disagree, 3 Neutral, 4 Agree, 5

Strongly Agree). The health education needs subscale includes 13 questions, the information needs subscale has 6 questions and the emotional support needs subscale includes 4 questions. In the present study the Cronbach's α of the subscales were 0.758, 0.741 and 0.731 respectively.

Data analysis

A comparison between the two groups of caregivers was carried out using Independent samples t-test, after applying the Levene's test for the equality of variances. Significance was set at 0.05. All analyses were conducted with the use of SPSS (Version 15.0).

Results

Seventy five (75) informal caregivers of patients hospitalized in the Department of Physical Medicine and Rehabilitation filled the questionnaire. The participants were 30-79 years old, mostly women 73.3% (n=55) and married 90.7% (n=68) A 64.0% (n=48) of the participants stayed by the bed of the patient for the whole day and night. The duration of the patient's hospitalization was from 14 to 90 days. The participants expressed that they feel a need for support 84% (n=63) and that this support was expected to be given mainly by the nursing staff 94.7% (n=71). A multiple regression analysis revealed that when the caregivers were asked to state the professional that is expected to deliver support to them, 69.3% (n=52) replied nurses, 68% (n=51) expect support from doctors, 50.7% (n=38) from psychologists, while another 8% (n=6) stated from social workers and 4% (n=3) from physical therapists.

The Neurosurgery Department sample consisted of thirty seven (37) informal caregivers aged 24-70 mostly women 82.1% (n=30) and married 83.8% (n=31), spouses 35.1% (n=13) but also parents 29.7% (n=11) who stayed by the bed of their hospitalized relative assisting with care. The range of patients' hospitalization was 13-38 days. Their answers showed that health care professionals should be providing support to caregivers 86.5% (n=32) and that this support should be given mainly by the nursing staff 94.6% (n=35). Thirty three of the participants (89.2%) agreed that it is within the health care professionals' duties to provide emotional support to caregivers. When asked on the person providing support 81.1% (n=30) stated the

nurses, 81.1% (n=30) the doctors, 56.8% the psychologists (n=21) and 10.8% (n=4) the social workers.

The needs recorded on health education, emotional support and information by caregivers of both Departments are presented on Table 1. More caregivers 89.2% (n=33) of the Neurosurgery Department needed to get education related to the specific disease than those of the Department of Physical Medicine and Rehabilitation 70.7% (n=53) while those from the specific department needed more information on social security benefits for the necessary supporting medical equipment 98.7% (n=73) compared to caregivers of the Neurosurgery Department 73% (n=23). Almost half of the sample of caregivers of the Department of Physical Medicine and Rehabilitation 46.8% (n=35) stated they need to be in contact with the health care professionals as a means of stress relief in comparison to 40.5% (n=15) caregivers of the Neurosurgery Department.

The analysis presented on Table 2, showed that there is a statistically significant higher need for health education ($p=0.006$) and information ($p=0.019$) in caregivers of the Department of Physical Medicine and Rehabilitation compared to the caregivers of the Neurosurgery Department. The p-value for the comparison of emotional Support needs was 0.603 showing no differences between the two Departments. The significance level was set at 0.05 for all comparisons.

Discussion

The results of the study lead to the conclusion that informal caregivers of the department of Physical Medicine and Rehabilitation need health education more intensely. This is probably due to their frequent and intense involvement with the patients, something that requires of acquisition of improved caregiving techniques. Improving health education in conjunction with providing better information can improve caregiving and lead to better recovery while creating feelings of satisfaction and reward.

There is also greater need for information about ward (local) resources, manifested by their wish to be able to rely more on themselves in provision of care. Our findings are in accordance with these of the Eurofamcare study (2006),

where great lack of information was observed on existing services and their availability, as well as for the criteria to access them. (Triantafillou & Mestheneos, 2006).

The need for emotional support is common in the caregivers of the two departments. But people cannot always manage by themselves, negative feelings such as sadness, anger and disappointment caused by acute cases or chronic diseases. Creating a supporting environment for

informal caregivers will encourage them to express feelings of abandonment, isolation from external support systems, loss of confidence or the burden of care. The need for support of caregivers provide an integrated approach to care environment where nurses can recognize informal caregivers' degree of adaptability in the acute phase and promote their adaptability, by bridging the gap between theory and clinical practice.

Table 1: Frequencies and percentages of positive answers recorded by caregivers on needs relating to Health education, Emotional support and Information.

	Caregivers of patients of the Department of Physical Medicine and Rehabilitation		Caregivers of patients of the Neurosurgery Department	
Health Education Needs				
on treating the patient after being discharged from the hospital	55	73.3%	30	81.1%
on the patient's need for emotional support	54	72.0%	28	75.7%
related to each specific disease	53	70.7%	33	89.2%
Information Needs				
on the patient's recovery path	74	98.7%	37	100%
on social security benefits for the necessary supporting medical equipment	74	98.7%	27	73%
on social security benefits covering the occupation of an exclusive nurse	68	90.7%	37	100%
on treatment options for the discharged patients besides home treatment	62	82.7%	30	81.1%
Emotional Support				
related to the caregiver's need to talk about their fears and the patient's status	62	82.7%	34	91.9%
related to their need to know whether they will manage to efficiently support the patient in the future	68	90.7%	33	89.2%
related to their need to be in contact with the health care professionals as a means of stress relief	35	46.8%	15	40.5%

Table 2: Comparisons of the Need for Health Education, for Information and Emotional Support in the caregivers of the two Departments.

Health Education Needs by Department					
Department	n	Mean	Standard Deviation	Levene's test for equality of variances	p-value of the T- test
Physical Medicine and Rehabilitation	75	3.72	0.380	p=0.291	p=0.006
Neurosurgery	37	3.52	0.309		
Total	112	3.66	0.369		
Information Needs by Department					
Physical Medicine and Rehabilitation	75	4.18	0.373	p=0.089	p=0.019
Neurosurgery	37	4.01	0.301		
Total	112	4.13	0.358		
Emotional Support Needs by Department					
Physical Medicine and Rehabilitation	75	3.82	0.555	p=0.728	p=0.603
Neurosurgery	37	3.77	0.497		
Total	112	3.80	0.535		

Informal caregivers' relatives and friends' contribution can be of great importance in reducing feelings of loneliness and disappointment in caregivers. Our study also emphasizes on specific emotional needs and informational needs of caregivers recorded by both departments. These concern their need to feel the closeness and availability of the nursing staff and to be encouraged by them, discussing the current and future needs of their patient relative. Much evidence by other researchers report also informal caregivers' high levels of stress, anxiety and depression, general health problems, loneliness and social isolation (Parker, 1993; Twigg & Atkin, 1994; Warner, 1995; Henwood, 1998; Keeley, & Clarke, 2002). A well-structured and organized context providing information and support to the caregivers is very likely to lighten the burden for them but also for the nursing staff.

Worldwide families' are expected to provide care for their chronically ill or disabled members. More specifically in Greece, where there are not enough rehabilitation centers or services of assistance in patient caring, family is burdened with this duty regardless of its' ability to provide the required support and little attention has been paid on caregivers' needs. It is often not an option to not undertake the patient's care because of the conditions in the shade of the prevailing belief, that care is an inherent feature of the family and an obligation (Triantafillou & Mestheneos, 2006). After the start of the economic crisis in Greece a major change was also applied in hiring staff policy, where the rule "One new employee for every ten departures" in conjunction with the retirement of thousands of employees led the National Health System to significant understaffing. In order to prevent or to relief caregiver's burdening complex interventions are needed. Such interventions will

empower, strengthen and will make him/her more effective. Some of them might be maintaining a relation based on mutual respect between informal caregiver and patient, maintaining a dynamic interpersonal relationship, devoting time for themselves, reducing stress, get adequate sleep, having social support as well as emotional professional empowering about the significance of what they offer. Preserving emotional health of the caregiver provides an ally to the patient fight against disease or disability but an ally to professional work of care.

Conclusions

Caregivers, according to our study, are not passively present. They are close to the hospital's personnel trying to gain knowledge to enhance the patients' recovery, but also for their personal need. Adjustment for the caregivers' needs is an integrated part of successful caregiving as they will have to support the patient after hospital discharge and many times for the rest of their lives. This kind of care requires a certain way of communication and information provision, and the way to define health education needs must be adequate and considerate of the needs of education, information and emotional support. Rehabilitation continues for a long time after the patient's hospital discharge. Relatives are invited to gradually replace services, to fulfill basic and functional needs of their loved ones and in order to do so they should receive proper guidance and education. They need to develop care skills, to be able to recognize changes in behavior manage possible relapses of the disease and manage medication properly, while more generally speaking knowledge about the disease helps them cope better with future demands of the disease. Informal caregivers should be well trained and well-informed in order to become good patient advocates. Creating a caring atmosphere for the carer will encourage them to express themselves and share their feelings.

Nurses should not expect from informal caregivers to be responsible for resolving any patient problem, but they need to create a positive collaborative environment so caregivers would not feel trooped in a lonely struggle. In this way, caregiver will endure this commitment and he/she will promote his the professional caring team.

The quality of communication that develops between the nursing staff and the caregivers,

mostly at the acute period of the disease, will motivate the caregivers to participate substantially. The responsibility to develop effective communication with the caregivers and therefore make them capable to face their worries and anxiety lies with the nursing staff. And effective communication is actually about supportive care. The nursing staff will be aided to carry their working burden, through the thorough understanding of the caregivers' needs, as they alter in the disease course, and through the right interpretation of attitudes that emerge as the impact of the need to constantly adopt to new situations and as the impact of the overall crisis introduced by the presence of a disease.

During the disease's acute period, and the period next to that, protecting the sentimental reactions of informal caregivers and tracing their major concern and stress factor will reduce their own burden and the burden on nurses.

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