

PERCEPTION OF THE CAREGIVER TOWARDS EATING AND FEEDING ISSUES AMONG ADULT WITH DEMENTIA

By

Sifat-E-Jannat

4th Year, B.Sc. in Speech & Language Therapy Department

Session: 2015-2016

Supervised by

Md. Sazzad Hossain

Assistant Professor & Head (Acting)

Department of Speech and Language Therapy

BHPI, CRP, Chapain, Savar, Dhaka-1343

Title: "Perception of The Caregiver Towards Eating and Feeding Issues Among Adult with Dementia"

Aim of the study: To explore the caregiver's perception of eating and feeding issues among dementia patients.

Methodology: The study was conducted using a qualitative phenomenological study design. The researcher selected a total of 8 caregivers to participate in the study by using purposive sampling. A semi-structured questionnaire was used to collect data and content analysis was used to analyze the data.

Result: The result of the study indicates towards the fact that, the caregivers do not have any knowledge about eating and feeding issues (Dysphagia) among the dementia patient but they understand the changing eating behaviors among the patients.

Conclusion: Swallowing problems are very common among various types of dementia. The study points out the challenges the caregivers face and the strategies they have found, their own way to cope with those changes or challenges without any advice from other health professionals. The analysis also indicates that the caregivers are not aware about the Speech and Language Therapy service for dysphagia managementin Dementia patient.So it is necessary to bring the currentscenario in the knowledge of Speech and Language Therapy service in the speech and the speech and Language Therapy service in the speech and Language Therapy service in the speech and Language Therapy service in the speech and the speech and

knowledge of the health professional specially the Physician so the patient can get proper management for their condition and Speech and Language Therapy service will be recognize as a part of the multidisciplinary team.

Limitation

This is the first primary study on caregiver's perception about swallowing difficulties among older adult patients with dementia in Bangladesh. So, there were some limitations and impediments during conducting the study in different aspects. They are:

- There were only 8 caregivers participated in this study. Which is not adequate for a study to explore caregiver's perception towards eating and feeding issues among dementia patient.
- The sample size was not sufficient to generalize the result.
- The time period for the study was short.
- As a result of small number of participants, the external validity of the study is reduced.

Recommendations

While conducting the research the investigator found some limitation and barriers

- There should be further research on prevalence of dysphagia among Dementia patient in Bangladesh.
- This study was done within a short period of time with a small sample size and data was collected from only Dhaka city so further study can be conducted using a large sample size and from other cities to generalize the result.
- Further study can be conduct on the quality of life of the Dementia patient with dysphagia.

Reference:

Alagiakrishnan, K., Bhanji, R. A., & Kurian, M. (2013, February). Evaluation and management of oropharyngeal dysphagia in different types of dementia: A systematic review. Archives of Gerontology and Geriatrics, 56(1), 1–9. doi:https://doi.org/10.1016/j.archger.2012.04.011

- Affoo, R. (2016, March). Dysphagia Care for Individuals with Dementia. doi:10.13140/RG.2.1.1519.2720
- ALZ. (2017). WHO global plan on dementia. Retrieved from ALZ: https://www.alz.co.uk/dementia-plans/global-plan
- Alzheimer's Society. (2019). What is dementia?. Retrieved from Alzheimer's Society: https://www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia
- ASHA. (2020). Dementia: Treatment ASHA. Retrieved from ASHA: https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935289§ion=Tr eatment
- Bailey, D. M. (1997). Research for the Health Professional: A Practical Guide.Philadelphia: F.A. Davis Company.
- Boustani, M., Schubert, C., & Sennour, Y. (2007, December). The challenge of supporting care for dementia. *Clinical Interventions in Aging*, 2(4), 631–636. doi:10.2147/cia.s1802
- Bowling, A. (2014). Research Methods In Health: Investigating Health And Health Services. UK: McGraw-Hill Education.
- Coppelmans, T. M. (2019, October 09). Wijstijd, Supporting Time Orientation Designed for and with People with Dementia. *Dementia Lab Conference*, *1117*, 150-155. doi:https://doi.org/10.1007/978-3-030-33540-3_15
- Chang, C. C., & Roberts, B. L. (2008, September 13). Feeding difficulty in older adults with dementia. *Journal of Clinical Nursing*, 17(17). doi: https://doi.org/10.1111/j.1365-2702.2007.02275.x
- Chaudhuri, J. D., & Das, S. (2006, December). The Role of Caregivers in the Management of Alzheimer's disease. Sultan Qaboos University Medical Journal, 6(2), 11-18. doi:PMC3074921
- Cheng, S. T. (2017). Dementia Caregiver Burden: a Research Update and Critical Analysis. *Current Psychiatry Reports*, 19(9), 64. doi:DOI 10.1007/s11920-017-0818-2

ConsultGeri. (2012). *Mealtime Difficulties*. Retrieved from ConsultGeri: https://consultgeri.org/geriatric-topics/mealtime-difficulties

- Dementia Care Notes. (2018). Understand the caregiver's role / Dementia Care Notes. Retrieved from Dementia Care Notes: https://dementiacarenotes.in/caregivers/understand-caregiving-role/
- Drummond, A., & Campling, J. (1996). *Research Method for Therapists*. London: CHAPMAN & HALL.
- Easterling, C. S., & Robbins, E. (2008). Dementia and Dysphagia. *ELSEVIER*, 29(4), 275-285. doi:https://doi.org/10.1016/j.gerinurse.2007.10.015
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., . . . Scazufca, M. (2006, January). Global prevalence of dementia: a Delphi consensus study. *The Lancet Neurology*, 366(9503), 2112-2117. doi:10.1016/S0140-6736(05)67889-0
- Flynn, E. P., Smith, C. H., Wals, C. D., & Walshe, M. (2018, September 24). Modifying the consistency of food and fluids for swallowing. *Cochrane Database of Systematic Reviews*(9). doi:https://doi.org/10.1002/14651858.CD011077.pub2
- Fraenkel, J. R., & Wallen, N. E. (2009). *How to Design and Evaluate Research in Education*. New York: McGraw-Hill.
- Haq, A. I., Sarkar, M., Roy, S., & Alam, M. (2015). Dementia among older patients attending National Institute of Mental Health (NIMH), Dhaka, Bangladesh. Bangladesh Journal of Psychiatry, 29. doi: https://doi.org/10.3329/bjpsy.v29i1.32744
- Hicks, C. M. (1999). Research methods for clinical therapists : applied project design and analysis. New York: Churchill Livingstone.
- Jansen, S., Ball, L., Desbrow, B., Morgan, K., Moyle, W., & Hughes, R. (2015, March). Nutrition and dementia care: Informing dietetic practice. *Nutrition & Dietetics*, 72(1), 36-46. doi: https://doi.org/10.1111/1747-0080.12144

- Kaplan, D. B., & Berkman, B. J. (2020). Family Caregiving for Older Adults. Retrieved from Merck Manual: https://www.merckmanuals.com/professional/geriatrics/social-issues-in-olderadults/family-caregiving-for-older-adults
- Kennedy, G. D. (1992, July). The role of the speech and language therapist in the assessment and management of dysphagia in neurologically impaired patients. *Postgraduate medical journal*, 68, 545 - 548. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2399382/
- Koger, S., & Brotons, M. (2000, January 01). Music therapy for dementia symptoms. *The Cochrane Database of Systematic Reviews*, 3, CD001121-CD001121. doi:DOI: 10.1002/14651858.cd001121
- Kramarow, E. A., & Vera, B. T. (2019, March 14). Dementia Mortality in the United States, 2000–2017. National Vital Statistics Reports, 68. Retrieved from https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_02-508.pdf
- Logemann, J. A. (1998). Evaluation And Treatment Of Swallowing Disorder. Taxas: Proed.
- Mayeux, R., & Stern, Y. (2012). Epidemiology of Alzheimer Disease. PMC, 2(8). doi:10.1101/cshperspect.a006239
- Miller, N., & Carding, P. (2007, August). Dysphagia: implications for older people. *Reviews in Clinical Gerontology*, 17(03), 177 - 190. doi:10.1017/S0959259808002463
- NCI. (2019). Definition of caregiver NCI Dictionary of Cancer Terms. Retrieved from National Cancer Institute: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/caregiver
- Nishino, T. (2013). The swallowing reflex and its significance as an airway defensive reflex. *ResearchGate*, *3*, 489. doi:https://doi.org/10.3389/fphys.2012.00489
- O'Rourke, F., Vickers, K., Upton, C., & Chan, D. (2014). Swallowing and oropharyngeal dysphagia. *Clinical medicine (London, England)*, 4(2), 196-9. doi:10.7861/clinmedicine.14-2-196

- Payne, M., & Morley, J. E. (2018). Dysphagia, Dementia and Frailty. *The journal of nutrition, health & aging*, 22(5), 562-565. doi:https://doi.org/10.1007/s12603-018-1033-5
- Pelletier, C. A. (2004, May 01). What Do Certified Nurse Assistants Actually Know About Dysphagia and Feeding Nursing Home Residents? *American Journal of Speech-Language Pathology*, 13(2), 99-113. doi:https://doi.org/10.1044/1058-0360(2004/012)
- Priefer, B. A., & Robbins, J. (1997, August). Eating Changes in Mild-Stage Alzheimer's Disease: A Pilot Study. *Dysphagia*, 12(4), 212–221. Retrieved from https://link.springer.com/article/10.1007%2FPL00009539
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta analysis. *Alzheimer's Association*, 9(1), 63-75. doi: https://doi.org/10.1016/j.jalz.2012.11.007
- Pulia, N. R., Malandraki, G. A., Johnson, S., & Robbins, J. (2015, March). Understanding Dysphagia in Dementia: The Present and the Future. *Current Physical Medicine* and Rehabilitation Reports, 3(1), 86–97. Retrieved from https://link.springer.com/article/10.1007/s40141-015-0078-1
- Queensland, A. A. (2019). *Recognising and managing swallowing difficulties for people with*. Retrieved from Alzheimer's Association Queensland: https://www.alzheimersonline.org/page/about-us/whats-on/blog/recognising-andmanaging-swallowing-difficulties-for-people-with-dementia/
- Rofes, L., Arreola, V., Almirall, J., Cabré, M., Campins, L., Peris, P. G., ... & Clavé, P. (2010, February 15). Diagnosis and Management of Oropharyngeal Dysphagia and Its Nutritional and Respiratory Complications in the Elderly. *Gastroenterology Research and Practice*, 2011. doi:http://dx.doi.org/10.1155/2011/818979
- Rösler, A., Pfeil, S., Lessmann, H., Höder, J., Befahr, A., & Renteln-Kruse, W. V. (2015). Dysphagia in Dementia: Influence of Dementia Severity and Food

Texture on the Prevalence of Aspiration and Latency to Swallow in Hospitalized Geriatric Patients. *Elsevier*, *16*(8), 697-701. doi:https://doi.org/10.1016/j.jamda.2015.03.020

- Schulz, R., McGinnis, K. A., Zhang, S., Martire, L. M., Hebert, R. S., Beach, S. R., . . . & Belle, S. H. (2008). Dementia Patient Suffering and Caregiver Depression. *Alzheimer Disease & Associated Disorders*, 22(2), 170-176. doi:10.1097/WAD.0b013e31816653cc
- Shinagawa , S., Honda, K., Kashibayashi, T., Shigenobu, K., Nakayama, K., & Ikeda , M. (2015). Classifying eating- related problems among institutionalized people with dementia. 70(4), 175-181. doi:https://doi.org/10.1111/pcn.12375
- Shinagawa, S., Adachi, H., Toyota, Y., Mori, T., Matsumoto, I., Fukuhara, R., & Ikeda, M. (2009). Characteristics of eating and swallowing problems in patients who have dementia with Lewy bodies. 21(3), 520-525. doi:https://doi.org/10.1017/S1041610209008631
- Suh, M. K., Kim, H. H., & Na, D. L. (2009, Apr-Jun). Dysphagia in Patients With Dementia Alzheimer Versus Vascular. *Alzheimer Disease and Associated Disorder*, 23(2), 178-84. doi:10.1097/WAD.0b013e318192a539
- Sultzer, D. (1996, October 01). Behavioral Syndrome in Dementia: Neuroimaging Insights. Seminars in Clinical Neuropsychiatry, 4(1), 261-271. doi: 10.1053/scnp00100261
- Sura, L., Madhavan, A., Carnaby, G., & Crary, M. A. (2012, July 27). Dysphagia in the elderly: management and nutritional considerations. *Clinical Interventions in Aging*, 7, 287-298. doi:10.2147/CIA.S23404
- UN. (2015). World Population Ageing the United Nations. Retrieved from United Nations:https://www.un.org/en/development/desa/population/publications/pdf/age ing/WPA2015_Report.pdf
- Volicer, L., Seltzer, B., Rheaume, Y., Karner, J., Glennon, M., Riley, M. E., & Crino, P. (1989, October 1). Eating Difficulties in Patients With Probable Dementia of the

Alzheimer Type. *Journal of Geriatric Psychiatry and Neurology*, 2(4), 188-195. doi:https://doi.org/10.1177/089198878900200404

- Volicer, L., Seltzer, B., Rheaume, Y., Fabiszewski, K., Herz, L., Shapiro, R., & Innis, P. (1987, March 01). Progression of Alzheimer-Type Dementia in Institutionalized Patients: A Cross-Sectional Study. *Journal of Applied Gerontology*, 6(1), 83-94. doi:https://doi.org/10.1177/073346488700600107
- Watson, R. (1993, January). Measuring feeding difficulty in patients with dementia: perspectives and problems. JAN Leading global Nursing Researh, 18(1), 25-31. doi: https://doi.org/10.1046/j.1365-2648.1993.18010025.x
- Wasson, K., Tate, H., & Hayes, C. (2001). Food refusal and dysphagia in older people with dementia: ethical and practical issues. *International Journal of Palliative Nursing*, 7(10), 465-471. doi:https://doi.org/10.12968/ijpn.2001.7.10.9902
- Whear, R., Abbott, R., Coon, J. T., Bethel, A., Rogers, M., Hemsley, A., ... & Stein, K. (2014, March). Effectiveness of Mealtime Interventions on Behavior Symptoms of People With Dementia Living in Care Homes: A Systematic Review. *Journal of the American Medical Directors Association*, 15(3), 185-193. doi:https://doi.org/10.1016/j.jamda.2013.10.016
- WHO. (2019). *Dementia World Health Organization*. Retrieved from World Health Organization: https://www.who.int/news-room/fact-sheets/detail/dementia
- WHO. (2020). Ageing and health World Health Organization. Retrieved from WHO: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health
- WHO. (2020). *Dementia World Health Organization*. Retrieved from World Health Organization: https://www.who.int/news-room/fact-sheets/detail/dementia

[N.B. For better understanding of the study, please see hard copy & for any further information please contact: jannatsifate@gmail.com]