NEEDS OF HIGH-RISK PRIMARY CAREGIVERS HANDLING STROKE PATIENTS: A MIXED METHOD STUDY IN A TERTIARY CARE HOSPITAL OF RAWALPINDI

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ABSTRACT

Objective: To identify high-risk caregivers, understand their needs and explore the factors affecting the caregivers of stroke patients in a tertiary care hospital of Rawalpindi.

Study Design: A cross-sectional, mixed-method study.

Place and Duration of Study: The study was carried out in OPD of Pak Emirates Military Hospital, Rawalpindi from Jul 2019 till Dec 2018.

Material and Methods: A mixed-method approach was employed using non-probability convenience sampling followed by purposive sampling. The quantitative study was conducted on 71 caregivers, identified and approached through stroke patients in PEMH OPD. A pre-structured, pre-tested questionnaire was used to filter the caregivers with the high risk and determine their situation. Furthermore, a qualitative interview was conducted with nine high-risk caregivers to have a profound understanding of their needs. Frequencies and percentages were computed and chi-square and fisher exact was used to find associations between socio-demographic variables and variables of caregivers' situation. Themes were identified from the qualitative data through thematic content analysis.

Results: The mean age of the participants was 35.25 years and the mean total duration of care giving was 27.50 months. Out of seventy one participants, 27 (38%) participants were recognized as high risk CGs whereas 5 (7%) CGs was at a very high risk. A significant association was found between caregiver's risk and relationship with the CG (9.471 *p*-value 0.029) as well as duration of care giving (6.705 *p*-value 0.050). Further, the results also indicated that caregiver's physical health, social activities, control on life and mental health was negatively affected by the care giving. Results of qualitative interviews identified six main themes including physical care, support and supervision, juggling responsibilities, financial cost of care giving, personal life, and future needs or demands.

Conclusion: In conclusion, the results indicated that physical health, social and mental health of the caregivers of stroke patients are adversely affected by their numerous responsibilities of care giving putting them at a very high risk of deteriorating quality of life and making them a public health concern. The research has great implication as it addresses and identifies the needs and demands of the caregivers of stroke patients.

Keywords: High risk caregivers, Psychological health, Stroke patients.

INTRODUCTION

Stroke is clinically defined as a sudden injury to a part of the brain resulting in oxygen deprivation. It is a debilitating illness and is marked as the third leading cause of death and one of the main causes of permanent or long-term disability globally. In 2013, 6.5 million deaths across the globe were attributed to stroke[1]. With an abrupt and immediate onset, stroke leaves varying degree of disability, critically affecting both the patients and their caregivers. Stroke also presents one such alarming situation in Pakistan where its incidence is increasing rapidly in recent years. In Pakistan, along with the patient; substantial burden of stroke is experienced by the caregivers, who are either spouses or immediate family members like siblings, children and grand-children[2]. Although robust figure of stroke prevalence in Pakistan is still missing owing to lack of large scale epidemiological studies, available figure suggests that 4.8% of the

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population suffers from stroke which roughly translates to 4 million people[3] with the estimated incidence of roughly 250/100,000 i.e. adding 350,000 thousand new cases of stroke each year[4].

The population of Pakistan is not well versed with the modifiable risk factors of stroke, their comorbid conditions and consequences which has followed a rising trend in recent years[5]. With an under-developed neurorehabilitation and in-patient rehabilitation service for Stroke and non-existent home support services in Pakistan, it is not surprising that the entire responsibility of stroke survivor's care fall on the family caregivers of the patient[6] often under unanticipated circumstances with little preparedness and guidance from the healthcare settings. This, when continued for prolonged period, results in stress and deteriorating physical and mental well-being of the caregivers along with adverse effect on their quality of life[7]. All these detrimental consequences of caregiving often remain unsaid and unexpressed by the caregivers. They also remain unnoticed by the health care providers who feel their prime responsibility towards the patient alone.

The roles and responsibilities of the caregivers are usually shaped by the family structure, cultural norms and religious beliefs and often has to engage in tasks like bathing, dressing, and feeding, providing assistance in mobility, giving medication and providing a supportive and empathetic ear while keeping up an encouraging and consoling attitude[8]. In addition to this many have to deal with the juggling responsibilities of their children, household chores, finances of the family and their occupational role[9]. There is a widely reported mental and emotional strain among caregivers from caring for the loved one and has been demonstrated as an independent risk factor for deteriorating quality of life and increased mortality[10]. Furthermore, caregivers have a significantly higher risk of developing cardiovascular problems and psychiatric morbidity. Depression is also widely examined and reported by the caregivers of stroke survivor[11]. Depression associated with caregiving has a prevalence of 52% among the caregivers[12]. A number of studies have also tried to highlight the lived experiences and expressed needs of the caregivers and have often found them to be under-expressed or rather concealed under the burden and undue stress of caregiving[13]. Needs are very much dependent and changes with different phases of the stroke trajectory as identified by Cameron and Gignac[14].

The results caregiving studies from the west cannot be directly extrapolated to Asian countries, particularly Pakistan, owing to contrasting health care delivery system, health financing and differing facts, circumstances and context of care. A significant gap exists in recognizing and acknowledging the needs of the caregivers that are not accommodated in our healthcare systems, the challenges they face and risks to physical and mental health. Considerable efforts need to be done in assessing the needs of the caregivers attending stroke patients in Pakistan. This study, therefore, contributes to emerging data on caregiving situation, helping to present a rich account of caregiving experiences, burden and the needs expressed by the caregivers. It will also highlight the factors resulting and aggravating the caregiving burden that will enable the public health researchers to realize the importance of the submerged portion of the caregiving iceberg and design interventional studies to combat this emerging threat.

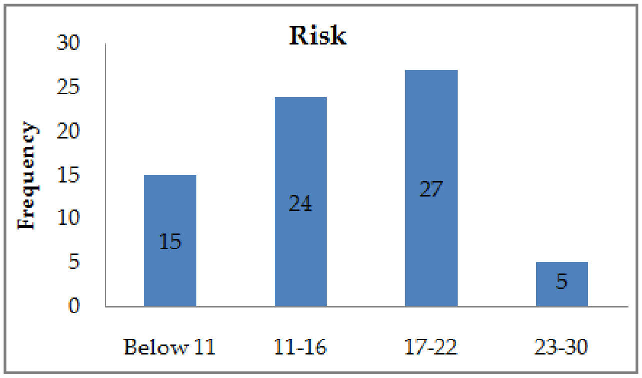

Figure-1: Bar chart showing caregiver's risk.

PATIENTS AND METHODS

It was a mixed-method approach (quantitative and qualitative) carried out on the caregivers of stroke patients attending Pak Emirates

Military Hospital, Rawalpindi. Non-probability convenience sampling was used to identify the stroke patients in Neurology OPD of PEMH, followed by purposive sampling to include the caregivers. Sample size was 71 caregivers calculated based upon the prevalence of stroke in Pakistan (4.8%) and confirmed via Open Epi. For quantitative portion, A pretested, structured questionnaire (Caregiver Risk Screen Tool) was administered to the caregivers of the stroke patients who fulfilled the inclusion criteria and their risk was scored according to the giver criteria. Furthermore, a qualitative interview was conducted with nine high-risk caregivers to have a profound understanding of their needs. Frequencies and percentages were computed and Chi-square and fisher exact was used to find associations between socio-demographic variables and variables of caregivers' situation. Themes were identified from the qualitative data through thematic content analysis.

Table-I: Associations between demographic variables and caregiver's situation.

		Fisher Exact Test					
S. No	**Demographic Characteristics**	**Effect on Physical Health**	**Effect on Social activities**	**Effect on Family Relationships**	**Depression**	**Coping ability**	**Burden of CG**
1.	Gender	*p*=0.143	*p*=0.817	*p*=0.110	*p*=0.117	*p*=0.920	*p*= 0.834
2.	Marital Status	*p*=0.003	*p*=0.448	*p*=0.305	*p*=0.006	*p*=0.164	*p* =0.456
3.	Education	*p*=0.095	*p*=0.173	*p*=0.791	*p*=0.05	*p*=0.491	*p* =0.467
4.	Occupation	*p*=0.293	*p*=0.608	*p*=0.342	*p*=0.899	*p*=0.821	*p*=0.718
5.	Relationship with CR	*p*=0.636	*p*=0.015	*p*=0.215	*p*=0.013	*p*=0.244	*p*=0.910
6.	Duration of caregiving in a day	*p*= 0.516	*p*=0.669	*p*=0.155	*p*=0.012	*p*=0.331	*p*=0.339

RESULTS

Socio-Demographics

Out of 71 caregivers, 26 (36.6%) were male and 45 (63.4%) were females. Mean age of the caregivers was 35.25 ± 10 years. Most of the caregivers i.e. 50 (70.4%) were married and only 7 (9.9%) caregivers had acquired no formal education. 39 (54.9%) caregivers were not working at all and 42 (59.2%) caregivers mentioned that they were engaged in caregiving all the time. Children, either a daughter or a son, to the care-receiver was identified as the most frequent relation who steps forward as a caregiver, followed by spouses. Total duration since the caregivers has been caring for their stroke stricken relative was 27.50 ± 32.4 in months.

Caregiver's Risk

Figure-1 presents the frequency of CGs against their respective risk category calculated on the basis of the questions assessed in Caregivers Risk Screen Tool. Out of seventy one partiipants, 27 (38%) participants were at high risk whereas 5 (7%) CGs were at a very high risk. Moreover 24 (33.8%) CGs had moderate risk while 15 (21.1%) had a low risk.

Table-I shows a significant association between marital status and effect on physical health presented by Fisher's exact value of 13.217 with *p*-value of 0.003. Unmarried CGs are more likely to have their physical health disturbed. We also find evidence of significant association between marital status and depression as depicted by fisher's exact value of 11.799 with *p*-value of 0.006. Gamma value of -0.10 (*p*=0.954) shows a weak negative association suggesting higher depression among married CGs. For education, a significant association has been found with depression shown by a fisher's exact value of 17.444 with *p*-value of 0.05. Gamma value of 0.08 (*p*=0.961) shows a weak negative association signifying a higher level of depression among less educated. Moreover, significant associations have been found between relationship with the CR and a number of variables of caregiver's situation as presented in table-I. Fisher's exact value of 16.605 with p-value of 0.015 is strong evidence of a significant association between relationship with CR and effect on social activities. Similarly, 20.679 fisher exact value with p-value of 0.013 and Gamma value of 0.235 (p=0.154) is a strong evidence of weak negative association between relationship with CR and depression, suggesting higher depression among a child and spouse CG. Fisher's exact value of 20.277 with p-value of 0.031 and Gamma value of 0.114 (p=0.49) suggests a significant weak positive association portraying that grand children and daughter-in laws find it more hard to continue caring for the CR. Lastly, fisher exact value of 16.967 with p=0.050 and Gamma value of -0.292 (p=0.050) gives a strong evidence of weak negative association between relationship with CR and losing control over life. Similarly, fisher exact value of 14.449 with p-value of 0.050 and gamma value of -0.443 (p=0.009) gives a strong evidence of significant moderate negative association between duration of caregiving in a day and losing control over life suggesting that those

Table-II: Themes emerging from caregivers In-depth Interviews.

S. No	Theme	Category	Sub-category
1.	Physical care	Physical tasks Difficulty in physical tasks	1.Feeding 1.bathing 1.dressing 1.Mobility and transfer PT exercise, 1.Incontinence care, 1.Giving mediations Exhaustion
2.	Support and Supervision	Patient's Safety Emotional Support Difficulty in support and supervision	1.Can't leave patient alone 1.Prevention of accidents and injuries 1. Vigilant at night 2.Encourage Patient 3.Emotionally drained 3. Sleep deprived, 3. Tired
3.	Juggling Responsibilities	Other responsibility Managing responsibility Abandoned responsibility	1. Household chores, 1. Work 1. Children, 1. Studies 2. Division of work, 3. Education 3.Time to family/friends 3.Self-care
4.	Financial Cost of caregiving	Financial situation Problems in financial situation	1. Separate/same income 1. No income 2. Affordability 2.loans 2. No job 2. Out of pocket spending
5.	Personal Life	Physical health Private life Emotional health Personal traits in caregiving Rewards	1. Sleep 1.Nutrition 1.Headache 1.Backache 1.Tiredness Time to spouse 2.Attension 2.Complications 3.Nervousness 3.Exhaustion 3.Frustration 3.Loneliness 3.Sadness 3.Anger 3.Depression 3.Overwhelmed 3.Ways of relief, 4. Patience, 4. Courage 4. Bravery 5.Appreciation 6.Religious beliefs
6.	Future Needs/ Demands	Services for patients Service for caregivers	1.Adult day-care 1. Financial Aid 1. Transport services 1. Wheelchairs Priority in OPDs 1.Rehab 2.Information Counselling 2.Support groups 2.Training in specialized tasks 2.Support in emergency 2.Professional help

who spend all their time in caregiving are more likely to lose control over their lives.

Qualitative

Six main themes were identified from the in-depth interviews of 9 high-risk caregivers as shown in table-II.

Help with physical tasks are the most widely reported caregiving responsibilities. Incontinence care is also provided by all CGs and some even have to help the CR urinate on the bed. Most of the CGs, despite facing hitches realized it as their duty. One 43 year old, female who was taking care of her mother said, "I face a lot of difficulty. I get tired, lose courage but I have to do it, she is my mom".

All CGs want to support their patients and ensure their safety, emotionally uplift and encourage them but they often feel like they require support themselves too. A 27 year old daughter of a stroke patient said, "She often loses hope and gets very depressed about being dependent. I encourage her emotionally that this is Allah's test. You will be better soon". CGs also had to stay vigilant at night while a few CGs also said that they have to deal with the difficult, unwanted and sometimes abusive behavior of the CR.

For most female caregivers, their major responsibilities included looking after their children and spouses along with managing household chores. Young and unmarried CGs were struggling with their studies while the male caregivers were occupied by their employment. All of them faced challenges dealing with added responsibilities.

Financial situation was troublesome for most CGs. This often required them to take loans or give up on essential treatment and services for the patients. Most of the CGs belonged to a low-middle income family and earning enough was always a struggle. A few had to leave their jobs too. Issues of affordability and spending out of pocket on treatments, mediations, fees etc was highlighted in every other interview.

Personal life was affected for all CGs, most significantly, on the levels of physical health, emotional health and private or married life. Feeling tired and exhausted was common. In addition to this, a negative effect was observed on sleep pattern and nutrition. Similarly, emotional health was disturbed for all the CGs who were questioned. Not all CGs had found a way to relive these feelings and are in a dire need of some sort of help or support, although they reluctantly agree to this. A strain in married lives was also observed. A 27 year old daughter, taking care of her mother explained, "I can't give time to my husband. He often complains about it".

Multiple needs were expressed by the CGs, both directly and indirectly. Almost all CGs were facing financial troubles and were desperately in need of knowing of a financial aid for stroke patients. They were not aware of any in existence and strongly suggested that there should be one. Secondly, a dire need of special transport for such patients was expressed by all along with hindrance for patients to move anywhere.

DISCUSSION

Needs of primary caregivers of stroke patients are usually suppressed in Pakistani community owing to lack of social and familial support. Primary caregivers of stroke patients have to assume multiple roles and responsibilities about which they have little guidance from the health care settings. When this happens for a prolonged period of time, it results in stress and deteriorating physical and mental health for the caregivers, negatively impacting their quality of life. They have multiple unexpressed and unmet needs resulting in mental health problems and isolation for them[15].

People who are engaged in the caregiving tasks of the stroke patients are more likely to suffer from health problems owing to lack of self, exhausting errands and sleep deprivation Furthermore, lack of information about the impairment and the functioning of stroke leads to anxiety and frustration in caregivers, putting a strain on them thus they are at higher risk of developing physical and emotional problems[16]. An association was also found between the caregiving duration and the caregiver's risk. Those who spend more time in a day caregiving are at higher risk of psychological problems owing to excessive engagement with patient and finding no time for other activities. Marital status was found to have association with physical health and depression[17]. An unmarried person who takes responsibility of stroke patients is more likely to suffer from depression and anxiety. Education was also found to be related to depression of caregivers. Caregivers who are less educated are more likely to feel depressed, frustrated and stressed[18].

Qualitative result of the study highlighted the main responsibilities and challenges of the caregivers as well as the needs and demands that are often left unstated. Physical care was found to be the major responsibility of the caregivers as the stroke survivors cannot help themselves in bathing, cleaning, feeding and etc. A study reported that physical care during the first few months after stroke is most testing, demanding a lot of time and energy from the caregivers resulting in depressive symptoms but sufficient information and support during first few months to the caregivers an help them function well[19]. Emotional support was found to be a significant need for caregivers too. Caregivers always need support no matter in order to remain successful in their efforts. If the caregivers are provided sufficient support, it can result in positive well-being as well as increased effort for caregiving[20]. The result indicated that caregivers juggles with their responsibilities and find it difficult to manage everything on their own, often under-mining their own activities to give time to their patients[21]. Financial cost of caregiving was also reported by the participants. Caregivers had to deal with such issues as well because they found it humiliating to take money from others. Caregiver's income was mostly not sufficient to meet the demands of the home as well as patient[22]. In Pakistan, support programs for stroke caregivers are non-existent, leaving them to deal with the patient as well as the consequences of their situation on their own. Caregivers frequently express the need for financial as well as social support. Also, they felt the unmet need sufficient information from health care settings about the stroke and it's effects[23]. Counseling was another need expressed by the participants that could help them function well by sharing their concerns and challenges[24].

CONCLUSION

The study found that the caregiving of stroke patients puts an enormous strain on the care-giver, physically, socially as well as mentally. The undue responsibility imparted on them under unanticipated circumstances renders them highly vulnerable to deteriorating health, relations, work, personal life and overall quality of life. The caregiving situation is worrisome and the needs and challenges faced by the caregivers often go unexpressed and unmet. Unless an intervention is provided, caregiver's physical and mental well-being will be in jeopardy and the care being provided can deteriorate.

Therefore, it is suggested that in addition to the stroke patients, the caregivers must also be screened for risk factors especially for mental health problems like stress and counselling services should be developed for the care givers to motivate and support them in their task of proper care provision.

CONFLICT OF INTEREST

This study has no conflict of interest to be declared by any author.

REFERENCES

1. Correction to: Heart Disease and Stroke Statistics—2017 Update: A Report From the American Heart Association. Circulation 2017; 136(10): 1-4.
2. Lou M, Tsai P, Yip P, Tai J. Needs of family caregivers of stroke patients: a longitudinal study of caregivers’ perspectives. Patient Preference Adherence 2015; 449.
3. Ain Q, Dar N, Ahmad A, Munzar S, Yousafzai A. Caregiver stress in stroke survivor: data from a tertiary care hospital -a cross sectional survey. BMC Psychology 2014; 2(1): 9-11.
4. Khalid W, Rozi S, Ali T, Azam I, Mullen M, Illyas S et al. Quality of life after stroke in Pakistan. BMC Neurology 2016; 16(1): 76-79.
5. Wasay M, Khatri I, Kaul S. Stroke in South Asian countries. Nature Reviews Neurology 2014; 10(3): 135-43.

6. Rathore F, New P, Iftikhar A. A Report on Disability and Rehabilitation Medicine in Pakistan: Past, Present, and Future Directions. Archives Physical Medicine Rehabilitation 2011; 92(1): 161-66.
7. Bartolo M, De Luca D, Serrao M, Sinforiani E, Zucchella C, Sandrini G. Caregivers burden and needs in community neurorehabilitation. J Rehabilitation Med 2010; 42(9): 818-22.
8. Gillick M. The Critical Role of Caregivers in Achieving Patient-Centered Care. JAMA 2013; 310(6): 575.
9. Sterling M. Palliative care through the eyes of the family caregiver. Caring for the Ages 2017; 18(2): 15.
10. Chuluunbaatar E, Pu C, Chou Y. Caregiver Burden and Quality of Life of Informal Caregivers of Stroke Patients: A Prospective Study. Value in Health 2016; 19(7): A658.
11. Berg A, Palomäki H, Lönnqvist J, Lehtihalmes M, Kaste M. Depres-sion among caregivers of stroke survivors. Stroke 2005; 36(3): 639-43.
12. Wan-Fei K, Hassan SS, Sann ML, Ismail SF, Raman RA, Ibrahim F. Depression, anxiety and quality of life in stroke survivors and their family caregivers: A pilot study using an actor/partner interdependence model. Electronic Physician 2017; 9(8): 4924-33.
13. MacIsaac L, Harrison M, Buchanan D, Hopman W. Supportive Care Needs After an Acute Stroke. J Neuroscience Nursing 2011; 43(3): 132-40.
14. Cameron J, Gignac M. “Timing It Right”: A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. Patient Education and Counseling 2008; 70(3): 305-14.
15. Raju R, Sarma P, Pandian J. Psychosocial Problems, Quality of Life, and Functional Independence Among Indian Stroke Survivors. Stroke 2010; 41(12): 2932-37.
16. Saban K, Sherwood P, DeVon H, Hynes D. Measures of Psychological Stress and Physical Health in Family Caregivers of Stroke Survivors. J Neuroscience Nursing 2010; 42(3): 128-38.
17. Gillespie D, Campbell F. Effect of stroke on family carers and family relationships. Nursing Standard 2011; 26(2): 39-46.
18. Cruz D, Caro C. Correlation between poststroke patients’ Independence and cognition, and their family caregivers’ burden and quality of life. Am J Occupational Therapy 2017; 71(Suppl-1): 7111500022p1.
19. Lou M, Tsai P, Yip P, Tai J. Needs of family caregivers of stroke patients: a longitudinal study of caregivers’ perspectives. Patient Preference Adherence 2015;449.
20. Steiner V, Pierce L, Drahuschak S, Nofziger E, Buchman D, Szirony T. Emotional Support, Physical Help, and Health of Caregivers of Stroke Survivors. J Neuroscience Nursing 2008; 40(1): 48-54.
21. Lutz B, Ellen Young M, Cox K, Martz C, Rae Creasy K. The Crisis of Stroke: Experiences of Patients and Their Family Caregivers. Topics Stroke Rehabilitation 2011; 18(6): 786-97.
22. Elliott T, Shewchuk R. Social problem-solving abilities and distress among family members assuming a caregiving role. British J Health Psychology 2003; 8(2): 149-63.
23. Bartolo M, De Luca D, Serrao M, Sinforiani E, Zucchella C, Sandrini G. Caregivers burden and needs in community neurorehabilitation. J Rehabilitation Medicine 2010; 42(9): 818-22.
24. Rajan B. Assessment of stress among caregivers of the stroke survivors: community based study. Intl J Community Medicine Public Health 2016; 4(1): 211.

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