

Original Article

Educational Needs of Caregivers Of Patients Hospitalized in a Neurology Clinic: Results of Questionnaire

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Abstract

Introduction: Caring for a relative or friend with a chronic illness is a role that is becoming increasingly accepted by parents. Many family members feel themselves responsible for the care given by the proximity ratings to the patient. Training of caregiver family members is of great importance in providing professional care and reducing the cost of health care.

Aim: The aim of this study was to assess educational needs of caregiver during their patient care .

Methods: The sample of the study consisted of patients who were staying in a neurology clinic of a university hospital. Patient relatives who are clinically inpatient and who agree to participate in the study are asked to complete questionnaires to determine their educational needs. A total 152 caregivers were screened and basic information collected.

Results: Topics which patients wanted to take information about *specific problems* include infection prevention (31.6%), communication with patients with speech impairment (25.0%), pressure injury prevention (23.6%), about *self care* include oral care (45.4%), bed bath making (42.8%), hair care (32.9%); about *stress and coping strategies* include relaxation exercises (46.7%), anger management (36.8%), depression (30.3%), problem solving methods (34.9%) and time management (28.9%).

Conclusion: There is need to educate caregivers and such educational programs should also target high risk group.

Key word: care , educational needs, caregivers, nursing

Introduction

Many neurological disorders and conditions affect an individual's functioning and result in disabilities or limit activities and restrict participation (Vardi et al., 2007). There are a number of complexities in the neurological disorders as patients can present with diverse sequelae, including the Physical functioning limitations Cognitive impairments Behavioural

problems Communication impairments Psychosocial limitations (World Health Organization 2006). The effect of symptoms, the mood of the patient, the need for physical and emotional support creates an additional burden on caregivers and family members. On the other hand, caregivers and family members directly influence many aspects of the patient such as physiological adjustment of the patient and management of the disease, adoption of

behaviors affecting healing, and adaptation of the patient to treatment (Girgis et al., 2012).

As advances in medical treatment continue to improve survival rates for neurological patients especially stroke and multiple sclerosis, more family members will be called upon to provide some level of assistance postdischarge. In recent years, the deleterious effects of caregiving have been identified as a major public health concern (Talley et al., 2007). A preponderance of literature has established that caregivers are often adversely affected by the demands of their informal caregiving role. Stroke caregivers have been identified as a group at high risk for poor outcomes as a result of the suddenness of stroke and the potential for the patient to require a high level of care due to significant functional loss following stroke. [Talley et al., 2007; Brereton et al., 2000; van Exel et al., 2005; van Exel et al., 2004; Lutz, 2011; Cameron et al., 2008]

Education in neurology contains important aspects of quality assurance and continuing improvement in the delivery of the best care to people with neurological disorders. As front line caregivers in many resource-poor countries, primary care providers need to receive basic training and regular continuing education in basic diagnostic skills and in treatment and rehabilitation protocols. Such training should cover general skills (such as interviewing the patient and recording the information), diagnosis and management of specific disorders (including the use of medications and monitoring of side-effects) and referral guidelines (World Health Organization 2006).

Many family members feel themselves responsible for the care given by the proximity ratings to the patient. Training of caregiver family members is of great importance in providing professional care and reducing the cost of health care. On the other hand, it can lead to many problems such as lack of education, anxiety, fear, deterioration of health condition and depression in patients and health care providers. For example, care of family members in stroke patients affects many areas in the caregiver's physical, psychological, social and cognitive support activities (Schulz et al., 2008). The aim of this study was to identify the educational needs of caregivers of patients hospitalized in a neurology clinic.

Differences in culture, along with differences in income, education, neighborhood environments, lifetime access to health care, and occupational hazards will have a significant impact on the need for care, the availability and willingness of family caregivers to provide it, and the most effective and appropriate ways to provide caregiver support. Developing programs and services that are accessible, affordable, and tailored to the needs of diverse communities of caregivers presents significant challenges (National Academies of Sciences, Engineering, and Medicine, 2016)

Needs Of Family Caregivers

In the studies have explored the needs of new stroke caregivers as care recipients' transition from hospital to home, (Greenwood et al., 2010) and those that have consistently indicate that these caregivers are inadequately assessed and/or trained for their new roles (van Exel et al., 2004; Visser-Meily et al., 2004; Bakas et al., 2006; Hafsteinsdottir et al., 2011). Specifically, studies exploring the needs of caregivers during discharge planning indicated that caregivers 1) were not adequately assessed or prepared for the caregiving role (Lutz et al., 2011; Bakas et al., 1999; Brereton, 1997) 2) had many unmet educational needs (Hafsteinsdottir et al., 2011); 3) had difficulty applying training and information received prior to discharge once they were home (Lutz, 2011); and 4) need to be kept informed about the patient's progress and involved in the discharge planning throughout the hospital stay (Lutz et al., 2011; Brereton et al., 1997) even though this may be problematic due to confidentiality issues (Shyu, 2000)

Studies identifying the educational and information needs of caregivers suggested patients and caregivers want training in the following areas: 1) clinical information on causes, effects, and prevention of disease; disease recovery and prognosis; and treatment decisions; 2) practical information related to daily care of the patient, e.g., bathing, toileting, nutrition; and 3) information on follow-up care and community resources (Greenwood et al., 2010; Hafsteinsdottir et al., 2011)

Bakas et al. stated that in the first 6 months post-discharge, stroke caregivers had needs and concerns related to information, emotions and behaviors, physical care, instrumental care, and personal responses to caregiving (Bakas et al.,

2002) and that their information needs change during the course of patients' recovery from stroke (Bakas et al., 2009). This trajectory of needs indicates the importance of assessing the match between caregiver capacity and patient need, and coordinating and tailoring caregiver educational programs as patients transition through the continuum of care from acute care to inpatient rehabilitation to home. Without this assistance, caregivers develop their own solutions and strategies to meet the needs of the care recipient after discharge (Bakas et al., 2002; Pierce et al., 2004). Unfortunately, these strategies are often ineffective and may result in safety issues for patients (e.g., falls, skin breakdown, choking) and care related injuries and poorer health for caregivers (e.g., back injuries, increased stress and anxiety) (Bakas et al., 2002; Lutz et al., 2009)

Sample and Methods

Design and sample

This research design was cross-sectional, descriptive. The data were collected from March 2013 to January 2014. A total 152 caregivers who had primary caregivers were evaluated in Turkey. Participants were selected through convenience sampling. The inclusion criteria for the caregivers were as follows (1) being at least 18 years of age; (2) being a primary caregivers (3) cognitively intact to communicate and participate in the study and (4) giving consent to participate in the research.

Data Collection

Data were collected by using "Caregiver Information Form" and "Questionnaire Form Care Related Needs". Before starting to collect data, primary caregivers were informed about the purpose and content of the research and their verbal consent was received.

Caregiver Information Form: This form was composed of 20 questions, which examined caregivers's socio-demographic characteristics such as caregiver's age, gender, education level, working status, marital status, proximity to the patient, presence of chronic illness, drug use, state of health, weekly care time, diet situation, accompany day, number of helpers and patient characteristics such as patient's age, diagnosis, hospitalization duration, dependence level, gender, education level and functional state.

Questionnaire Form Care Related Needs: This form was used to assess the caregivers' their patients care related needs. The questionnaire was designed especially for the purpose of this study. It was based on literature review of previous studies concerning caregivers needs (Schulz et al., 2008) . This Questionnaire form (19 item) included three subject such as special problems (eg; prevention infection, communication with patients with speech disorders, prevention pressure ulcer etc.) self care (eg; oral care, bed bath making, changing bed lining etc) and stress and coping strategies (eg;anger management, relaxation techniques etc).

Additionally, This form was firstly tested on a sample of 10 caregivers as a pilot study. The aim was to detect problems with the questionnaire form such as wording, terminology, instructions, items and whether the questionnaire was understandable or not. After completion of the questionnaire, an interview was held with caregivers to investigate the understandability of each item. They were asked to comment on items and offer recommendations for improvement. All caregivers reported that the questionnaire was easily understandable, readable and culturally relevant. No problematic items were observed in the form.

Procedure

The sample of the study consisted of patients who were staying in a neurology clinic of a university hospital. Patient relatives who are clinically inpatient and who agree to participate in the study are asked to complete questionnaires to determine their educational needs. Participants were asked "What do you need to know about regarding the care of your patient" and then they answered questions form as 'I want very much, 'I want a little bit' and 'I want not at all". Completing the forms took around 15 minutes.

Statistical Analysis

The SPSS 17.0 software was used for statistical analysis. Descriptive statistics (frequencies, means, Standard deviations) were used to describe the demographics of the caregivers.

Ethical consideration

The study was approved by the ethical committee of faculty of nursing of the university where the study was performed. Caregivers who met the inclusion criteria were informed of the purpose of

the research and invited to take part as volunteers by the researchers. Participants were assured of their right to refuse to participate or to withdraw from the study at any stage without detriment to their patients treatment and care. At the same time, they were told that the information they gave would be -identified, no names would be stored and that their identity would be kept confidential. In this way, the anonymity and confidentiality of participants were guaranteed. And written permission was received from caregivers. This was conducted in consideration of Declaration of Helsinki.

Results

Characteristics of Caregivers

A total 152 caregivers were involved in this survey. The distribution of characteristics of respondents is shown in Table 1. The average age of the patients who were taken to the study was 46.99 ± 13.6 . Majority (69.7 %) of respondents were female. 76.5 % of respondents were married and 84.2% of the participants were first-degree relatives of the patients. Regarding educational status 38.7 % of respondents have studied up to primary school and 19.3 % graduated from a university. Majority (70.4%) of participants did not work and 74.3% had no chronic disease.

Table 1. Characteristics of Caregivers

	n	%
Sex		
Female	83	69.7
Male	36	30.3
Marital status		
Married	91	76.5
Divorced/widow	20	16.8
Single	8	6.7
Educational levels		
Literate- Illiterate	13	10.9
Primary school	46	38.7
High school	23	19.3
University	22	18.5
Working status		
Full time /Part time	45	29.6
Does not work	107	70.4
Have chronic disease		
Yes	39	25.7
No	113	74.3
The degree of closeness with the patient		
First degree relative (exp:father , mother etc.)	128	84.2
Second degree relative (exp:aunt etc.)	24	15.8
Total	152	100

Table 2: Patient's Disease State

	n	%
Patient diagnosis		
<i>Stroke</i>	73	48
<i>Multiple sclerosis (MS)</i>	17	11.2
<i>Amiotrophic lateral sclerosis (ALS)</i>	2	1.3
<i>Parkinson</i>	9	5.9
<i>Guillain Barre</i>	3	2
<i>Myasthenia Gravis</i>	1	0.7
<i>Epilepsy</i>	11	7.2
<i>Demantia</i>	2	1.3
<i>Other</i>	34	22.6
Patients' dependence level		
<i>Independent</i>	42	27.6
<i>Low</i>	42	27.6
<i>Moderate</i>	32	21.1
<i>High</i>	34	22.4
Total	152	100

Table 3: Educational Needs Of Caregivers

	So Much		A little		Never		Total	
	n	%	n	%	n	%	n	%
Special Problems								
<i>Communication with Patient with Speech Impairment</i>	38	25	15	9.9	99	65.1	152	100
<i>Aspiration</i>	29	19.1	17	11.2	106	69.7	152	100
<i>Prevention Pressure Ulcer</i>	36	23.6	20	13.2	96	63.2	152	100
<i>Infection Prevention</i>	48	31.6	15	9.9	89	58.6	152	100
<i>Nasogastric Tube Feeding</i>	15	9.9	14	9.2	123	80.9	152	100
<i>Secretion Reduction Methods</i>	30	19.7	14	9.2	108	7.1	152	100
Self-Care Needs								
<i>Oral Care</i>	69	45.4	21	13.8	62	40.8	152	100
<i>Bed Bath Making</i>	65	42.8	20	13.2	67	44.1	152	100
<i>Hair Care</i>	50	32.9	17	11.2	85	55.9	152	100
<i>Bed Linen Changing</i>	37	24.3	24	15.8	91	59.9	152	100
<i>In-Bed Dressing Change</i>	34	22.4	21	13.8	97	63.8	152	100
<i>Perineum Care</i>	34	22.4	18	11.8	100	65.8	152	100
<i>Use Of Special Tools For Movement</i>	33	21.7	16	10.5	103	67.8	152	100
Stress And Coping Strategies								
<i>Anger Management</i>	56	36.8	22	14.5	74	48.7	152	100
<i>Depression</i>	46	30.3	20	13.2	86	56.6	152	100
<i>Problem Solving Methods</i>	53	34.9	22	14.5	77	50.7	152	100
<i>Relaxation Exercises</i>	71	46.7	20	13.2	61	40.1	152	100
<i>Time Management</i>	44	28.9	15	9.9	93	61.2	152	100

Patient's Disease State

The distribution of disease state of caregivers is shown in Table 2.

When the distribution of the medical diagnoses of the patients in the clinic is looked at, it is seen that 48 % had stroke, 11.2% had MS, and 7.2% had epilepsy. In the distribution of the dependency levels of the patients, 27.6% were independent, 27.6% were low level dependent, 21.1% were moderate dependent and 22.4% were high level dependent.

Educational Needs Of Caregivers

The questionnaire for educational needs includes 19 topics under three headings: special problems, self-care needs, stress and coping strategies. The topics are as follows; communication with patient with speech impairment, aspiration, prevention pressure ulcer, infection prevention, nasogastric tube feeding, secretion reduction methods, oral care, bed bath making, hair care, bed linen changing, in-bed dressing change, perineum care, use of special tools for movement, anger management, depression, problem solving methods, relaxation exercises, time management and drug use. The distribution of training needs of respondents is shown in Table 3.

Topics which patients wanted to take information about specific problems include infection prevention (31.6%), communication with patients with speech impairment (25.0%), pressure injury prevention (23.6%), about self care include oral care (45.4%), bed bath making (42.8%), hair care (32.9%); about stress and coping strategies include relaxation exercises (46.7%), anger management (36.8%), depression (30.3%), problem solving methods (34.9%) and time management (28.9%).

Discussion

This study is the first study to assess educational needs of caregivers patients hospitalized in a neurology clinic in a Turkey. The primary objective of this study was to assess educational needs among caregivers of patients. Also, the primary our aim was not to develop a study tool to measure care needs of caregivers, its perception therefore we did not vigorously test our questionnaire for validity or reliability.

Chronic diseases seriously affect not only patients but also family members who have to

look after them at the same time. Since chronic illness affects the maintenance of rehabilitation and well-being, it is important to address the impact of disability and care responsibilities on family members. Research conducted in this area has examined the difficulties in physical, psychological, social and family life of family members who have given care to chronic illnesses and how physical health and social and family life are influenced by increased stress, anxiety and depression. Personality traits, family stressors, coping strategies, and social support of caregivers are the most prominent factors affecting the quality of life of caregivers. Generally the role of women caregivers in cases of disability and two-thirds of all caregivers are females. It is also seen that the majority of caregivers are women in the results of our study. Rivera and colleagues found that caregivers of women with spinal cord injuries were mostly mothers, sisters, or daughters, showing that mental problems may be more likely to occur when problem solving skills are low. The majority of caregivers in our study are first-degree relatives and the fact that they are women is similar to this finding. We detected no statistical association between caregiver characteristics and the most common education needs.

The majority of caregivers want to teach for educational needs are following: for special problems include infection prevention (31.6%), for self care topics include oral care (45.4%) , bed bath making (42.8%) and hair care (32.9%); for stress and coping strategies; relaxation exercises (46.7%), anger management (36.8%) and depression (30.3%).

In this study by Hayashi et al. was revealed that in the caregivers identified the following care needs before and after discharge from a stroke unit: dealing with psychological, emotional and behavioral problems and local service information (Hayashi et al.,2013). Likewise, Pierce et al.(2004) found that the most reported educational needs were fall prevention, maintaining adequate nutrition, staying active, managing stress, and dealing with emotional and mood changes. Hinojosa and Rittman reported that 22–50% of caregivers needed for information related to the stroke recovery, other important topics identified included prescriptions and medications, safety issues, managing behavior, managing emotional instability and the changing

relationship with a patient (Hafsteinsdóttir et al., 2011).

Pierce et al. (2004) reported that caregivers of stroke patients assessed the issues that needed the most information for self-care; (63%), stress management (58%), and emotional changes (50%), as well as prevention of dropouts (71%), maintenance of adequate nutrition (63%). The topics of education under stress and coping strategies are similar to the findings of our study (Hafsteinsdóttir et al., 2011). Bakas et al. (2002) found that in their study, emotional problems and coping methods (anger, anxiety, depression, personality changes, social support, etc.) and strategies for their physical maintenance issues (nutrition, bathing, changing clothes, use of private vehicles, prevention of falls, etc.) information needs on the subject (Selwood et al., 2007).

Implication for Nursing

In the patient who is confined to bed is at risk of developing problems such as skin break down, breathing difficulties, constipation, anxiety etc.. So care giving to patients confined to bed is among the major tasks of nursing profession. In the case of requiring long-term care, this task belongs to caregivers. The majority of caregivers do not have the required knowledge and skills to provide long term care. As the members of professional health care team, starting from the diagnostic phase, nurses should prepare the caregivers for home care after discharge from hospital. Nurses have to fulfill their tasks such as providing training, care, counseling, guidance and organizing their work etc. in this process.

Conclusion

Patient relatives were found to have significant information needs for patient care. Failure to meet the information needs of caregivers is known to increase costs as anxiety, depression, burnout, self-care problems, increased complications, adverse effects on the length and frequency of hospital stay. In line with these results; it is recommended that the nurses plan the implementation of the training initiatives, provide counseling services and arrange brochures. Neurological conditions are quite common among patient groups receiving home care services. Family members provide important support to individuals with neurological disease. Indeed, as provided by informal caregivers, the provision of this care may also cause a negative

effect on informal caregivers. It is suggested that more comprehensive studies should be undertaken to evaluate the needs of neurological patients for caregivers.

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