Family Caregivers' Difficulties in Caring for Bedridden Stroke Patients

Yatağa Bağımlı İnmeli Hastalara Bakım Veren Hasta Yakınlarının Yaşadıkları Güçlükler

(Araştırma)

Sağlık Bilimleri Fakültesi Hemşirelik Dergisi (2009) 17–31

Yard. Doç. Dr. Sevgisun KAPUCU*, Yard. Doç. Dr. Sevinç KUTLU TÜRKAN,**
Prof. Dr. Hatice FESCİ**
*Hacettepe Üniversitesi Sağlık Bilimleri Fakültesi Hemşirelik Bölümü
**Gazi Üniversitesi Sağlık Bilimleri Fakültesi Hemşirelik Bölümü

ABSTRACT

Objective: The aim of this study was to determine the difficulties experienced by bedridden CVA patients' caregivers at home and suggest some solve advice for problems.

Methods: This is a descriptive study designed to identify difficulties experienced by bedridden CVA patients' caregivers at home and suggest some solve advice for problems. The sample group consisted of 38 relatives of CVA patients. The patients had been discharged from one of three health centers: the Hacettepe University Neurology Ward, Ankara University's Ibn-i Sina Hospital, or Ankara Numune Hospital. Using questions form that contained open-ended questions, we interviewed 38 caregivers of stroke survivors to identify their characteristics and their difficulties experienced. Data were given as numbers and percentages.

Results: The results of the study indicate that family caregivers need information about the disease (CVA), and about patients' care, medications, diet, excretory system function and sleep schedule. The results also indicate that the caregivers commonly face psychosocial problems, fatigue, and insomnia. Caregivers reported financial problems in purchasing medicines and medical care. They also stated that because of limited family resources, they tend to hospitalize their patients in government-funded facilities.

Conclusion: Caregivers of CVA patients encounter a variety of informational, psycho-social and financial problems and many of these can be solved successfully by education-based intervention.

Key Words: Home care, cerebrovascular accident, family caregiver, nursing

ÖZET

Amaç: Bu çalışmanın amacı yatağa bağımlı inmeli hastalara evde bakım veren hasta yakınlarının yaşadıkları güçlükleri belirlemek ve sorunların çözümünde yardımcı olmaktır.

Gereç-Yöntem: Araştırma yatağa bağımlı inmeli hastalara evde bakım veren hasta yakınlarının yaşadıkları güçlükleri belirlemek ve sorunların çözümünde yardımcı olmak amacıyla tanımlayıcı olarak yapılmıştır. Araştırmanın örneklemini Hacettepe Üniversitesi Erişkin hastanesi, Ankara Üniversitesi İbni Sina Hastanesi ve Sağlık Bakanlığı Ankara Numune hastanesinin Nöroloji servislerinden SVO tanısı ile taburcu olan 38 hasta yakını oluşturmuştur. Araştırmada hasta yakınlarının demografik özelliklerini ve yaşadıkları güçleri belirlenmek amacıyla oluşturulan açık ve kapalı uçlu soruları içeren soru formu kullanılmıştır. Veriler sayı ve yüzdelik olarak verilmiştir.

Sonuçlar: Çalışma sonucunda hasta yakınlarının hastalığa, kullandıkları ilaçlara, konstipasyon ve diyare gibi boşaltım sorunlarına ve beslenmeye ilişkin bilgi gereksimi olduğu saptanmıştır. Aynı zamanda hasta yakınlarının yaygın bir şekilde psiko-sosyal, yorgunluk ve uykusuzluk sorunları yaşadıkları saptanmıştır. Çalışmada, inmeli hasta yakınlarına ekonomik, psiko-sosyal ve çeşitli konularda eğitim verildi, verilen eğitimlerle sorunların çoğu başarıyla çözümlendi.

Anahtar Kelimeler: Evde bakım, serebro-vasküler olay, bakım vericiler, hemşirelik, güçlükler

Introduction

Life expectancy increases as medical technology, living standards, and early diagnosis and treatment methods improve. Along with the increase in life expectancy, there is an increase in the prevalence of chronic diseases[1,2]. Cerebrovascular accident (CVA) is a chronic illness with a high mortality rate. According to the World Health Organization (WHO) report (2005) CVA caused 12% of the deaths from all illnesses. CVA is responsible for 85% of all deaths from neurological diseases[3,4]. Also according to Turkish annual statistics, morbidity and mortality due to CVA has steadily increased. According to the National Burden of Disease and Cost Effectiveness Study conducted in our country in 2000 of the top 20 diseases CVA is the second leading cause of death (15.0%)[5,6].

The disease entity known as CVA arises from vascular disease in brain arteries, and can result in motor, sensory and psychological dysfunction[7]. Because of these functional disturbances CVA patients' recovery requires long term care both at the hospital and at home. In general after discharge patients are cared for in their homes by their spouses or daughters. In Turkish society, family integrity is a fundamental concept, and caring for a sick family member is seen as a responsibility rather than a burden. Because there is no organized home health care available in our country the caregivers provide care in their own homes. These caregivers do not receive adequate institutional support and experience physical, emotional and social difficulties[8,9,10].

At first a patient's family might expect complete recovery, but when they realize that the symptoms may continue for months or even for life, they can feel unhappy and isolated[11]. In this context, studies indicate that caregivers need emotional, educational, and practical support. More generally, the patient's process of recovery involves a complex interaction of many factors beyond the severity of the disease, and includes the family's adaptation to the disease in terms of changes in lifestyle and roles[12,13].

A 2004 study indicated that those persons who provided the most intense caregiving reported substantially poorer health than non-caregivers or those with modest caregiving responsibilities[14]. Studies indicate that providing sufficient information for patients and families helps to ease their adaptation process. CVA patients and their families usually do not receive enough information about the disease, its prognosis and treatment, or the process of recovery[12,13,15].

Aim

The aim of this study was to determine the difficulties experienced by bedridden CVA patients' caregivers at home and to support their abilities to cope with these difficulties.

Methods

Research type

This research was a descriptive type of study.

Research setting and characteristics

This research was conducted in Ankara province capital with patients hospitalized on the neurology wards at Hacettepe University Adult Hospital, Ankara University İbn-i Sina Hospital, and Health Ministry's Ankara Numune Hospital.

Hacettepe University Adult Hospital's neurology service has a 26-bed capacity and nine staff nurses. There is also one dietician and five Physical Therapy and Rehabilitation university teaching staff on the neurology service to provide for patients' nutritional, dietary and physical therapy rehabilitation needs.

Ankara University İbn-i Sina Hospital's neurology service has three separate wards with 25 beds each and an 8-bed Neurology Intensive Care Unit. There are 16 staff nurses, one dietician and one physiotherapist on the neurology service.

Health Ministry's Ankara Numune Hospital's neurology service has two separate wards with a total capacity of 24 beds and an 8-bed Neurology Intensive Care Unit. The neurology service and Neurology Intensive Care Unit has 15 staff nurses, one dietician and but no physiotherapist.

Research population and sample

The research population was comprised of individuals who were the caregivers of patients hospitalized between November 3, 1998 and January 22, 2001, and discharged from neurology wards in Ankara province capital at Hacettepe University Adult Hospital, Ankara University İbn-i Sina Hospital, and Health Ministry's Ankara Numune Hospital. The research sample was comprised of 38 individuals who were caregivers of patients discharged from these hospitals with the diagnosis of CVA between the dates of the research and who met the research inclusion criteria. All of the research population was targeted for inclusion in the sample; those who were not included were the caregivers of

CVA patients who died during the acute stage, patients who did not live in the capital, and those who did not agree to be visited in their homes.

Research inclusion criteria

- Patients and their families who lived within the capital of the province where the research was conducted
- Caregiver for bedridden patient
- Agreed to home visit

Data collection

I. Data collection tools

I.1. Patient assessment form

This form was prepared by the investigators and included questions about age, gender, educational level, occupation, social security insurance, income level, number of hospitalizations for CVA, diagnosis, medications, diet, resources for getting to hospital, vital signs, level of consciousness-sensory-motor function (evaluated according to scala of GLASKOW Coma) status with patients.

I.2. Caregivers' questionnaire

This form asked questions to obtain information about the individuals giving one on one care to the patient at home including age, gender, marital status, education status, occupation, relation to patient, whether or not they lived together with the patient, assistance received caring for patient, status of having financial difficulties from their relative's illness, whether or not they themselves had a health problem, status of having received education about caring for the patient, whether or not they experienced physiologic, psychological or social problems while caring for patient and methods used to solve these problems by themselves, and their expectations on this subject.

I.3. Care plan form

This form was prepared for the purpose of determining difficulties experienced by caregivers during care. On this form there are the steps of assessment of problems experienced by caregivers, implementation of recommendations given by investigators, status of resolution of problems by recommended procedures.

II. Data collection tools' pilot study

To determine whether there were any deficiencies on the three forms described above and to complete them expert opinions were requested from the neurology service team members including a physician, nurse, dietician and physiotherapist. After receiving their opinions a pilot study was conducted, deficiencies were corrected and the forms were put into their final format.

III. Data collection tools' administration

Meetings were conducted by the investigators (individuals who were instructors in classroom settings and were responsible for students' one on one education in the clinical setting) with the neurology service team members (physician, nurse, physiotherapist and dietician) to explain the research aim. Written permission to conduct the research was obtained from the medical directors of the hospitals (because there were no ethics committees when the research was conducted) and verbal permission was obtained from the caregivers. And we explained anonymity and confidentiality issues to care givers.

Team Preparation: Home care team member consist of five researcher nurse and a physiotherapist.

Educational Meetings with Home Care Team;

- Preparation of Educational Brochures about Patient Care
- Preparation of Data Collection Forms

First Meeting: Participating caregivers were identified as a result of interviews with members of the hospital team which would conduct the study by the investigators. In these interviews the patients and caregivers were told about the purpose of the research and their verbal permission to participate was received. Then the Patient Assessment Form and Caregiver's Questionnaire were completed by interviewing the participants. Then the monitoring of caregivers began.

Team Meeting: After visiting the hospital, investigators organized a meeting and an analysis was made of the patient and caregiver's status. Then some recommendations were given to the investigator who would conduct the monitoring.

Caregivers Visits and Telephone Calls in Hospital: During hospital visits planned according to the recommendations from the team meeting problems that developed in the caregivers were added to the Caregiver's Questionnaire. Then meetings were conducted with the health care team and the patient's discharge status and a convenient time to meet the caregivers in their homes were determined. Contact was also maintained with caregivers by telephone throughout the patient's hospitalization according to patients needs.

1st Home Visit: There were at least two investigators at the first home visit. The home visits were completed during a period of time that lasted from 60 to 240 minutes. During the visits the following activities took place:

- Patients were given a physical examination, additions about changes in the patient's conditions were made on the Patient Assessment Form completed in the hospital, and the care plan directed at problems determined during hospitalization was implemented (to determine difficulties experienced by caregivers and provide guidance in solving them),
- New problems and difficulties in caring for the patient experienced by caregivers were added to the Caregiver's Questionnaire and problems experienced at home by caregivers after hospital discharge and care plan which had recommendations for problems determined during hospitalization were implemented
  - Education and consultation were given using educational materials prepared

about problems experienced in patient care and solving problems experienced at home,

- Patient care and consultation according to patient's and caregiver's needs were given that had been recommended by other members of the health care team (physiotherapist, dietician, psychologist, psychiatrist, speech therapist, etc.)

- An assessment of the home environment was made, new problems about difficulties experienced by patient and caregiver while care was being given were determined and the day and frequency of visits were determined.

Team Meeting: After the first home visit problems identified during the home visits were shared with other members of the team and recommendations to solve the problems were made. The 2nd and following home visits were similar to the 1st home visit. Other than the home visits telephone call consultations were also made according to the needs of caregivers. An average of five home visits were made (minimum of 2, maximum of 11 home visits) based on the needs of the caregivers. The decision to stop home visits was made in team meetings after home visits.

The administration of data collection forms and stages are shown below.

Diagram: Administration diagram

Team preparation

Home Care Team Education Meetings

- Preparation of Home Care Educational Brochures
- Preparation of Data Collection Forms

1st Meeting- hospital visit

- Patient Assessment Form
- Caregiver's Questionnaire

Team meeting

- Assessment of status of caregiver who will be followed

Caregivers visits and telephone calls in hospital

- Caregiver's Questionnaire
- Caregiver and health care team determine patient and caregiver's discharge status
- Determination of day for home visit

1st Home visit

- Patient Assessment Form
- Caregiver's Questionnaire

- Care Plan Form
- Home Environment Assessment

Team meeting

- Assessment of status of caregiver being followed

Other home visits

- Caregiver's Questionnaire
- Care Plan Form

Telephone calls (according to patients needs)

- Education and Consultation

Team meeting

- Assessment of caregiver's status and discharge

Data analysis

The data obtained in this research were analyzed on the computer in the SPSS 9.0 program. Because there were only 38 individuals in the sample only percentage calculation was done.

Results

Assessment of the obtained demographic data showed that 58% of the caregivers were under the age of 50 (Median age 42.2) and that 89.5% were female. Less than half of the family caregivers were married (42.1%). In terms of educational level, 50% had graduated from primary school, and 28.9% had graduated from high school. For employment, 79% were housewives, and 15.8% were retired. In this study 60.5% of the patients who were given care by family caregivers were over the age of 50 (Median age 67.9) and 57.9% were female. Most of them were married (73.7%). In terms of educational level, 52.7% had finished primary school and 31.6% were retired (Table 1).

In terms of the family caregivers' relation to the patients, 42.1% of the caregivers were the spouse of the patients. Most of the caregivers (86.8%) were living together with the patients, and 84.2% were getting help from other family members, nearly half of whom were the patients' children (47.4%). More than half of the families (60.5%) did not have financial problems due to the cost of care. Almost a third of the caregivers (31.6%) had healthcare problems of their own (Table 2) and among this hypertension occurred in 21%.

In the examination of problems determined in caregivers at discharge of the patient from the hospital psychosocial problems ranked first among the problems observed at the discharge stage. All (100%) of the caregivers experienced a psychosocial problem at hospital discharge. However the majority (83.1%) of the psychosocial problems were

Table 1. Baseline Characteristics of Participants (n: 38)

Characteristic	**Caregivers**		**Stroke Survivors**	
Age	**(Median: 42.2)** **n**	**%**	**(Median: 67.9)** **n**	**%**
50- ↓	22	58.0	15	39.5
50-↑	16	42.0	23	60.5
Gender				
Female	34	89.5	22	57.9
Male	4	10.5	16	42.1
Marital Status				
Single	22	57.9	10	26.3
Married	16	42.1	28	73.7
Education Status				
Not graduates Primary School	8	21.1	14	36.8
Primary School	19	50.0	20	52.7
High school-university	11	28.9	4	10.5
Occupation				
Housewife	30	79.0	18	47.4
Retired	6	15.8	12	31.6
Farmer	-	-	4	10.5
Others*	25.2		4	10.5

*Others include civil servant, laborer and tradesman

solved after discharge home. The most commonly reported psychosocial problems were inadequate family support, family disruption, social isolation, restriction in social activities, inability to leave the patient alone, fear of making mistakes, reluctance to give patient care in general, reluctance to provide bowel management care, anger, depression, anxiety, hopelessness, suicidal thoughts, and disruption of professional life (Table 3).

Knowledge deficit about patient's physical care was another problem that caregivers encountered. At the discharge and home monitoring stages, 94.7% and 42.1% of the caregivers, respectively, were in need of information about the physical care of the patient. The resolution rates, after education, were 100% respectively (Table 3).

At the discharge stage, caregivers' needs for information about diet, medication, and the disease (CVA) were expressed by 94.5%, 65.7%, and 63.1% respectively. The corresponding rates during the home monitoring phase were 7.8%, 10.5%, and 39.4%, and all were resolved completely. Patients' exercise-related problems at discharge and

Table 2. Characteristics of Caregivers (n: 38)

Family relationship	**n**	**%**
Spouse	16	42.1
Daughter–in-law	10	26.3
Adult Child	7	18.6
Sibling	3	7.9
Others*	2	5.2
Live in same house with stroke survivor		
Yes	33	86.8
No	5	13.2
Help in the care		
Yes	32	84.2
No	6	15.8
Person who helps with care (n=32)		
Adult Child	18	47.4
Daughter in law	3	7.9
Mother- Sister/brother	3	7.9
Sister/brother	2	5.3
Unrelated Caregiver	2	5.3
Others**	4	12.5
Economical difficulties due to patient's health problems		
Yes	15	39.5
No	23	60.5
Health problems of caregiver		
Yes	12	31.6
No	26	68.4

*Others include parent and unrelated caregiver

**Others include spouse, grandchild child-grandchild, partner- daughter in law.

monitoring stages were estimated at 47.3% and 31.5% respectively. The corresponding rates of resolution were 95.5% (Table 3).

Caregivers' needs for information about the patient's wound care were observed at discharge (26.3%) and all were resolved completely. During the home monitoring period we educated the caregivers, so there were no problems with wound care. As for

Table 3. Caregiver' Problems in Hospital Discharge and Home and Status of Resolution (n: 38[*])

Problems	Caregiver' Problems				Resolution Status in Home			
	At Hospital Discharge		In Home		Resolved		Unresolved	
	n	%	n	%	n	%	n	%
Psycho-social problems[1]	38	100	38	100.0	34	89.4	4	10.5
Need for information about patient's physical care[2]	36	94.7	16	42.1	16	100.0	-	-
Need for information about patient's diet[3]	35	94.5	3	7.8	3	100.0	-	-
Need for information about patient's medicine	25	65.7	4	10.5	4	100.0	-	-
Need for information on disease	24	63.1	15	39.4	15	100.0	-	-
Problems with the patient's exercise[4]	18	47.3	12	31.5	11	95.5	1	4.5
Need for information about the patient's wound care	10	26.3	-	-	10	100.0	-	-
Difficulty in communicating with the patient	10	26.3	3	7.8	3	100.0	-	-
Fatigue	9	23.6	12	31.5	10	83.3	2	16.7
Need for information on house set-up	8	21.0	5	13.1	4	80.0	1	20.0
Need for information on patient's bowel regularity[5]	6	15.7	9	23.6	9	100.0	-	-
Need for information about patient's sleep schedule	5	13.1	3	7.8	3	100.0	-	-
Insomnia	5	13.1	5	13.1	5	100.0	-	-
Need for information on body mechanics [6]	4	10.5	4	10.5	4	100.0	-	-
Others[7]	7	18.4	13	34.2	11	84.6	2	15.4

[*] Percentages calculated according to n

[1] Lack of adequate family support, family disruption, social isolation, restriction in social activities, inability to leave patient alone, fear of making mistakes, reluctance to give patient care in general, reluctance to provide bowel care, anger, depression, anxiety, hopelessness, suicidal thoughts, or disruption of professional life.

[2] Need for information about hygienic care, mouth ulceration, changing position, excretory care, or dressing,

[3] Patient nutritional issues including gastrostomy or nasogastric tube, lack of appetite, difficulty in swallowing.

[4] Difficulty in getting the patient to do exercises or therapeutic practice, need for information about respiration and coughing practices.

[5] Need for information about constipation or diarrhea.

[6] Not able to give patient care due to lower back pain, lumbago, herniated disc, etc.

[7] Others: Need for information on caregiver's own health conditions, Not able to give care because of low back pain and old age

communication problems with patients, 26.3% of caregivers at the discharge stage and 7.8% at the home monitoring stage encountered these problems. These were solved at rates of 100% respectively in home by researchers. The proportion of caregivers experiencing fatigue was determined to be 23.6% in the discharge stage and 31.5% in the home monitoring stage. These were solved at rates of 83.3% respectively at home (Table 3).

At the discharge stage, 21% of the caregivers needed information about in-house set up, 15.7% needed information about bowel regularity and 13.1% needed information about the patient's sleep schedule. The corresponding figures for the home monitoring stage were 13.1%, 23.6% and 7.8% respectively. Most of these problems were solved. Insomnia was resolved at rates of 100% after discharge in home monitoring stages respectively.

It was determined that 10.5% of the caregivers in the discharge stage and 10.5% in the home monitoring stage needed information about their body mechanics and most of these problems were solved (Table 3).

It was also determined that 18.4% of the caregivers in the discharge stage and 34.2% in the home monitoring stage had other problems (not able to give care to their patients because of low back pain and old age) and these problems were solved at rates of 84.6% respectively in home.

About 0.7% of the caregivers in the discharge stage and 2.9% in the monitoring stage reported anxiety related to bringing the patient for follow-up clinical visits. We resolved this problem at rates of 50% and 66.7% respectively by making and confirming their clinic appointments (not shown in table).

Discussion

The demographic characteristics of participants in this study were similar to those in two other studies in Turkey, where females comprised 78.03% and 89% of the caregivers, respectively[8,9]. According research results of a study conducted in North Carolina, a greater percentage of caregivers (59.5%) were women than men (40.5%)[12]. Jullamate et al. findings revealed that the majority of Thai informal stroke caregivers in this study were female, mostly daughters[13]. Most people who perform caregiving related tasks are women. Wives often outlive their husbands and therefore care for their husbands in their later years. Daughters tend to care for their older mother and father. Also, caregiving tasks such as meal preparation, bathing, and toileting are often viewed as women's work and in regard to taking care of patient, it is the daughters who typically perform these tasks[16].

Psychosocial problems ranked first among the problems reported by the caregivers, both at discharge and during home monitoring. Some of the psychosocial problems continued into the home monitoring period, but psychosocial problems encountered after discharge were solved at a rate of 83.1% at home. Stroke is called a family disease because the patient and family members are affected both physically and psychosocially. This issue is clearly documented by studies. Hackl et al. also examined the psychosocial problems of family members of CVA patients and emphasized the negative effects these problems have on quality of patient care[18]. Dramalı et al. estimated that 76% of family caregivers do not have enough time for themselves, and this affects their family and social lives[8].

Knowledge deficit was another problem encountered by the caregivers in our study. Caregivers expressed a need for information across the whole spectrum of patient care, diet, from medicines to home set-up. Most of these problems were overcome. In many instances these had a higher resolution rate than other problems, and this is encouraging from the standpoint of intervention programs that could focus on providing information. These data suggest that the education of caregivers is critically important in improving quality of care. With this in mind, families should be actively included in discharge planning, and nurses are in an excellent position to provide the needed education. Yoon, in a study conducted on CVA patients aged 65 or older, emphasized that the quality of life of patients is strongly affected by the quality of given care[19]. A recent systematic review indicated that the educational needs of stroke patients and their caregivers are not being met and that further research is needed to identify specific information needs of stroke survivors and caregivers[20]. O'Connell et al. reported that "most caregivers stated that they had to actively seek information from health professionals within the hospital, because information was not routinely given" in a study about the educational needs of caregivers of stroke survivors[21].

Patients' exercise-related problems at discharge and monitoring stages were estimated at 47.3% and 31.5% respectively (Table 3). The corresponding rates of resolution were 95.5%. Knowing about and doing exercises with CVA patients was an important part of patient care for caregivers. Within the first weeks after CVA patients were discharged home a physiotherapist to determine whether or not they were effectively participating in the exercise program evaluated the patients. An exercise program was not recommended to the majority of patients in our study; however those who had recommended exercises did not do them adequately. Support from a physiotherapist was received to resolve this problem. Eng et al evaluated the physical and psychosocial effects of an 8-wk community-based functional exercise program in a group of individuals with chronic stroke in their study. They also evaluated the effect of the exercise intervention on measures of health-related quality of life[22].

Some of family caregivers experienced chronic fatigue in our study. The family members who lived with patients and the caregivers in our study stated that they were exhausted. In addition, the caregivers stated that their 24-hour responsibility for care meant that they remained sleepy and could not find time to rest. Support from family members other than the caregivers was recruited to help solve this problem. In a study conducted by Jullamate et al. on Thai stroke patient caregivers the majority of the caregivers provided care to their relatives 24 hours a day.[13] According to research results from North Carolina caregivers averaged 20.1 hours per week of care, 13.6% provided $\geq$40 hours per week[12].

We responded to the caregivers' needs for information about in-house set up, bowel regularity and sleep schedule by educating them. In particular we taught caregivers that loss of bowel control is common in CVA and we helped them to adapt by training them in perinea care. We trained the caregivers to overcome patients' insomnia by keeping the patients busy during the day and establishing a regular sleeping schedule. This is important because insomnia in the patient also disrupts the sleep of the caregivers. Olov et al showed that sleep apnea patients had a higher frequency of ischemic heart disease and had more often uffered from an earlier cerebral infarction in their study[23]. Wound care was observed in some patients at discharge, but during the home monitoring period we educated the caregivers and no further problems with these arose. The need for information about body mechanics was also overcome by education. For the caregivers who experienced communication problems with their patients, we provided training that included nonverbal communication skills. These communication problems were overcome at a rate of 100% respectively, with the educator role of the researchers and the presence of a speech therapist on the research team being key factors. Handschu et al showed that 25.5% of stroke patient had speech problems in their study [24].

Some of the caregivers in our study needed information about their own health conditions. We assessed their diseases carefully and gave them useful advice and recommendations. The caregivers described their own health problems in terms that included old age and chronic disease. The investigators recommended that a physician see one patient and support be given by other family members.

Many of the problems encountered by caregivers were rooted in common causes - limited support from other family members, depression, and hopelessness. This problem was overcome at a rate of 25% by encouraging the caregivers to share their feelings with other family members and ask them for help if needed. In response to questions as to why they tend to hospitalize their patients, answers included inability to afford the drugs and medical devices, and inability to take their patients for checkup visits. To help resolve the anxiety caregivers had toward clinical visits, we helped them schedule appointments and prepare for the visit date. In a study conducted by Williams caregivers were found to have a low incidence of physical symptoms but a significantly high incidence of emotional stress [25]. In the research conducted in North Carolina when asked to name the one or two greatest difficulties they experienced from caregiving, 29.9% of caregivers cited stress, 27.9% cited not enough time for themselves or their families, and 12.0% indicated that caregiving had created a financial burden [12].

Conclusions

The treatment and care of the CVA patient continues at home after discharge. Since both the patient and family are affected by CVA, both family and the patient need to be supported by the health team taking into consideration potential problems (psychosocial, economic, and physical problems). Considering the results of this study, family caregivers face numerous problems in our country, and at present families are mostly left to their own coping strategies. Psychosocial problems were common among the caregivers. Knowledge deficits were observed related to physical care, diet, medications, the disease, exercise, pressure ulcer care, and excretory system function and its regulation. In addition caregivers reported fatigue and sleep disorders. They had problems in affording medications and in taking the patients to checkups. Some caregivers stated that due to financial problems they would prefer to hospitalize their patients in a government facility.

At discharge, an integrated care plan needs to be made with active family participation, with a focus on the problems caregivers will encounter. Therefore, that includes assessment of the patient, discussion of treatment options and objectives, and provision of a long term care plan involving the patient, family, and all team members is quite important. Assessment of caregivers' problems shows that most can be solved by regular home visits. This suggests that home care services reduce the rate of repetitive hospitalization and lower the cost of treatment for families and the government.

Limitations of the study

Generalization of the study findings is limited in view of the number sample and the study data is 8 years old.

Acknowledgements: This project has been supported by the T.R. Prime Ministry State Planning Organization (Project number: 98K121780)

References

1. Utku U. İnme tanımı, etyolojisi, sınıflandırma ve risk faktörleri, *Türk Fiz Tıp Rehab Derg* 2007; 53 Özel Sayı 1:1-3.
2. Okuyucu E E, Coskun O, Inan L E, Tunc T, Ozkan S. Serebrovaskuler hastalıklarda sirkadian ve sirkannual ritim, *Türk Serebrovaskuler Hastalıklar Dergisi* 2006; 1:11-14.
3. Global Burden of Neurological Disorders Estimates and Projections (chapter 2). URL :http://www.who.int/mental_health/neurology/chapter_2_neuro_disorders_public_h_challenges.pdf. June 10, 2008.
4. Truelsen T, Begs S, Mathers C. The Global Burden of Cerebrovasculer Disease. URL: http://www.who.int/healthinfo/statistics/bod_cerebrovasculardiseasestroke.pdf. June 10, 2008.
5. Türkiye Istatistik Kurumu (TUİK): Turkish Statistical Institude (TSI) Hastanelere Yatan Hastaların Seçilmiş 150 Hastalık Nedenine Göre Dağılımı (Distribution of 150 Specified Disease Causes for Hospitalization). URL: http:/www.tuik.gov.tr/veriBilgi.do?tb_id=6&ust_id=1.
6. TC Sağlık Bakanlığı Refik Saydam Hıfzıssıha Merkezi Başkanlığı Hıfzıssıha Mektebi Müdürlüğü. Başkent Üniversitesi Ulusal Hastalık Yükü ve Maliyet- Etkilik Projesi Hastalık Yükü Final Raporu. Ankara: 2004.
7. Effects of Stroke, National Stroke Association. URL: http://www.stroke.org/site/PageServer?pagename=EFFECT. October 5, 2009.
8. Dramalı A, Demir F, Yavuz M. Problems encountered by family caregivers caring for patients at home (in Turkish). Proceedings of 1st National Congress of Domestic Care, Marmara University; 24-26 September 1998; Istanbul.
9. Altun İ. Patients' family members in the obligatory caregiver role (in Turkish). Proceedings of 1st National Congress of Domestic Care, Marmara University; 24-26 September 1998; Istanbul.
10. Nahcivan ÖN. Evaluation of risks reported by individuals in the home care process (in Turkish). Proceedings, of 1st National Congress of Domestic Care, Marmara University; 24-26 September 1998; Istanbul.
11. Johnson P, Chaboyer W F, Vooren R. Caregivers of ICU patients discharged home: What burden do they face? *Intensive and Critical Care Nursing* 2001;17:219-277.
12. Characteristics and Health of Caregivers and Care Recipients - North Carolina, 2005. URL: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5621a3.htm. October 5, 2009.
13. Jullamate P, Azeredo Z Pául C Subgranon. Thai Stroke Patient Caregivers: Who They Are and What They Need, Cerebrovasc Dis 2006;21:128-133. URL: http://content.karger.com/produktedb/produkte.asp?typ=fulltext&file=CED20060211_2128 October 5, 2009.
14. National Alliance for Caregiving and AARP. Caregiving in the U.S. Washington, DC: National Alliance for Caregiving and AARP; 2004. URL: http://www.caregiving.org/data/04finalreport.pdf. February 10, 2009.

15. Aksayan S, Çimete G. In-home care for chronically ill individuals: requirements, possibilities and choices (in Turkish). Proceedings of 1st National Congress of Domestic Care, Marmara University; 24-26 September 1998, Istanbul.
16. Quinn W. A new look at the old-family caregivers: Considerations, assessment, and support. Gerontology 2006 Trinity Healthforce Learning: EDA 424-0014.
18. Hackl M, Holzner B, Gunther V, Saltuari L. Care of stroke patients by relatives: social support and coping strategies. *Dtsch Med Wochenschr* 1997; 122:669-75.
19. Yoon H. Factors affecting quality of life of the Korean aged stroke patients. *Int J Aging Hum Dev.* 1997; 44(3): 167-181.
20. Forster A, Young J, Smith J, Knapp P, House A, Wring J. Information provision for stroke patients for stroke patients and their caregivers. URL: http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD001919/frame.html. October 5, 2009.
21. O'Connell B, Baker L, Prosser O. The educational needs of stroke survivors in acute and community setting. *Journal of Neuroscience Nursing* 2003 Feb; 35(1): 21.
22. Eng JJ, Chu KS, Maria KC, Dawson AS, Carswell A, Hepburn KE. A Community-based group exercise program for persons with chronic stroke. *Medicine & Science in Sports & Exercise* 2003; 35(8): 1271-1278
23. Olov S, Bucht G, Yngve G. Sleep apnea, delirium, depressed mood, cognition, and ADL ability after stroke. *JAGS* 2001;49: 391–397.
24. Handschu R, Poppe R, Rauß J, Neundörfer B, Erbguth F. Emergency Calls in Acute Stroke. *Stroke* 2003; 34:1005.
25. Williams M. Caregivers of persons with stroke: Their physical and emotional wellbeing. *Quality of Life Research* 1993; 2(3): 213-220.