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Family Needs of Caregivers of Stroke Survivors

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Abstract

Background: After a stroke, patient often suffers varying degree of disability that requires immediate hospital care and extended home care. Therefore, caregivers assume multiple roles to fulfil the needs of survivors at home. The current study aim to explore various needs felt by the caregivers of stroke survivors at home.

Methods: A cross sectional community-based survey was carried out. Hundred participants were enrolled purposively. Modified family needs questionnaire (FNQ) was used to identify the needs of the caregivers. Descriptive statistics was used to analyze the results.

Results: 'Health information', 'Professional support' and 'Involvement of care' sub scales were the most important needs areas of the caregivers. The most important needs were within 'Health information', 'Instrumental support' and 'Professional support' sub scale and least important needs fell within 'Emotional support', and 'Community support' areas in the caregivers.

Conclusions: Assessment of Family needs amongst the caregivers of individuals with stroke is important for all health care professionals in understanding problems from the caregivers' perspective. Intervention should be designed and implemented for successful home rehabilitation of stroke survivors.

Keywords: Family needs; Caregiver; Stroke survivors

Introduction

Stroke is presently turning into a major public health problem pushing cardiovascular disease at the back as a cause of mortality in developing countries, particularly in the Asian subcontinents [1]. Based on current estimate approximately 1.8 million people are affected yearly by stroke; one third die and a similar proportion remain disabled [1,2]. Increasing incidence of stroke in India demands swift action.

Stroke is a family disease and has the potential to affect the health and quality of life not only of the individuals but their family caregiver as well [3]. After discharge approximately 80% of stroke survivors live in community, more than a third of whom are dependent on the informal caregivers [4,5]. It is evidenced that, caregivers play a major role in long term well-being and stroke rehabilitation. The emphasis on stroke rehabilitation should shift from being patient focused to an approach focused on both the patients and their caregivers.

Family caregivers provide a substantial amount of care to the stroke survivors [6]. The increasing needs and recognition of the caregivers should draw the attention of policy makers towards identification of their varied needs, provide necessary information about available services and to provide appropriate training according to their roles [7,8].

The previous studies reflect that the caregivers are not always well prepared to take such a task nor are they supported as per the changes in circumstances. Many caregivers reported unmet needs despite available community services, government policies and recommend that caregivers should be involved as health team members from hospital admission to discharge and rehabilitation planning of their patients.

Research demonstrates that stroke survivors and their caregivers often lack the information required to help manage the recovery process at home. Many stroke caregivers lack basic information about stroke, strategies for caring for stroke survivors, and the ways to prevent complication and future attacks of stroke [9-11].

A range of unmet needs have been demonstrated. Caregiver and stroke survivors have identified gaps in knowledge and information about stroke as a condition, its treatment and available services. Caregivers are in need of user friendly relevant information and various other services at successive stages of rehabilitation, particularly during transition from hospital to community. Giving effective and timely education and information will definitely benefit the caregivers [12].

As a first step toward this, a cross sectional survey was conducted to contribute knowledge regarding varied family needs of the caregivers of the individuals with stroke.

Material and Methods

The study was conducted in the month of April 2014 to January 2015 at conveniently selected community settings of district, Amritsar, Punjab, India. The study population comprised of 100 caregivers of survivors of stroke. Inclusion criteria included healthy caregivers aged more than 18 years, staying with the patients and are involved in the direct care of the patient for at least one month after getting discharge from the hospital. Caregivers with chronic psychiatric and medical conditions were excluded from the study. The caregivers who were coming for follow up along with the patient were interviewed in the hospital. Others were contacted in their home care settings only. Finally, 60 caregivers were interviewed at hospital and remaining 40 caregivers were at their home settings. The tools used for the study were 'Caregiving data sheet' and modified 'Family Need Questionnaire' (FNQ).

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Family Need Questionnaire (FNQ): The tool is modified version of Family Need Questionnaire (FNQ) Serio et al. (1997) [13]. The FNQ consists of 40 items reflecting commonly reported family needs. It provides information regarding the extent to which these needs are perceived to be important. The questionnaire is a four point rating scale in which caregiver has to rate the needs items related to caregiving of stroke patient as 'Not important (1)', Slightly important (2), Important (3) and 'Very important (4)'. Forty items are grouped into six independent scales, namely: 'Health Information' (HI, 11 items), 'Emotional Support' (ES, 10 items), 'Instrumental Support' (IS, 6 items), 'Professional Support' (PS, 6 items), 'Community Support Network' (CSN, 5 items), and 'Involvement in Care' (IC, 2 items). Obtaining higher score indicates more importance of a particular need in a particular domain. The Cronbach alpha for Punjabi language version was 0.87 for this study.

The permission for data collection was obtained from the competent authorities in the Institutes. After screening the subjects as per the inclusion and exclusion criteria, an informed written consent was obtained from them. The caregivers were interviewed using FNQ to identify different caregiving needs. In the hospital, the caregivers were interviewed in a separate room at outpatient department and at home setting, caregivers were asked to sit at a comfortable place like rest room that was quite far away from the patients to avoid any bias in findings. It took around 1-1.5 hours to conduct one interview.

All the quantitative data was then transferred into SPSS 20.0 Evaluation Version and was analyzed using descriptive statistics (mean, standard deviation and percentage were computed). A simple count was made to identify the number of respondents who mentioned the item 'important' or 'not important'. From this count the items of needs of the individuals were ordered according to frequency under broad themes.

Ethical Consideration

The study was approved by the Ethics Committee (EC) of Sri Guru Ram Dass Institute of Medical Sciences and Research (SGRDIMSR), Amritsar, Punjab, India (wide letter no. 140/Surg/13). Participation in the study was voluntary and each participant was informed that their decision to participate or not to participate would in no way affect his/her patient's routine care. Anonymity and confidentiality of the subjects was maintained during the study and they were given full autonomy to withdraw from the study at any time without conveying any reason.

Results

The mean age of caregivers was 41.79 years (SD ± 14.12, range 21-79). It was observed that 55% of the subjects were males, studied up to secondary education (56%), and higher secondary education (27%) and were married (86%). In terms of employment, around 37% of caregivers were housewife, followed by 21% working in private sector, and 7% in government sector and earning more than Rs 10,000 per month (71%). Majority of caregivers have their own (98%) houses and staying in joint family (56%) with five or more than 5 members (71%) in the family.

In terms of care giving, 30% caregivers were son, followed by 25% wife and 12% as daughter in-law, providing care round the clock (58%) with the duration of 2.68 ± 1.89 months. Majority of the caregivers (94%) expected availability of another caregivers at home to take care of patient and were found healthy (85%) at the time of furnishing information.

Data also reveals that approximately 37% of the caregivers were primary earning members in family and helps in activity of basic daily living (ADLs) (94%). Family history of stroke was reported by 8% of the caregivers and approximately 19% mentioned the experience of care giving in the past. Majority of caregivers (86%) agreed for the availability of family support in the care of their patients.

The first set of analyses examined the level of importance of caregivers' needs. The importance of the six FNQ sub-scales as reported by the caregivers was examined. The 'Health Information' sub scale had the highest mean importance (M=37.46, SD=4.13, Mean%=86.67) rating whereas the 'Instrumental Support' (M=6.52, SD=1.12, Mean%=81.50) sub-scale had the lowest mean rating of importance. The mean importance ratings for each item were rank ordered as shown in Table 1.

Tables 2 and 3 enlists the lowest ranked needs (Mean range=1.80-3.00). These lowest ranked needs were primarily items from the Emotional Support and Instrumental Support sub scales. Two

Need domains	Mean ± SD	Mean %
Health Information (HI)	37.46 ± 4.13	85.14
Emotional Support (ES)	28.67 ± 3.90	71.68
Instrumental Support (IS)	19.18 ± 2.08	29.92
Professional Support(PS)	20.80 ± 2.45	86.67
Community Support Network (CSN)	15.96 ± 2.56	79.80
Involvement in Care (IC)	6.52 ± 1.12	81.50

Table 1: Pattern of care giving needs in caregivers of stroke survivors (n=100).

Scale	I need	Mean
HI	To know early symptoms of future attack of stroke in my patient	3.70
HI	To have information on the patient's rehabilitative or educational progress	3.66
HI	To know how to meet physical needs of the patients (i.e. oral hygiene, elimination, comfort, nutrition, exercise, and medications etc.)	3.65
HI	To have complete information on the patient's physical problems (e.g. weakness, headaches, dizziness, problems with vision or walking)	3.63
IS	To get enough rest or sleep	3.63
IS	To have help from other family members in taking care of patient	3.62
CSN	To have other family members understand the patient's problems	3.61
PS	To know what to do when the patient is upset or acting strange.	3.57
HI	To know about government services for stroke patient and their caregivers	3.54
PS	To Help in deciding how much to let my patient do by himself/herself	3.52

Table 2: Needs rated as most important by the family caregivers. (n=100).

needs from the Health Information (i.e. To have complete information on the medical care of stroke (e.g. medication, injections, or surgery) and Community Support Network sub scale (To pay attention to my own needs, job, or interests while providing care to patient) were on this list at the lowest ranked needs.

The second set of analyses examined the extent to which needs were perceived as important by the caregivers. The extent to which these needs of six FNQ areas were important was examined. Eight needs from Health Information sub scale were perceived important to very important while two needs from Community Support Network were perceived important to very important among all needs. Under Health Information domain, it was reported that caregivers' were curious to know early symptoms of future attack, meeting physical need and problems, rehabilitative and educational needs and best method to obtain recovery of the patient. Further under instrumental support area, it was also reported that caregivers also demanding adequate rest and support of other family member to complete the household chores while caring the patients. It is also revealed that caregivers also wish that their family members should understand their problems and need of professional advice/services to meet the patient care (Table 4).

Discussion

Stroke is a crisis for the family because of sudden onset of nature and multiple impairments in the survivors. After emergency treatment, it becomes responsibility of the family members to take care of their patients at home. Caregivers experience multiple needs at home while providing care to their loved one. The aim of the present study was to explore different home felt needs of 100 family caregivers of the stroke survivors and to examine which of those needs were more likely to be perceived important to very important. It was found that needs with Health Information, Instrumental Support, and Community Support network sub scale were most important to this group of caregivers. These findings coincide with the results of the past studies wherein also the Family Needs Questionnaire [14,15], was used and some other studies [16,17], using some other instruments.

In some of the other studies, Caregivers Need Scale (CNS) [18], Family Education Need Questionnaire (FENQ) [19] and Home Caregivers Needs Survey (HCNS) [20] were used to explore the needs of the caregivers of stroke survivors. Authors criticized all instruments for their strength, weakness, applicability, feasibility and permission issue and selected Family Needs Questionnaire (FNQ) to identify the needs of the caregivers. The tool used in the present study was modified by adding home related items and tested for psychometric properties before proceeding to final data collection.

The current study evidenced that the caregivers were not aware of the symptoms of stroke, how to provide care in the domains like elimination, hygiene, comfort, exercise etc., and the availability of existing government services for these stroke patients. The lack of awareness of the caregivers regarding these parameters like stroke as disease, risk factors, prevention and available medical services etc. has also been documented in other studies [21-24].

In the present study multiple information needs among family caregivers of stroke survivors were explored. Furthermore, the caregivers also wanted to know about various practical issues i.e. information regarding various practical issues, the best method to deal with the thinking process and rehabilitation of the patients. In line findings also reported in various studies, wherein it has been reported that information needs, education on future maintenance of their own self, and survivors' health and prognosis, were the most important needs among caregivers.

In Indian settings, in majority of the circumstances, such type of patients are taken care by the formal or informal caregivers at home only. So, it is very important that the caregivers be trained and provided instructions regarding care at the time of discharge of the patient from the hospital. Various other studies have also reported that inadequate

Scale	I need	Mean
ES	To have my family members understand how difficult it is for me to care the patient	1.80
ES	To be assured that it is usual to have strong negative feeling about patient	1.89
ES	To have my spouse understand how difficult to care of patient for me.	2.01
IS	To spend time with my friends & colleagues	2.30
HI	To have complete information on the medical care of stroke (e.g. medication, injections, or surgery)	2.65
IS	To have the patient's employer, co-workers or teachers understand his/her problems	2.73
CSN	To pay attention to my own needs, job, or interests while providing care to patient	2.78
IS	To have my patient's friends understand his/her problems.	2.86
ES	To have statewide 24 hours free transport services	3.97
ES	To help getting over my doubts and fears or consequences about the future of my patient	3.00

Table 3: Needs rated as least important by family caregivers (n=100).

Scale	I need	IM +VM %
HI	To know early symptoms of future attack of stroke in my patient	98
HI	To know how to meet physical needs of the patients (i.e. oral hygiene, elimination, comfort, nutrition, exercise, and medications etc.)	98
IS	To get enough rest or sleep	96
CSN	To have other family members understand the patient's problems	96
HI	To have information on the patient's rehabilitative or educational progress.	97
HI	To have complete information on the patient's physical problems (e.g. weakness, headaches, dizziness, problems with vision or walking)	99
CSN	To have available a professional for advice or services when patient need help	96
HI	To know best method to obtain full functioning recovery from stroke impairment/residual effects	96
HI	To have complete information on the patient's problems in thinking (e.g. confusion, memory or communication).	97
IS	To have help of family members in completing in household duties (i.e. cooking, shopping, cleaning, washing, bathing etc.)	96

Table 4: Ten needs most frequently rated as Important to Very important (IM+VM).

instruction on patient care, not being aware of getting the patient in to best rehabilitation programme, the best method to obtain full functional recovery from disease, and getting their quarries answered about the patient in a truthful manner, as the important needs. Closely related findings are also presented in a research which reported that caregivers needs more information on certain aspects of patient care i.e. certainty of diagnosis and prognosis before and after the discharge from the hospital [25,26].

Findings related to Instrumental Support sub-scales depicts that caregivers expressed needs of enough rest and sleep and to have help from other family member in proving care to the patient as equally important. Similar findings indicated that 71.1% Indian caregivers in 48% Columbian [27], 36% in Moules et al. [28], 34% Krutzer et al. [29] and 36.8% in demanded to get break from problem and responsibilities of caregiving. Similarly, it is also reported that getting help from family members (28%) and family support (18%) is equally important in successful home rehabilitation of stroke patient. It meant that caregivers involved in patient care suffering with some chronic disorders face distressed and the need of rest from such kind of unwanted job and responsibilities. It is important to understand this issue critically to avoid many psychological problems in caregivers. It is enforced to design a plan to have a support group for the caregivers to share their feelings and access related to patient care. It is equally important to meet the psychological needs at the mobile clinic or community health clinic by the stroke or community nurse.

In terms of need of professional help, it is reported that at times it becomes difficult for the caregivers to manage strange behaviour of patient and take decision for them Similarly, it is evidenced that instrumental need is one of three important needs in a study conducted on caregivers of individual with brain injury. Similar findings have been reported amongst the caregivers in India (64%) and some other parts of the world (22-29%) wherein the difficultly in managing the patients' behaviour without professional help has been reported.

Conclusions

The present study reinforced that handling and providing care to stroke survivors is a difficult task. Various needs were felt by the family members while taking care for the patients. The caregivers were lacking various sorts of needs, especially pertaining to Health Information, Community Support Network and Instrumental Support areas.

It is pertinent to identify the needs of the family members taking care for the stroke survivors at home. It will help to develop a greater understanding of home felt needs and plan home rehabilitation for stroke survivors. Meeting the home felt needs of family member's may lead to successful home rehabilitation of stroke survivor.

Limitations

The number of participants in the study was small. An increased number of interview and focus group session would have generalized the findings. However, perhaps the more significant limitation is that selection of participants was purposive. Cross sectional survey also impede the generalization of the findings over a larger population. Still, preliminary findings of this study will draw the attention of policy makers towards planning for a successful home rehabilitation of stroke.

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