

## HEALTH NEEDS OF PATIENTS WITH STROKE AT GAZA GOVERNORATES, PALESTINE: A MIXED DESIGN APPROACH

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### ABSTRACT

There is a lack of knowledge about how health care services should be organized to meet patient's needs after stroke. This study aimed to assess the health needs of people with stroke residing in Gaza Strip. The design for this study was a descriptive, analytical, cross-sectional using a qualitative and quantitative approach for data analysis. The study population consisted of 221 health care providers (nurses physicians, and physiotherapists) who work at medical wards and dealing with patients with stroke. For quantitative data collection, the researchers used a self-administered questionnaire. In total, 192 respondents completed the questionnaire with a response rate of 86.8%. For qualitative data collection, a focus group consisted of 10 patients was used to explore their health needs. SPSS version 20 was used for data analysis. The results from quantitative data analysis revealed that the most important physical need for client with stroke is to demonstrate safe transfer techniques (83.2%), followed by understanding the importance of adhering to low fat diet (83.0%).

Regarding social needs, the results showed that the most important social needs were managing changes in roles and relationships and dealing with behavioral changes (78.8%) followed by dealing with changes in body image (78.4%). Regarding the mental needs, the first priority was understanding disease process of stroke (79.8%) followed by comprehending and use of assistive or adaptive devices (79.2%). Results from qualitative data analysis revealed that the main concerns related to physical needs were the need for learning how to prevent pressure ulcers, how to monitor blood pressure and preventing aspiration. While social needs focused on the loss of autonomy and control in managing their personal finances and the need to know how to deal with changes in body image. The need for assistive devices to cope with stroke ranked as the first priority among mental needs. The findings of this study expand our knowledge toward the willingness of the interdisciplinary health care team to coordinate the care and education of persons with stroke and their caregivers to provide a comprehensive teaching program in health care setting.

**KEYWORDS:** Mental Needs, Stroke, Social Needs, Patients, Physical Needs

### INTRODUCTION

People who have suffered a stroke for one to eleven years reported several long- term needs, (1). These needs are related to different aspects of disability and to rehabilitation and are to a large extent unmet. The reasons behind the many

unmet needs for rehabilitation have been only slightly explored, but studies indicated that people with more severe disability after stroke are more likely to report unmet needs for rehabilitation. There is a lack of knowledge about how rehabilitation services should be organized to meet patient's needs after stroke. However, rehabilitation services of different levels of complexity might be considered (2). A study conducted by Hafsteinsdottir and colleagues concluded that patients with stroke and their caregivers have many and diverse educational needs, which often were not met. The educational needs of stroke patients and caregivers were those related to knowledge about the clinical aspects of stroke, prevention, treatment and functional recovery. The most commonly reported needs of caregivers involved patient's moving and lifting, exercises, psychological changes and nutritional issues. Patients and caregivers wanted information that was tailored to their situation (3).

Due to shortened hospital and rehabilitation lengths of stay, health care providers must become adept at assessing caregiver's needs for information and making caregiver education a priority to prevent complications and hospital readmissions. While caring for a loved one who has suffered a stroke can be a satisfying experience, it can also be strenuous and emotionally draining. It was reported that spouses of people with stroke believe that they could have been told more and given more support during both hospitalization and rehabilitation periods (4). Collectively, cardiovascular disease (including stroke), cancer, and diabetes account for approximately two thirds of all deaths in the United States and about \$700 billion in direct and indirect economic costs each year (5). Yet no studies on stroke have been reported from Palestine. Many research studies have been done in relation to the educational needs of patients and families post-stroke based in Western countries but limited studies have been conducted in Arab countries especially Palestine concerning health needs of stroke patients. On the other hand, the qualitative studies regarding needs of patients with stroke in Palestine are scarce. The absence of these studies would create a problem in health care system because there are some of such patients needs requiring researchers to stimulate the patients to talk comfortably to express these needs without any limitation (6).

The significance of this study to the health profession is to identify the health needs of persons dealing with stroke. Knowing these health needs will better prepare the caregivers and survivors of stroke for the transition from inpatient rehabilitation treatment to living in the home environment. Using this information to develop health materials will help allay the caregiver's feelings of frustration and anxiety while providing care to the person with stroke in the home setting. This study is unique because of its focus on the importance of interdisciplinary health care teams in the formulation of health programs. The results of this study can be used to develop educational interventions for stroke patients and their caregivers in future.

## **MATERIALS AND METHODS**

The design for this study was a descriptive, analytical, cross-sectional using a qualitative and quantitative approach for data analysis. The triangulation of using quantitative and qualitative methods was applied to add depth to the data and results of this study (7). This study was conducted in governmental hospitals at Gaza Strip, Palestine. Participants were selected from the five major hospitals that provide care to patients with stroke in Gaza Strip. The hospitals (Kamal Edwan, Shifa medical complex, Aqsa hospital, Nasser medical complex and Alnajjar hospital) represent the five governorates of Gaza Strip and were selected randomly. The sample of qualitative approach was selected by a simple random method.

The target population consisted of allied health professions who provide care for stroke patients, and currently working in Gaza governmental hospitals. The total number of health care providers population is 221 including (physicians, nurses and physiotherapists). For qualitative data, ten patients who were diagnosed with stroke were recruited directly from governmental hospitals. Data were collected immediately before discharge to select these participants, two hospitals (Nasser medical complex and Alnajjar hospital) were selected randomly, then ten patients were selected randomly from these two hospitals.

A structured self-administered questionnaire was used to collect quantitative data from health care providers. Respondents answered the questions on a Likert scale - (1= Strongly Disagree, 2 = Disagree, 3 = Neutral, 4= Agree, 5 = Strongly Agree), the questionnaire of this study was based on Orem's (2001) universal self-care requisites (USCRs) (8).

A focus group discussion was used to collect qualitative data from patients diagnosed with stroke. During the group discussion, participants were asked different types of questions and they were allowed to express their needs by themselves comfortably. Data were systematically analyzed within steps, raw data were carefully processed by open coded thematic analysis in order to make analytical interpretations.

The qualitative approach was divided into four phases: 1) establishing the questions; 2) planning the focus groups (number and size of group, time and place of meetings, selection and recruitment criteria of participants, choice of moderator); 3) leading of the focus group; 4) analysis and report.

Prior to conducting this study, approval from the ministry of health and hospital's administration were obtained to conduct this study. The aim of the study was explained to all participants (health care providers and patients diagnosed with stroke) and they were asked to sign a consent form to participate in the study.

To test the questionnaire, a pilot study was conducted on 30 subjects from health care providers before the start of actual data collection. Reliability of the instrument was measured through Cronbach's Alpha coefficient and Split half test. The general reliability for all items was 0.750 which is considered good (Nunnaly, 1978) and ensures reliability of the questionnaire. Internal consistency of the questionnaire is correlation coefficients between each paragraph in one field and the whole field. The results showed that the P-Values were less than 0.05.

## RESULTS

A total number of a 192 health care providers (out of 221 recruited) completed the questionnaire with a response rate was 86.8%. Twenty nine of health care providers didn't respond to the study, some of them refused to participate and the others were in leave at that time. On the other hand, all ten patients who were recruited to participate in the discussion group agreed to be part of this study.

## QUANTITATIVE DATA

### Socio-Demographic Characteristics of the Sample

Table 1 summarizes the socio-demographic data of health care providers who participated in this study. The number of respondents were 192 out of 221 (response rate was 86.8%) from the governmental hospitals which have been selected in this study. Twenty nine of health care providers didn't respond to the study, some of them refused to participate and the others were in leave at that time.

The majority (66.1%) of study participants were males. The age of majority of participants (82, 42.7%) was between 36 and 50 years. On the other hand, the majority (60.9%) of study participants have (1 -10 years) of experience and there are only 11 (5.7%) have more than 20 years of experience. Fifty four (28.1%) of study participants were working with stroke patients more than 75% of their time, while 41 (21.4%) of study participants are working with stroke patients less than 25% of their time.

**Table 1: Sample Distribution According to Age, Gender and Residence**

Variables		Number	%
Age (Years)	(30) years and less	69	35.9
	(31 – 45) years	82	42.7
	More than (45) years	41	21.4
	<b>Total</b>	<b>192</b>	<b>100.0</b>
Gender	Male	127	66.1
	Female	66	33.9
	<b>Total</b>	<b>192</b>	<b>100.0</b>
Residence	Gaza	56	29.2
	North Gaza	25	13.0
	Middle area	40	20.8
	Khanyounis	35	18.2
	Rafah	36	18.8
	<b>Total</b>	<b>192</b>	<b>100.0</b>
Title	Physician	62	32.3
	Nurse	86	44.8
	Physiotherapist	44	22.9
	<b>Total</b>	<b>192</b>	<b>100.0</b>

## HEALTH NEEDS OF PATIENTS WITH STROKE

Table 2 ranks the needs reported by participants as the most important, the need to demonstrate safe transfer techniques (mean percentage = 83.2) was ranked by health care providers as the most important need followed by understanding low fat diet (mean percentage = 83). The least important need according to health care providers was managing and dealing with changes in sexuality (mean percentage = 75.6).

Regarding the mental needs, the table shows that the first priority of mental needs for the patients with stroke is understanding stroke disease process (79.8%) followed by comprehending and use of assistive or adaptive devices (79.2%), the third one is managing sleep disturbances (79.0%). The fourth mental need is learning diversional or recreational activities (78.6%) and there are two fifth mental needs and they are: managing depression and identification of problems using language (aphasia and dysarthria) (78.4%).

**Table 2: Mean, Standard Deviation (SD) and Percentage of Health Needs of Stroke Patients Based on Priority**

No.	Item	%	Mean	SD
1.	Physical needs Demonstrating safe transfer techniques	83.2	4.16	0.77
2.	Understanding low fat diet	83.0	4.15	0.84
3.	Learning foot care	82.8	4.14	0.82
4.	Understanding mechanical soft diet	82.4	4.12	0.80
5.	Managing oxygen therapy	82.2	4.11	0.
	Staying active	82.2	4.11	0.92

Table 2: Contd.,

Social Needs				
1.	Managing changes in roles and relationships	78.8	3.94	0.91
	Dealing with behavioural changes	78.8	3.94	0.83
2.	Dealing with changes in body image	78.4	3.92	0.89
3.	Dealing with problem in communication	78.0	3.90	0.99
4.	Dealing with emotional changes	77.6	3.88	0.91
5.	Managing and dealing with changes in sexuality	75.6	3.78	0.97
Mental Needs				
1.	Understanding stroke disease process	79.8	3.99	0.90
2.	Comprehending and use of assistive or adaptive devices	79.2	3.96	0.95
3.	Managing sleep disturbances	79.0	3.95	0.91
	Identifying care givers support group	79.0	3.95	0.85
4.	Learning diversional or recreational activities	78.6	3.93	0.93
5.	Managing depression	78.4	3.92	0.82
	Identification of problems using language (aphasia and dysarthria)	78.4	3.92	0.81

## QUALITATIVE APPROACH

### Sample Characteristics

Ten patients diagnosed with stroke were interviewed as a focus group, Five participants were from Alnajjar hospital and the other five were from Nasser hospital. Six patients were males, and four were females. Seven of them were aged between (50-65 years) and the other were less than 50 years old.

### Physical Needs of People with Stroke

More than half of the participants mentioned that they experienced fatigue after the stroke. Nearly half of them reported that they had problems with concentration after the stroke. Four patients said they had problems with their memory. Nearly a quarter said they had problems reading. About half of those who were working before their stroke said that they were not able to return to work or had to reduce their activities as a result of the stroke.

Two patients said “we need to learn how to prevent pressure ulcers and how to monitor blood pressure and preventing aspiration”. Three patients said “we need to manage memory loss during stroke”

### Social Needs of People with Stroke

About three patients said that they had negative changes in their family relationships after the stroke. Five patients said that they had a negative change in their relationship with their spouses. Some patients reported that they no longer can perform most activities of daily living independently. Now, they have to wait patiently for others to provide help to them. Some described how they managed to reduce their sense of loss and maintain some level of control by being able to leave residential care on a regular basis and visit their home; decide on when their friends should visit and having some involvement in planning their own daily activities. For others having the financial resources to purchase home help or to purchase equipment reduced their sense of loss and promoted self-reliance.

One patient said “I know they were trying to get someone to come in and give me meals, but anyway, I don’t know whether, they’re paying for it. So she comes in and gives me my meals... My nieces pay them actually, now I have it,

*my nieces pay them*". Four patients said *"we need to know how to deal with changes in our body image"*. Two patients frankly said *"we need to know how to communicate with others"*

### **Mental Needs of People with Stroke**

When interviewing the patients for this section, they have had a sense of loss experienced and the mechanisms used to retain some control over their lives. Some mourned the changes in their sense of identity and sense of self, the loss of control over managing their personal affairs, and the loss of personal pastimes. Some reported that the stroke meant that they had to retire and they therefore lost their occupational role and their sense of identity. Others reported that they felt differently about themselves. Having a stroke therefore fundamentally altered their sense of identity and reduced their sense of self-worth.

One patient said *"I can do some jobs but I can't do all the jobs. I wouldn't have a hope of being a farmer like I used to be"*. Nine patients said strongly *"we need assistive devices to cope with stroke"*

One patient said *"I need to manage sleep disturbances after stroke"*

They therefore were no longer able to retain their managerial and caring role within the household which had a negative effect on their quality of life. Not being able to drive and go where they wished unassisted or tend the garden was a particularly poignant loss for most.

### **DISCUSSIONS**

One of the top four health needs of people with stroke, identified by the health care providers, were classified under Orem's (2001) prevention of hazards universal self-care requisite (USCR) (8). Demonstrating safe transfer techniques was the most frequently reported health need. According to Orem, the maintenance of human integrity and functioning is accomplished through the prevention of hazards to life. Prevention of hazards is linked to all of the other USCR and focuses on the control the person has over both their internal and external environments (8).

Since people with stroke are in need of some form of dependent care due to physical limitations, the caregivers must take actions to identify, remove or protect the patient of stroke away from actual or potential hazards that may affect their functional well-being. Safety and prevention of hazards are priority needs not only for the person with stroke, but for the caregivers as well. Safe transfer techniques are critical to both individuals in the homecare setting to prevent injuries and to maintain functional integrity. This is consistent with the study of Pierce and Steiner which concluded that family caregivers of patients of stroke were most concerned with gathering information regarding safety measures and the prevention of falls (9).

The results from a qualitative study by Talbot and colleagues showed that most of health care providers stated that the psychological needs were the top priority for people with stroke; then came the need to do some home adaptation followed by community living needs (10). Their results also showed that most of caregivers stated the less fulfilled needs were mainly related to psychological needs and associated with community living. Specifically, they meant medication and its side effects, adaptation to this new situation for the caregiver and acceptance by the beneficiary. Respite, emergency help, supportive care and attention, training of family members were also needs partially fulfilled in these categories.

On the other hand, the study results are not consistent with the study of Yonaty (2012) which showed that the medical knowledge and medication treatment were rated the most important to learn, treatment of stroke with herbal or alternative medicine and dietary habits were the least important of the eight domains (11).

The results of qualitative approach in this study revealed that there is a need to learn how to prevent pressure ulcers, how to monitor blood pressure and preventing aspiration. Despite that these needs were ranked by health care providers in the middle of physical needs, these needs should be taken seriously into consideration and should be respected because the patients have a previous background on the danger of high blood pressure as they are risky for stroke.

Regarding social needs, managing changes in roles and relationships and dealing with behavioral changes are very important for both (patient and care giver). Because the person with stroke experience deterioration in mental and social functioning, he/she will have some changes in their behaviors and in their relationships with others. Other health needs identified by more than half of the physical and occupational therapists surveyed included (dealing with problems in communication and social interaction, dealing with emotional changes and social interaction, managing changes in roles and relationships and social interaction; and understanding the disease process of stroke. According to Orem, other USCRs that these priority needs fall into include social interaction and normalcy (8). Orem believed that there should be a balance between solitude and social interaction. This balance helps individuals to acquire knowledge, form values and expectations and is essential for developmental growth (8).

Solitude provides individuals with quiet, reflective time while social interaction provides a sense of belonging and is an essential part of the educational process for caregivers and people of stroke. This USCR fosters all aspects of human development and helps the individual with stroke strive to develop and maintain a positive self-concept and body image (8). Learning to adapt to changes in lifestyle can be challenging for the survivor of stroke and his/her caregiver. As the people with stroke become more adjusted to their environment and changing life circumstances, they will gain a greater sense of self and wholeness. This in turn will decrease the survivor's need for dependent care and promote a positive sense of self for both the person with stroke and the caregiver.

The results of Talbot and colleagues showed that the needs of stroke patients as stated by health care providers that were less fulfilled mainly concerned related to community living, psychological needs and speech impairment, more precisely, they included: leisure activities, awareness, long-term family support, bond between spouses, respect of the person's pace, delivery of timely and simplified medical information to the patient and his/her spouse, adaptation of the home and respite (10). These results are consistent with the results of this study which revealed that some of patients had negative changes in their family relationships since the stroke, problems related to changes in body image and how to deal with and problems with communication with others. This supports the study results and creates an opportunity to study these needs seriously in the future because of the consensus regarding the social needs between patients with stroke and health care providers.

Regarding the mental needs, the results are supported by the results of qualitative approach which revealed that the majority of patients stated that they want to know how to use of assistive or adaptive devices.

The results of mental needs are consistent with Cook which showed that the second most frequent health need identified by physical and occupational therapists involved comprehending the availability and use of assistive and adaptive devices (78%) (12). This need is identified by Orem as the promotion of normalcy (8).

According to Orem, the promotion of normalcy prevents the development of conditions that lead to internal hazards to human life. Therefore, the promotion of normalcy and prevention of hazards are closely related. Also, by assisting the caregiver and patient with stroke with the proper use of assistive devices, the patient is encouraged to become more independent, as they strive to reach their maximum functioning capacity post-stroke (8). Managing sleep disturbances for people with stroke seems to be very important because it was also mentioned by the patients during their interview. Because stroke process affects the brain functions directly, it has a major effect on sleeping process, so it is considered a very important need from patient's perspective. These results are supported by the results of focus group discussion (qualitative approach) which revealed that most of patients need assistive devices to cope with stroke and this is a normative need for patients with stroke. They need assistive devices to cope with this problem in the future.

## CONCLUSIONS AND RECOMMENDATIONS

The study concluded that there is a need to look at patients with stroke and their health needs seriously. Introducing advanced practice by the health care providers can take a leading role in preparing effective plans for people with stroke and their caregivers that are specific to patient's needs. The findings of this study expand our knowledge toward the willingness of the interdisciplinary health care team to coordinate the care and education of persons with stroke and their caregivers to provide a comprehensive teaching program in health care setting.

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