

Adherence Of Primary Caregiver To Post Stroke Dysphagia Recommendations In Pakistan

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ABSTRACT

Objective: To find the adherence of primary caregivers to post-stroke dysphagia recommendations in Pakistan.

Study Design: Cross-sectional study

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

Methodology: We recruited 92 primary caregivers of either gender aged ≥ 18 years, assisting stroke patients with dysphagia in feeding and activities of daily living. Caregivers of cases with multiple disabilities, those not aware of dysphagia recommendations and those not involved in the implementation of dysphagia recommendations were excluded. Caregiver Mealtime and Dysphagia Questionnaire (CMDQ) were used for data collection.

Results: Out of 92 Caregivers 17(18.48%) were non-compliant while 75(82%) reported significant compliance to dysphagia recommendations with mean scores of 3.11 ± 0.48 and 1.98 ± 0.51 , respectively. In addition, the significant difference between scores of compliant and non-compliant groups was noted for the domains of Quality, Avoidance and Disagreement ($p < 0.001$).

Conclusion: Most primary caregivers were compliant and adhered to the dysphagia recommendation of stroke in Pakistan.

Keywords: Caregivers, Dysphagia, Oropharyngeal, Stroke.

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INTRODUCTION

Stroke is a prevalent public health concern characterized by disruption of blood supply to any part of the brain.¹ Developed countries have a significant prevalence, with China alone having a prevalence of 3.1%. A much higher prevalence has been reported for Pakistan and its financial burden of treatment is rising with an increase of the ageing population.^{2,3}

One-third of stroke survivors initially suffer aphasia, and 40 % of aphasia becomes chronic.⁴ Swallowing problems affects another 50% of stroke survivors accompanied by malnutrition and pulmonary aspiration, resulting in serious morbidity in some cases.⁵ In other stroke survivors, recovery of swallowing to a safe level is observed.⁶ The prevalence of post-stroke dysphagia varies markedly, with a frequency of 20.7% reported in one study. Such cases face odds like persistence of dysphagia at discharge (60%), with a nasogastric tube in place (30.5%), suffering from pneumonia (23.1%), and a longer hospital stay.⁷ Though highly prevalent,

oropharyngeal dysphagia (OD) is still an underdiagnosed and undertreated problem throughout the world, and even today, the majority of patients fail to receive comprehensive care.⁸ Stroke survivors become dependent on primary caregivers for bathing, feeding, dressing, etc., due to multiple disabilities like communication difficulties, dysphagia or motor deficits. The provision of effective and evidence-based management of OD to prevent aspiration and consequent infection and to enhance nutrition should focus on compensating swallowing impairments through the modification of viscosity and textures of both liquid and solid food.^{9,10}

Assisting feeding, primary caregivers become a prime pillar of implementing recommendations. Hence, this study was conducted to determine the primary caregiver's adherence to post-stroke dysphagia recommendations in the Pakistani population. This study will help in improving the effectiveness of dysphagia management, hence improving the quality of life in stroke patients and lessening the primary caregiver stress by enhancing the understanding of dysphagia. It will highlight barriers faced by Speech and Language Pathologists during the management of post-stroke dysphagia.

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METHODOLOGY

The cross-sectional study conducted at the Armed Forces Institute of Rehabilitation Medicine, Rawalpindi, Pakistan, from June 2019 to April 2020 after approval from the Institutional Research Board of the Isra Institute of Rehabilitation Sciences, Isra University, Islamabad, (Registration number 1709-M. Phil SLP-002 dated 17th June 2019) and from Armed Forces Institute of Rehabilitation Medicine (letter No. AFIRM/06/Trg dated 27th January 2020). The sample size was calculated using the sample size formula: $N = (z/\Delta)2p(1-p)$, taking the prevalence proportion of post-stroke dysphagia as 0.1.¹¹

Inclusion Criteria: Primary caregivers of either gender, aged ≥ 18 years, assisting stroke patients with dysphagia in feeding and activities of daily living were included.

Exclusion Criteria: Primary caregivers of cases with multiple disabilities, those not aware of dysphagia recommendations and those not involved in the implementation of dysphagia recommendations were excluded.

Caregiver Mealtime and Dysphagia Questionnaire (CMDQ), was used for assessment of adherence to Speech Language Pathologist’s dysphagia guidelines. It comprises three interpretable

The data tool was administered using the consecutive sampling technique after obtaining the consent of participants. Ample time of around 15-20 minutes was utilized for administration of the tool on each participant.

Statistical Package for Social Sciences (SPSS) version 21.0 was used for the data analysis. Quantitative variables were expressed as mean \pm SD and qualitative variables were expressed as frequency and percentages. Independent sample t-test was applied to explore the inferential statistics. Pearson correlation matrix was used to see any correlation between mean domain scores and Mean total CMDQ score. The *p*-value of ≤ 0.05 was considered statistically significant.

RESULTS

In this study, a high frequency, 75(82%) of caregivers reported compliance to dysphagia recommendations, while 17(18%) were non-compliant. The total mean CMDQ score for the complaint group was 1.9 \pm 0.51, and it was 3.11 \pm 0.48 for the non-compliant group, and the difference was statistically significant with *p*<0.001 (Table-I). Similarly, the difference between scores of compliant and non-compliant groups was statistically significant for the Quality, Avoidance and Disagreement domains with

Table-I: Statistics for the domain wise results of Caregiver Mealtime Dysphagia Recommendations Questionnaire (n=92)

Domain	Compliance to Diet (Mean \pm SD)		<i>p</i> -value
	Non-compliant (n=17)	Compliant (n=75)	
Quality	3.54 \pm 0.47	2.19 \pm 0.73	<0.001
Avoidance	2.61 \pm 1.07	1.74 \pm 0.55	<0.001
Disagreement	2.62 \pm 0.56	1.75 \pm 0.43	<0.001
Total Mean	3.11 \pm 0.48	1.98 \pm 0.51	<0.001

Table-II: Pearson Correlation Matrix for Domain and Total Mean Scores (n=92)

Domain (Mean \pm SD)		Quality	Avoidance	Disagreement
Avoidance (1.90 \pm 0.754)	Pearson correlation	.540**	1	
	<i>p</i> -value	<0.001		
Disagreement (1.91 \pm 0.57)	Pearson correlation	.616**	.533**	1
	<i>p</i> -value	<0.001	<0.001	
Total (2.19 \pm 0.67)	Pearson correlation	.953**	.732**	.768**
	<i>p</i> -value	<0.001	<0.001	<0.001

scales highlighting areas including quality of dysphagia diet as perceived by the caregiver (17 items), disagreement with the SLP (DSL) (8 items), and Avoidance (AV) towards dysphagia diet (7 items), which are internally consistent. It is scored on a Likert scale rating from 1-5 (strongly disagree to agree, with a higher scoring meaning more non-compliance).^{10,12}

p<0.001 (Table-II). Pearson Correlation Matrix for Domains and total Mean CMDQ score revealed a significant positive association between all domains of CMDQ and total mean score. Responses of CGs to the items of CMDQ are tabulated in Table- III.

Caregivers Compliance to Dysphagia Recommendations

Table-III: Response Distribution of Primary Caregivers to Items of Caregiver Mealtime Dysphagia Questionnaire (n=92)

Domain	Statements	Strongly Disagree n(%)	Disagree n(%)	Neutral n(%)	Agree n(%)	Strongly Agree n(%)
Avoidance	It takes too long to thicken liquids.	48(52.2)	16(17.4)	6(6.5)	6(6.5)	16(17.4)
	I am not sure how much thickener to use.	52(56.5)	18(19.6)	3(3.3)	8(8.7)	11(12)
	Sometimes I forget to use thickener	68(73.9)	8(8.7)	2(2.2)	9(9.8)	5(5.4)
	My family member/ significant others occasionally drinks his/ her liquids before I get a chance to thicken them.	58(63)	12(13.0)	3(3.3)	12(13.)	7(7.6)
	I don't thicken liquids because I have too much to do.	79(85.9)	7(7.6)	1(1.1)	2(2.2)	3(3.3)
	No one showed me how to thicken liquids.	53(57.6)	8(8.7)	1(1.1)	7(7.6)	23(25)
Disagreement	It is difficult to feed my family member/ significant others during mealtime.	5(63)	12(13)	1(1.1)	10(10.9)	11(12)
	I am not sure whether he is on thickened liquids.	66(71.7)	14(15.2)	5(5.4)	4(4.3)	3(3.3)
	I am not sure why my family member/significant others is on thickened liquids.	72 78.3)	13(14.1)	1(1.1)	2(2.2)	4(4.3)
	My family member does not need thickened liquids.	66(71.7)	13(14.1)	3(3.3)	5(5.4)	5(5.4)
	I am not sure which specific feeding technique to use.	61(66.3)	11(12.0)	6(6.5)	6(6.5)	8(8.7)
	Thickened liquids improve my family member swallowing function.	6(6.5)	4(4.3)	3(3.3%)	5(5.4%)	74(80.4)
	I don't have time to follow through on swallowing recommendations given by the SLP.	72(78.3)	13(14.1)	7(7.6)	-	-
Quality	It is not necessary to give my Family member small amount and wait between mouthfuls and sips.	68(73.9)	13(14.1)	2(2.2)	4(4.3)	5(5.4)
	I don't understand why specific feeding techniques were recommended by SLP.	60(65.2)	12(13.0)	12(13.0)	2(2.2)	6(6.5)
	I am embarrassed for my family member when they are serve the modified food or thickened liquids.	76(82.6)	5(5.4)	2(2.2)	4(4.3)	5(5.4)
	I don't want to deprive my family member of food	28(30.4)	12(13.0)	8(8.7)	15(16.3)	29(31.5)
	I don't use thickener because my Family member does not want it	57(62.0)	15(16.3)	5(5.4)	6(6.5)	9(9.8)
	The modified food look unappetizing.	39(42.4)	8(8.7)	7(7.6)	18(19.6)	20(21.7)
	My Family member does not drink as much when he/ she is on thickened liquids.	33(35.9)	9(9.8)	11(12.)	16(17.4)	23(25)
	A few sips of drink or a mouthful of food will not negatively affect the health of my family member	59(64.1)	5(5.4)	4(4.3)	11(12.0)	13(14.1)
	Without regular food or liquid the quality of life is negatively affected.	35(38.0)	8(8.7)	5(5.4)	16(17.4)	28(30.4)
	My Family member does not like the taste of modified foods or thickened liquids.	34(37.0)	12(13.0)	10(10.9)	13(14.1)	23(25.0)
	My Family member does not like texture of modified foods.	30(32.6)	12(13.0)	14(15.2)	16(17.4)	20(21.7)
	My Family member can handle a regular diet.	55(59.8)	11(12)	5(5.4)	8(8.7)	13(14.1)
	My Family member enjoys eating regular food and liquid with me.	31(33.7)	11(12)	4(4.3)	17(18.5)	29(31.5)
	I feed my Family member food because it is what he/ she wants.	46(50)	17(18.5)	4(4.3)	11(12)	14(15.2)
	Eating normal food and liquids is worth the risk of developing respiratory problems or choking.	75(81.5)	9(9.8)	4(4.3)	2(2.2)	2(2.2)
I want my Family member to experience the taste of food.	27(29.3)	5(5.4)	2(2.2)	16(17.4)	42(45.7)	
Regular food is comforting and will help heal my family member	46(50)	13(14.1)	7(7.6)	11(12)	15(16.3)	
The experience of eating regular food improves wellbeing.	31(33.7)	8(8.7)	8(8.7)	15(16.3)	30(32.6)	
My Family member has been eating regular food all his/her life and I am not going to stop that now.	64(69.6)	14(15.2)	5(5.4)	5(5.4)	4(4.3)	

DISCUSSION

A rapid increase in the elderly population over the years, with improved survival rates, has increased the demand for care provided by family caregivers (CG). This has especially increased the CG burden due

to dysphagia in recipients of care and resulted in worsening feeding-related behaviours related to the burden.¹³ In the current study, a high frequency (82%) of caregivers reported significant ($p<0.001$) compliance with dysphagia recommendations, with the total mean

CMDQ score for the compliant group being 1.9 ± 0.51 compared to 3.11 ± 0.48 for the non-compliant group. In contrast to our study, non-compliance towards dysphagia diet recommendations has previously been reported in the systematic review by Krekeler *et al.*, who identified 12 studies that reported patient-specific adherence to dysphagia recommendations with the average adherence rate ranging between 21.9 and 51.9%.¹⁴ which is lower than the adherence rate noted in our study. While Shim *et al.*, who studied Korean dysphagic patients for adherence with a diet which was viscosity modified, reported that 56.5% were compliers compared to 43.5% non-compliers.¹⁵ McCullough KC *et al.* reported a high level of compliance of acute care nurses to dysphagia recommendations given by SLPs.¹⁶

Concerning the AV items, we found strong agreement in 17.6% and 6.5% of primary CGs for avoidance items that "it takes too long to thicken liquids". Similarly, time necessitated to feed cases with dysphagia was the most common cause of frustration noted in a study by McCullough *et al.*¹⁶ At the same time, Shim *et al.* reported inconvenience in preparing meals.¹⁵ In the current study for item "no one showed me how to thicken the liquids", 25% strongly agreed, 7.6% agreed, while on item "I am not sure how much thickener to use", 12% strongly agreed and 8.7% agreed. Speech clinicians can address such issues by adapting standard date procedures for a recommendation of dysphagia diet, i.e. "International Dysphagia Diet Standardization Initiative (IDDSI)". This was the case in a study by Su M *et al.*, which confirmed the feasibility of the IDDSI framework for clinical and bedside applications.¹⁷

Of the quality response items, 82.6% CG's strongly disagreed with the item "I am embarrassed for my family members/ significant others when they are served modified food or thickened liquids", thus highlighting that modified diet was not a cause embracement to the majority of CG's in Pakistan. In contrast, Moloney and Walshe reported significant social and emotional impact.¹⁸ Also, for the item "the modified food looks unappetizing", 21.7% showed strong agreement, while 19.6% just agreed. In contrast, for the item "My family member does not like the taste of modified food or thickened liquids", 25% showed strong agreement, and 14.1% just agreed. Another 21.7% strongly agreed, and 17.4% agreed with the item "My Family member does not like the texture of modified foods".

Regarding item "My Family member does not drink as much when he/ she is on thickened liquids", 25% strongly agreed, and 17.4% agreed. This finding complies with a study by Crary *et al.*, which reported that prescribed liquid/ diet changes for dysphagia may impair hydration status for acute stroke patients.¹⁹

As regards items for disagreement with SLPs, an item, "I am not sure why my Family member is on thickened liquids ", was strongly disagreed upon by 78.3% and just disagreed by another 14.1%, thus highlighting the fact that they knew the reason of dysphagia diet recommendation. Our study population was aware of manoeuvres related to swallowing therapies. In response to the item "I am not sure which specific feeding technique to use", 66.3% strongly disagreed, and 12.0% disagreed. In response to the item "I am not sure why my Family member is on thickened liquid", 78.3% strongly disagreed, and 14.1% disagreed, indicating it to be a factor for CG adherence of CGs in the present study. In a review article, O'Connor *et al.* noted that adherence to recommendations was affected by CG's knowledge of managing dysphagia, the working of the multidisciplinary rehab team, type of recommendation type, and caregiver time and resource availability.²⁰

CONCLUSIONS

Our present study found that the majority of primary caregivers were compliant and adhered to the dysphagia recommendation for stroke in Pakistan.

Conflict of Interest: None.

Authors Contribution

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

RS & NM: Conception, study design, drafting the manuscript, approval of the final version to be published.

GS & MS: Data acquisition, data analysis, data interpretation, critical review, approval of the final version to be published.

NA: Data acquisition, drafting the manuscript, 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.

REFERENCES

1. Donkor ES. Stroke in the 21st Century: A Snapshot of the Burden, Epidemiology, and Quality of Life. *Stroke Res Treat.* 2018; 2018: 3238165. <https://doi.org/10.1155/2018/3238165>.
2. Feigin VL, Forouzanfar MH, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, et al. Global and regional burden of

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- stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2014; 383(9913): 245-255.
3. Yi X, Luo H, Zhou J, Yu M, Chen X, Tan L, et al. Prevalence of stroke and stroke related risk factors: a population based cross sectional survey in southwestern China. *BMC Neurol* 2020; 20(1): 5. <https://doi.org/10.1186/s12883-019-1592-z>.
 4. Khan MI, Khan JI, Ahmed SI, Ali S. The epidemiology of stroke in a developing country (Pakistan). *Pak J Neurological Sci* 2019;13(3):30-44.
 5. Flöel A. Computerised speech and language therapy in post-stroke aphasia. *Lancet Neurol* 2019; 18(9): 806-807. [https://doi.org/10.1016/S1474-4422\(19\)30199-1](https://doi.org/10.1016/S1474-4422(19)30199-1).
 6. Michou E, Sasegbon A, Hamdy S. Direct and Indirect Therapy: Neurostimulation for the Treatment of Dysphagia After Stroke. In *Dysphagia*. Springer; 2018.
 7. Arnold M, Liesirova K, Broeg-Morvay A, Meisterernst J, Schlager M, Mono ML, et al. Dysphagia in acute stroke: incidence, burden and impact on clinical outcome. *PloS One* 2016; 11(2): e0148424. <https://doi.org/10.1371/journal.pone.0148424>.
 8. Marin S, Serra-Prat M, Ortega O, Clavé P. Cost of oropharyngeal dysphagia after stroke: protocol for a systematic review. *BMJ Open* 2018; 8(12): e022775. <https://doi.org/10.1136/bmjopen-2018-022775>.
 9. Saqulain G, Mumtaz N. Swallowing Difficulties with Tracheostomy: A Neuro-Rehabilitation Perspective. *J Islamabad Med Dental Coll* 2020; 9(1): 57-62.
 10. Colodny N. Validation of the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ). *Dysphagia* 2008; 23(1): 47-58. <https://doi.org/10.1007/s00455-007-9094-3>.
 11. Naing NN. Determination of sample size. *The Malaysian journal of medical sciences: Malays J Med Sci* 2003; 10(2): 84-86
 12. González-Fernández M, Ottenstein L, Atanelov L, Christian AB. Dysphagia after stroke: an overview. *Curr Phys Med Rehabil Rep* 2013; 1(3): 187-196.
 13. Namasivayam-MacDonald AM, Shune SE. The Burden of Dysphagia on Family Caregivers of the Elderly: A Systematic Review. *Geriatrics* 2018; 3(2): 30. <https://doi.org/10.3390/geriatrics3020030>.
 14. Krekeler BN, Broadfoot CK, Johnson S, Connor NP, Rogus-Pulia N. Patient Adherence to Dysphagia Recommendations: A Systematic Review. *Dysphagia* 2018; 33(2): 173-184. <https://doi.org/10.1007/s00455-017-9852-9>.
 15. Shim JS, Oh BM, Han TR. Factors associated with compliance with viscosity-modified diet among dysphagic patients. *Ann Rehabil Med* 2013; 37(5): 628-632. <https://doi.org/10.5535/arm.2013.37.5.628>.
 16. McCullough KC, McCullough GH, Estes JL, Rainey J. RN Compliance With SLP Dysphagia Recommendations in Acute Care. *Top Geriatr Rehabil* 2007; 23(4): 330-340. <https://doi.org/10.1097/01.TGR.0000299161.44869.26>.
 17. Su M, Zheng G, Chen Y, Xie H, Han W, Yang Q, et al. Clinical Applications of IDDSI Framework for Texture Recommendation for Dysphagia Patients. *J Texture Stud* 2018; 49(1): 2-10. <https://doi.org/10.1111/jtxs.12306>.
 18. Moloney J, Walshe M. I Had No Idea What a Complicated Business Eating Is": A Qualitative Study of the Impact of Dysphagia During Stroke Recovery . *Disabil Rehabil* 2018; 40(13): 1524-1531. <https://doi.org/10.1080/09638288.2017.1300948>.
 19. Crary MA, Carnaby GD, Shabbir Y, Miller L, Silliman S. Clinical Variables Associated With Hydration Status in Acute Ischemic Stroke Patients With Dysphagia. *Dysphagia*. 2016; 31(1): 60-65. <https://doi.org/10.1007/s00455-015-9658-6>.
 20. O'Connor RC. Critical Review: What is the level of compliance with Speech-Language Pathology swallowing recommendations among acute and community caregivers for individuals with dysphagia? What are the factors affecting this compliance? *Medicine* 2018; 195889809.
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