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Original Article

Factors Associated with Post Stroke Dysphagia Recommendations in Pakistan: Compliance by Caregivers Perspective

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ABSTRACT

Objective: To determine factors associated with primary care givers' compliance to post stroke dysphagia and provide recommendations in Pakistan.

Study Design: Cross sectional survey

Place and Duration of Study: Armed Forces Institute of Rehabilitation Medicine Rawalpindi, Pakistan from Jun 2019 to Apr 2020.

Methodology: The study included 92 caregivers which were recruited through purposive sampling. The caregivers were assisting post stroke dysphagia patients of either gender above 18 years of age. Data collection was done using Caregiver Mealtime and Dysphagia Questionnaire (CMDQ). Demographic data was obtained using a basic demographic sheet.

Results: Study revealed association of Caregivers compliance to dysphagia recommendations with Patient's Occupation (p=0.001), Income (p=0.005) and Time Since Onset of Stroke (p=0.050). While no association was noted for Age, Gender, and Education of Patient and Caregiver; Occupation and Income of Caregiver; Type of Palsy and Number of Episodes; Individual Disabilities; Caregiver's relation with Patient, Time Spent with Patient, Frequency of visits, Marital Status and Area of Origin.

Conclusion: There was association of caregivers' compliance to speech language pathologist's dysphagia recommendations with Occupation and Income of the patient and Time Since onset with no association with other socio-demographic and clinical characteristics.

Keywords: Cerebrovascular accident, Caregivers, Dysphagia, Oropharyngeal.

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INTRODUCTION

Stroke or cerebrovascular accident (CVA) is a highly prevalent problem worldwide with global stroke prevalence rate reported for 2017 being 1300.6 per 100000.[1] with a much higher prevalence in developing countries like Pakistan.[2]

Stroke occurs when blood supply to an area of brain is compromised and has been described by World Health Organization (WHO) as a syndrome characterized by signs representing either focal or global change in brain function progressing or extending beyond 24 hours which may culminate in death without any other apparent etiology other than altered blood supply.[3] It may be associated with high mortality and chronic disability among survivors. As a result, it is a big source of economic burden with total cost incurred for initial five years following stroke being 46,039 pounds per patient in United Kingdom alone,[4] with highest outdoor patient care expenses being $883 per month in the United Kingdom, justifying further research.[5]

Stroke results in inescapable compromise of quality of life, with emotional disturbances, motor deficits like weakness of muscle and tendency to fall during activity, aphasia and swallowing problems affects almost half of the cases surviving stroke resulting in nutritional deficiencies, aspiration pneumonia and further serious morbidity.[6] The occurrence of post stroke dysphagia following acute stroke varies between 20-65%,[7] with persistent problems like swallowing issues at discharge, tube feeding, aspiration pneumonias and prolonged hospitalizations.[7] This significantly increases the cost of treatment.[8]

The highly prevalent, oropharyngeal dysphagia (OD) is still an under diagnosed and under treated problem worldwide and inspite of development in treatment strategies, most patients with oropharyngeal dysphagia (OD) still don't receive proper comprehensive care.[9] The speech-language

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pathologists are professionals involved in evaluation and management of dysphagia and provide compensatory as well as therapeutic dysphagia recommendations to modify diet, posture, and other feeding and safety option.[10]

With multiple disabilities including communication compromise, motor disabilities and dysphagia, stroke patients become dependent on primary caregivers for activities of daily living. However, a number of factors contribute to therapeutic non-compliance. These factors may be patient-centered, therapy-related, social and economic factors, healthcare system, disease factors. In spite of advances in medical treatment, management of post-stroke dysphagia remains a neglected area of research. Also in a systematic review, it was noted that feeding was not only essential to satisfy individuals nutritional and hydration needs, it also has emotional and social bonding. These complex interrelations of patient adherence with dysphagia recommendations need to be studied.

The primary care givers are the main manpower involved in implementing SLP's dysphagia recommendations, this study was conducted to determine factors associated with primary care givers' compliance to post stroke dysphagia recommendations in Pakistan. This study aimed to identify and highlight factors involved in non-compliance of SLP's dysphagia recommendations in the population and thus help improve the barriers resulting in better patient care.

METHODOLOGY

The cross sectional survey recruited 92 primary caregivers of post-stroke dysphagia patients using purposive sampling from Armed Forces institute of Rehabilitation Medicine, Rawalpindi, Pakistan from June 2019 to April 2020. Sample was calculated using sample size formula: $N=(z/\Delta)2p(1-p)$ taking post stroke dysphagia prevalence proportion as 0.1.[11]

Inclusion Criteria: The caregivers, assisting post stroke dysphagia patients of either gender aged 18 years or above were included.

Exclusion Criteria: Care givers of patients with multiple disabilities, those who were unaware and were not given of SLP's dysphagia recommendations were excluded from the study.

Study was initiated after obtaining Ethical Approval of from Institutional Research Board of Isra University, Islamabad with registration number 1709-M.Phil SLP-002 on 17th June 2019 and informed consent of caregivers for participation in research survey. In addition to basic demographic data, specific information was collected through Caregiver Mealtime and Dysphagia Questionnaire (CMDQ).[12] Caregiver Mealtime and Dysphagia Questionnaire (CMDQ) is a valid and highly reliable 33 item questionnaire which measures the compliance to dysphagia recommendations of SLP using three scales including Quality of Life, Disagreement with the SLP and Avoidance. The reliability coefficient of all the three scales being quite above the minimum required reliability with QoL scale having highest reliability.

Researcher collected the data from the primary caregivers after obtaining consent. The collected data was analysed using Statistical Package for Social Sciences (SPSS) version 23. Using descriptive statistics, scores of CMDQ were presented as Mean±SD. To compare means for different groups t-test and Anova statistics were employed, while Chi-square was used to see association with different variables with $p<0.05$ considered significant.

RESULTS

Study included 53(57.6%) males and 39(42.4%) female caregivers, with majority 68(73.9%) in the age group to 21-40 years with 17(18.5%) being non-compliant to SLP's dysphagia recommendations (Figure-1). Those non-compliant had a high mean CMDQ score (3.11±0.48) compared to those compliant (1.98±0.51) and difference was significant ($p<0.001$).

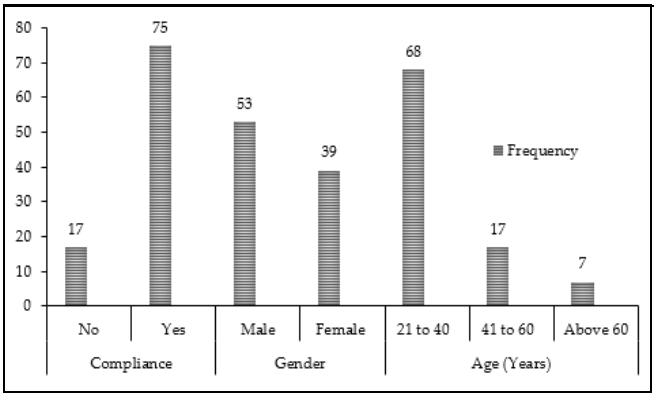

Figure-1: Caregiver Characteristics (n=92)

In this study, higher Mean CMDQ scores in both female patients and caregivers were noted, compared to males with significant ($p=0.013$) difference in patients, however it was not significant with $p=0.68$ in caregivers. Significantly ($p=0.017$) higher CMDQ score in older age group patients, however the difference

between age groups was not significant (p=0.547) in caregivers. There was also no significant difference of CMDQ score with Level of education of patient and caregiver with p=0.602 and p=0.526 respectively. A high mean CMDQ score was noted in those patients who were doing business, medical profession and housewives compared to other professions and difference was statistically significant with p=0.000, while the CMDQ score in caregivers, occupation wise did not reveal significant difference with p=0.052. Income wise CMDQ score did not reveal any statistically significant difference for patients (p=0.316) and caregivers (p=0.468).The caregiver characteristics including number of caregivers, relation with patient, time spent with patient, marital status of caregiver and area of origin of caregiver did not reveal any significant difference in mean CMDQ scores. Significantly higher CMDQ scores were present where there was family involvement (p=0.027) and visits of 4-6/ week and 2-3/ week (p=0.003)

As depicted in Table-I, side of palsy and number of episodes did not show statistically significant difference in mean CMDQ score with p=0.636 and p=0.671 respectively, while the time since onset

Table-I: Socio-Demographic and Clinical Characteristics Versus Compliance to Diet (n=92)

Variables		Groups	Categories	Non-compliant (n=17) Frequency (%)	Compliant (n=75) Frequency (%)	*p*-value
SOCIO-DEMOGRAPHIC VARIA	**Gender**	Patients	Males	11(11.96)	52(56.52)	0.775
			Females	6(6.52)	23(25)	
		Caregivers	Males	9(9.78)	44(47.83)	0.433
			Females	8(8.70)	31(33.70)	
	Age (Years)	Patients	<20	0	3(3.26)	0.135
			20-40	0	14(15.22)	
			41-60	9(9.78)	24(26.09)	
			>60	8(8.70)	34(36.96)	
		Caregivers	20-40	11(11.96)	57(61.96)	0.279
			41-60	4(4.35)	13(14.13)	
			>60	2(2.17)	5(5.43)	
	Education	Patients	Illiterate	7(7.61)	28(30.43)	0.225
			Matric	3(3.26)	24(26.09)	
			Intermediate	3(3.26)	7(7.61)	
			Graduate	1(1.09)	12(13.04)	
			Post-graduate	3(3.26)	4(4.35)	
		Caregivers	Illiterate	4(4.35)	11(11.96)	0.739
			Matric	4(4.35)	25(27.17)	
			Intermediate	5(5.43)	15(16.30)	
			Graduate	3(3.26)	18(19.57)	
			Post-graduate	1(1.09)	6(6.52)	
	Occupation	Patients	No	0	3(3.26)	0.002
			Retired	1(1.09)	19(20.65)	
			Service	0	8(8.70)	
			Business	5(5.43)	3(3.26)	
			Other	2(2.17)	12(13.04)	
			Medical	5(5.43)	5(5.43)	
			Student	0	4(4.35)	
			House wife	4(4.35)	21(22.83)	
		Caregivers	No	1(1.09)	4(4.35)	0.191
			Retired	1(1.09)	2(2.17)	
			Service	1(1.09)	13(14.13	
			Business	2(2.17)	8(8.70)	
			Others	3(3.26)	21(22.83)	
			Medical	0	5(5.43)	
			Student	5(5.43)	5(5.43)	
			House wife	4(4.35)	17(18.48)	
	Income	Patient	No Income	5(5.43)	30(32.61)	0.006
			Low	2(2.17)	23(25)	
			Average	55.43)	19(20.65)	
			High	5(5.43)	3(3.26)	
		Caregiver	No earning	10(10.87)	25(27.17)	0.15
			Low	3(3.26)	34(36.96)	
			Average	4(4.35)	15(15.30)	
			High	0	1(1.09)	

	Caregiver Characteristics	Family Involvement	Not present	0	2(2.17)	0.496
			Present	17(18.48)	73(79.35)	
		No of Caretakers	1	2(2.17)	7(7.61)	0.736
			2-3	8(8.70)	35(38.04)	
			< 5	6(6.52)	20(21.74)	
			>5	1(1.09)	7(7.61)	
			<7	0	6(6.52)	
		Relation with patient	Spouse	4(4.35)	6(6.52)	0.45
			Son	4(4.35)	17(18.48)	
			Daughter	4(4.35)	12(13.04)	
			Brother	1(1.09)	3(3.26)	
			Sister	0	1(1.09)	
			Nice/ Nephew/ Friend	0	8(9.78)	
			Paid attendant	2(2.17)	9(9.78)	
			Other relatives	2(2.17)	19(20.65)	
		Time spent with patient	1-2hrs	0	2(2.17)	0.299
			<3 hours	1(1.09)	1(1.09)	
			<5 hours	4(4.35)	8(8.70)	
			<10 hours	2(2.17)	20(21.74)	
			24hrs	10(10.87)	39(42.39)	
			Other	0	5(5.43)	
		Frequency of visit	2-3 /month	2(2.17)	7(7.61)	0.071
			1/ week	1(1.09)	7(7.61)	
			2-3 / week	7(7.61)	15(16.30)	
			4-6 / week	2(2.17)	1(1.09)	
			Daily	5(5.43)	41(44.57)	
			after 02 months	0	4(4.35)	
		Marital status	Unmarried	0	10(10.87)	0.179
			Married	15(16.30)	51(55.43)	
			Single	2(2.17)	14(15.22)	
		Area	Rural	6(6.52)	44(47.83)	0.081
			Urban	11(11.96)	31(33.70)	
CLINICAL VARIABLES	**Diagnosis**	CerebroVascular Accident with Palsy	Right sided	14(15.22)	52(56.52)	0.56
			Left sided	2(2.17)	15(16.30)	
			Bilateral	1(1.09)	8(8.70)	
		Time since Onset	15 days	2(2.17)	7(7.61)	0.05
			1Mths	3(3.26)	18(19.57)	
			2-4 Mths	0	19(20.65)	
			5-6 Mths	1(1.09)	8(8.70)	
			> 6 Mths	11(11.96)	23(25)	
		Episode	1st	13(14.13)	65(70.65)	0.508
			2nd	1(1.09)	4(4.35)	
			3rd	3(3.26)	5(5.43)	
			>3	0	1(1.09)	
	Disability	Communicational	Absent	1(1.09)	2(2.17)	0.5
			Present	16(17.39)	73(79.35)	
		Motor movement disability	Absent	2(2.17)	6(6.52)	0.61
			Present	15(16.30)	69(75)	
		Fine movement	Absent	2(2.17)	4(4.35)	0.332
			Present	15(16.30)	71(77.17)	
		ALDS	Absent	2(2.17)	9(9.78)	0.978
			Present	15(16.30)	66(71.74)	
		Psycho-logical	Absent	13(14.13)	44(47.83)	0.172
			Present	4(4.35)	31(33.70)	

showed significant difference in mean CMDQ score with highest score at >6 months following onset (p=0.002). Presence or absence of individual disabilities including communicational, motor movement, fine movement, psychological and ALDS disabilities, did not reveal any significant difference in mean CMDQ score.

DISCUSSION

This research focused factors associated with primary care givers' adherence to post stroke

dysphagia recommendations in Pakistan. The caregiver compliance to dysphagia recommendations mean CMDQ score were higher for female gender of patient and caregiver with higher frequency of males in the compliant group in the current study. Feeding is essentially required to cater to individual's nutritional and hydration needs, as well as it also results in emotional and social bonding, hence the complicated interrelations of adherence with dysphagia recommendations need to be studied.[12-15] The highest mean CMDQ score was noted in 41-60 years' age group in contrast to a study by MacDonald *et al.*[16] who reported a rapid increment in the population of elderly resulted in increased demand for care provided by family CGs especially increase in CG burden due to dysphagia in recipients of care and worsening feeding-related behavior was related to burden.[16]

A qualitative research study explored perceptions of speech-language pathologists' (SLP) regarding their potential to influence patient adherence to dysphagia recommendations. The themes identified within the data were SLP education for family and patient, SLP understanding of barriers to patient adherence to dysphagia recommendations, respect for patient decisions, and perpetuation of bad feelings toward SLPs.[17] In a study adherence with use of strategies to support mealtimes of parents with children with complex needs was over 50% in all but one case findings suggest that in order to implement dysphagia guidelines in the family home support it is necessary to promote safe mealtimes, and increase knowledge, confidence, and adherence.[18] Also in a review article, O'Connor noted that adherence to recommendations was affected by CGs knowledge of managing dysphagia, the working of the multidisciplinary rehabilitation team, type of recommendation, and caregiver time and resources availability.[19] However, in contrast to these in current study, level of education of patient and caregiver did not reveal any significant association with CMDQ score. However, in contrast different studies have highlighted importance of education like McCullough *et al*[20] reported 80% of rehabilitation nurses involved in dysphagia management reported desire of getting more educated on the subject.[20] Knowledge and training regarding dysphagia were also perceived as barriers to SLP's dysphagia recommendations in case of nurses in another study by Robbertse and Beer[21] SLP's belief that they have capacity and can improve patient adherence is also a factor and this can also improve the factors like education of healthcare workers and patient and their families.[22]

In this study no association was present with caregiver occupation with a high mean CMDQ score, the financial position of the patient is not important for caregiving by CG's. In contrast to this , Colodny N 15 noted noncompliance in CG's with higher income. This again indicates that since CG's with higher income were not interested in money and adherence to dysphagia recommendations was lower. In a review article by O'Connor *et al*,[19] it was noted that resource was important factor influencing compliance of caregivers. The patients' occupation and income are more important and a driving force for CG's compliance and it must be kept in mind that post-stroke dysphagia is a condition which is associated with longer hospital stays and hence higher costs incurred[23] hence finances significantly influence its management.

In the present study it was found that the side of palsy and number of stroke episodes had no association with mean CMDQ score, while the time since onset showed significant association with highest score at >6 months following onset. This might be due to the fact that longer period of caring by family careers increases the career's stress and according to Charpentier A *et al*. reduce family care givers' stress can increase compliance.[18]

No significant association of individual disabilities including communicational, motor movement, fine movement, psychological and ALDS was noted with mean CMDQ score. However, disabilities can result in psychosocial issues for caregivers.[24] The time spent with patient did not reveal significant association with mean CMDQ score while frequency of visits revealed significant association with highest mean CMDQ score for 4-6 visits per week and low score for daily visits. In contrast, CG's with daily visits were more compliant and Colodny *et al*[15] also reported noncompliance in those with fewer visits. Also, in contrast to our study, CG's time was an influencing factor in compliance to dysphagia recommendations in a study by O'Connor[19] The length of time required to feed dysphagics was also considered as a frustrating barrier in cases of rehab nurses experience.[20]

In present study, though no statistically significant association of mean CMDQ with relationship of caregiver with patient was present, however sons and daughters were most compliant

among different relations, while in a study by Colodny *et al,*[15] Spouse/ partner were most compliant, with those who were not close relatives being non-compliant. This difference might be due to the religious and cultural reasons.

CONCLUSIONS

There was association of caregivers' compliance to speech language pathologist's dysphagia recommendations with occupation and income of the patient and time since onset with no association with other socio-demographic and clinical characteristics.

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Authors' Contribution

Following authors have made substantial contributions to the manuscript as under:

RS & NM: Study design, data interpretation, drafting the manuscript, critical review, approval of the final version to be published.

GS & MS: Conception, data analysis, drafting the manuscript, approval of the final version to be published.

NA: Data acquisition, critical review, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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