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THE INFLUENCE OF TRAINING ON ALLEVIATING STRESS AND ENHANCING QUALITY OF LIFE AMONG CAREGIVERS OF INDIVIDUALS WITH DYSARTHRIA FOLLOWING STROKE

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Abstract:

Individuals with dysarthria experience speech impairment, which can diminish their Quality of Life (QOL). Given that effective communication is crucial for social interaction, speech issues may impact life satisfaction. While there is extensive research on the QOL of individuals with dysarthria, there is limited investigation into the QOL and level of stress of their caregivers.

This study aimed to compare the QOL and level of stress in caregivers of dysarthria pre and post communication trainings and see effectiveness of trainings.

Trainings helped in reduction of stress and improvement in quality of life of caregivers. Communicative partner trainings are essential to improve quality of life in caregivers of patients with dysarthria and reducing stress in them.

Keywords: Caregivers, Dysarthria, Quality of Life, Stress

1. INTRODUCTION

Approximately 20-30% of individuals who have undergone a stroke experience dysarthria, a condition characterized by diminished speech intelligibility due to inadequate coordination among the muscles involved in speech production (1-2). This condition can significantly impact individuals, leading to social isolation and compromised health. Dysarthria may result from issues within the respiratory, laryngeal, or oral articulator muscles, as well as the tongue, lips, cheeks, or palate (2). Speech challenges associated with dysarthria range from complete unintelligibility to hesitant and stuttering speech, or even comprehensible speech that requires careful internal practice and monitoring to maintain voice quality (3).Health-related quality of life is the subjective assessment of an individual's well-being within the cultural and value systems of their society. It considers ambitions, beliefs, values, and apprehensions, encompassing the perceived value of life duration. This assessment is influenced by factors such as impairment, functional states, perceptions, and social opportunities, all of which may be impacted by disease, injury, treatment, or policy (4).

The treatment for dysarthria is individualized, incorporating specific exercises, guidance, explanations, techniques, and psychological support based on the unique needs of each person. Interventions may include breathing exercises to improve breath support, non-speech movements to enhance oral muscular strength, speed, and accuracy. Additionally, text-to-speech tools and phonetic symbol charts can enhance communication success by adjusting speech pace or emphasizing words. Psychological support, including education on dysarthria, collaboration with communication partners, and participation in communication support groups, plays a vital role in enabling individuals to more fully engage with their communities.

Despite the prevalence of dysarthria post-stroke, research in this area is limited, with insufficient data on effective therapies, optimal initiation times, and suitable treatment durations or intensities. A recent Cochrane review highlighted the scarcity of well-powered, controlled studies on dysarthria (4).

Individuals with post-stroke dysarthria typically receive ongoing speech and language therapy. The success of treatment is closely tied to providing services aligned with the cultural values and objectives of the target population. Misunderstandings can lead clients and their families to disengage and resist active participation in the rehabilitation process (6).

Management of dysarthria is contingent on factors such as type, symptoms, and cause. Speech and language therapy may encompass addressing various speech problems, including improving speech rate, muscle strengthening, enhancing breath control, addressing articulation errors, and providing guidance to family members. In cases where speech therapy yields no improvement, alternative communication methods such as gestures, visual hints, alphabet boards, and computer-based technologies are recommended.

Various treatment approaches exist for dysarthric patients, and reducing speech rate is a common therapeutic technique for hypokinetic dysarthric patients (7-8). Researchers have explored pacing boards, tapping, metronomes, delayed auditory feedback (DAF), and computerized pacing to understand the impact of reduced speech rate on dysarthric patients (8-9).

Speech therapy goes beyond the mechanics of speech production to encompass interactive communication. Programs may involve group sessions lasting several hours a day for weeks, addressing various speech-related complaints. 'Therapy' is characterized by an intentional interpersonal relationship where a therapist creates an environment for each client to enhance their capabilities. The term 'group' signifies a shift from 'individual' therapy, with differences in structure. While individual therapy involves a two-person relationship between therapist and client, group therapy includes one therapist and two or more clients. The term 'group' typically refers to 6-15 individuals, but the exact number varies. At a psychological level, individual connections form a structure unrelated to numbers (10).

In a group setting, it is crucial to explore the life-altering implications of dysarthria. Groups provide a platform for organic interaction with diverse communication partners, facilitating discussions on personal experiences, collaborative problem-solving, and mutual support. Post-aphasic groups have reported positive psychological outcomes. Capturing affirming remarks from participants and professionals in both inpatient and outpatient settings regarding their experiences with dysarthria can provide valuable insights (11).

Communication difficulties induced by dysarthria result in social isolation, reduced quality of life, and changes in daily routines. These impairments can lead to psycho-emotional disorders such as depression and impaired cognitions. Even after therapy, older stroke patients may still require support from professional or informal caregivers, including family members and spouses. However, physical dependency or mental illness can negatively impact the patient's health and quality of life, increasing caregiver stress (12-13).

1.1 Support Group: Carers and Family:

The term "carer" refers to the individual residing with the patient, primarily responsible for providing unpaid care and assistance at home. This caregiving role, undertaken without financial compensation, can lead to stress and strain over an extended period. Caregiver burden encompasses various domains, including mental, physical, social, and economic factors (14).

In a study comparing family caregivers of stroke survivors with and without aphasia, approximately one-third of caregivers reported experiencing depression at the initial assessment. However, after four months, the group caring for individuals with aphasia did not show improvement. Caregivers of stroke survivors with aphasia faced additional challenges, particularly related to communication difficulties with the stroke survivor. The struggles with speech by the survivor were found to be distressing. Despite this, the research revealed lower well-being scores for caregivers, although satisfaction with their relationship with the partner who had aphasia did not decrease (5).

Zarit et al. define caregiver burden as tension arising from caregiving responsibilities or restrictions. Caregiver burden can be categorized into

- Objective burden, associated with caregiving tasks, such as physical help and care for daily activities due to physical impairment, cognitive disabilities, and household chores. This is measured by the Oberst Caregiving Burden Scale, consisting of 22 items covering tasks related to caring for stroke patients, further divided into time and difficulty subscales.
- Subjective burden includes the perceptions and feelings associated with caregiving tasks, acknowledging the dual responsibility of caregivers for stroke survivors and their own daily chores (14).

The needs of stroke patients encompass physical challenges (e.g., walking, shifting from bed to chair, chair to bathroom), interactional challenges (verbal and gestural communication with family and peers), nursing requirements (eating, changing clothes, personal hygiene), sentimental aspects, mental challenges in adapting to the effects of stroke, and economic considerations (unemployment and medication bills). Caring for stroke patients, due to its exhausting and recurrent nature, can impose a burden on caregivers. It is crucial to identify factors that may impact caregiver burden. In the context of Indian culture and society, where men are traditionally the breadwinners and women are responsible for family care, the severity of caring for an elderly family member, especially after a severe stroke, can lead to extreme burden and stress for female caregivers. A supportive environment and caregivers are essential for enhancing the recovery of stroke patients, as caregiver stress may hinder the recovery process (15).In less developed countries like India, where stroke mortality and morbidity rates are high, caregivers of stroke patients may experience a substantial amount of burden and stress. In 2005, India reported more than 53% of cases of all death from 44% were dead due to some chronic disease, i.e., stroke. Research showed that caregivers of stroke patients may experience a large amount of burden and stress most of the time.

Studies showed that Economic, physical, emotional and psychological problems are confronted by caregivers, with some having to manage their job schedules or quitting their jobs. Young caregivers, particularly daughters-in-law, often bear major burdens, while spouse caregivers may experience fewer burdens compared to others. In the joint family system of Indian culture, every family member is involved in taking care of the patient, with spouses providing physical help, men handling financial matters and medications, children creating a healthy environment, and even relatives and neighbors assisting with caregiving tasks. Factors such as caregiver's anxiety, the role of being a daughter-in-law as a caregiver, and the mental health of both caregivers and patients are significant contributors to the burden level of caregivers of stroke patients (16).

The psychological impact of dysarthria following a stroke has been infrequently explored, particularly concerning the participation (handicap) and activity (disability) dimensions of the condition. Evaluation and treatment of dysarthria post-stroke have primarily focused on pathology or impairment. Recent guidelines emphasize a more comprehensive approach, with efforts to create assessments gauging the psychosocial effects of dysarthria. Despite these advancements, our understanding of the psychosocial impact of dysarthria after a stroke remains incomplete. Further insight is necessary before the development, adoption, and evaluation of a participation-based approach can be fully realized (17).

2. AIMS AND OBJECTIVES

To assess the effects of training on stress reduction and the improvement of the quality of life in caregivers of patients with dysarthria.

3. METHODOLOGY

This study constituted a pilot randomized controlled trial involving 10 caregivers in each group, with an equal distribution of 50% males and 50% females. The experimental Group A underwent training in a classroom setting, while Group B, the control group, involved caregivers without specific training. The collected data were entered and analyzed using SPSS 20.0. Descriptive statistics, such as mean ± SD or median (IQR), were employed based on the normality of the data. For the comparison of scores between the two groups at pre and post-study times and for assessing differences, the independent sample t-test or Mann-Whitney U test was utilized. Additionally, within-group comparisons of pre and post-rehabilitation scores were conducted using the paired sample t-test. A significance level of $P \leq 0.05$ was considered. The study employed three tools in the Urdu language.

3.1 The Stroke Knowledge Test (SKT): The Stroke Knowledge Test (SKT), created by Sullivan, Karen, and Dunton, Natalie J. in 2004, serves as a valuable tool for assessing the knowledge of individuals affected by stroke. Specifically designed for healthcare professionals involved in the care of stroke patients, this versatile test is suitable for use in both individual and group settings. It effectively evaluates stroke knowledge in survivors, those at risk, caregivers, family members, and support staff who interact with individuals having a history of stroke. The results obtained from the SKT empower professionals to tailor stroke education programs, addressing the specific needs of clients and contributing to ongoing research initiatives. Acknowledged widely for its validity and reliability, the SKT consists of 20 well-crafted items demonstrating robust content, favorable properties, and positive expert reviews. Psychometric investigations confirm its strong reliability, covering internal consistency and test-retest reliability, along with construct validity, as indicated by notable increases in SKT scores following stroke education interventions (18).

3.2 The General Health Questionnaire (GHQ):

The General Health Questionnaire (GHQ), devised by Goldberg in the 1970s, serves as an evaluative tool for current mental health and finds extensive application in diverse cultural and professional settings. Originally consisting of 60 items, the questionnaire has undergone condensation into shorter versions, such as GHQ-30, GHQ-28, GHQ-20, and GHQ-12. Functioning as a self-administered screening tool designed for healthcare settings, it aids in identifying individuals with diagnosable psychiatric disorders. GHQ-12, known for its brevity, simplicity, and ease of completion, generates total scores of 36 or 12 through different scoring methods like bi-modal (0-0-1-1) and Likert (0-1-2-3) (19). Its efficacy as a screening instrument for common mental disorders, along with its role as a general measure of psychiatric well-being, contributes to its widespread adoption in busy clinical settings. The multidimensional nature of GHQ-12 enables the assessment of various facets of distress, extending its utility beyond a mere screening measure and enhancing its capacity to detect non-psychotic psychiatric issues (20).

3.3 Zarit Scale of Caregiver Burden: The Zarit Scale of Caregiver Burden, also recognized as Zarit Burden Interview (ZBI), was developed by Zarit et al. in 1980 and remains a widely employed instrument in the field. Initially comprising 29 items, it underwent refinement to 22 questions, with recent adaptations further enhancing its applicability. This scale evaluates the impact on caregivers' psychological well-being, financial situations, relationships with the care recipient, and social lives. The shorter 12-item and 4-item screening versions demonstrate a strong correlation with the complete 22-item version. The 4-item screening, intended for self-administration by caregivers (21), proves valid and reliable for its designated purpose. Although the factor structure of the Zarit Burden Interview is somewhat unclear, a two-factor model proposed by Hérbert, Bravo, and Préville (2000) is frequently cited for its reliability and validity. Their study, involving 312 caregivers from the Canadian Study of Health and Aging, exhibited robust internal consistency reliability, with a Cronbach’s alpha coefficient of .92, unaffected by the removal of any of the 22 items (22).

4. RESULTS AND OBSERVATION

Group A consisted of 6(60%) females and 4(40%), males whereas Group B comprised 4(40%) females and 6(60%) males. The majority of caregivers in both groups were literate, unmarried, and employed.

		Groups					
		Experimental		Control		Total	
		N	%	N	%	n	%
Gender	F	6	60	4	40	10	50
	M	4	40	6	60	10	50
Education	primary to middle	2	20	1	10	3	15
	Middle to matric	3	30	5	50	8	40
	matric to intermediate	1	10	2	20	3	15
	Intermediate to degree	4	40	2	20	6	30
Marital Status	Single	6	60	6	60	12	60
	Married	4	40	4	40	8	40
Occupation	Unemployed	3	30	2	20	5	25
	Employed	1	10	3	30	4	20
	Business	2	20	3	30	5	25
	Both	4	40	2	20	6	30

Table 1: Basic characteristics of the Caregiver

The ZCBS, GHQ, and SKT scores exhibited no significant differences between the two groups at both baseline and follow-up. However, noteworthy improvements were observed within each group, demonstrating statistical significance for all assessed variables. Specifically, the baseline SKT scores significantly increased by approximately 10 points in both groups, indicating a highly significant improvement. It is noteworthy that the experimental group demonstrated a significant improvement in GHQ and ZCBS compared to the control group, even though the scores between the two groups remained statistically insignificant at both baseline and follow-up assessments.

		Experiment	Control	P-value (Mann Whitney U) (t-test $)
		Mean±SD / Med(Q1-Q3)	Mean±SD Med(Q1-Q3)	
ZCBS	Pre	66(63-72)	72(59-78)	.471
	Post	87(80-93)	87(81-96)	.593
		<0.001	<0.001	
GHQ	Pre	27(26-29)	27(25-28)	.939
	Post	39(37-41)	39(40-37)	.969
		<0.001	<0.001	
SKT	Pre	9(7-9)	8(7-10)	.640
	Post	10(8-12)	9(8-11)	.354
		<0.001	<0.001	

Table 2: Comparative Analysis between Two Groups at Each Evaluation and Within Each Group over Two Assessments

Upon comparing changes between the two groups, it was observed that the experimental group exhibited a significantly higher increase in ZCBS, GHQ, and SKT scores compared to the control group, with a p-value of 0.000.

	Experimental	Control	P-value (t- test)
	Mean±SD	Mean±SD	
ZCBSD	20.3±2.11	17.6±9.59	<0.001
GHQ	12±.00001	12.1±0.32	<0.001
SKT	1.9±1.10	1±0.47	<0.001

Table 3: Comparative Analysis of Score Changes in Caregivers between Two Groups

Upon comparing caregivers, it was noted that the distinction between the two groups, either at baseline or post-treatment, was not significant. However, the enhancement in all three scores within each group showed remarkable significance, with p-values <0.001.

	Group				P-value (Independent sample t-test)
	Experimental		Control		
	Mean	SD	Mean	SD	
ZCBS pre	66.30	6.17	71.00	12.12	0.289
ZCBS post	86.60	6.90	88.60	9.99	0.609
P-value (Paired sample t-test)	<0.001		<0.001		
GHQ pre	27.10	2.23	26.70	2.83	0.730
GHQ post	39.10	2.23	38.80	2.94	0.800
P-value (Paired sample t-test)	<0.001		<0.001		
SKT pre	8.30	1.34	8.60	1.51	0.643
SKT post	10.20	1.55	9.60	1.26	0.355
P-value (Paired sample t-test)	<0.001		<0.001		

Table 4: Comparison of scores for care givers between two groups and within each group

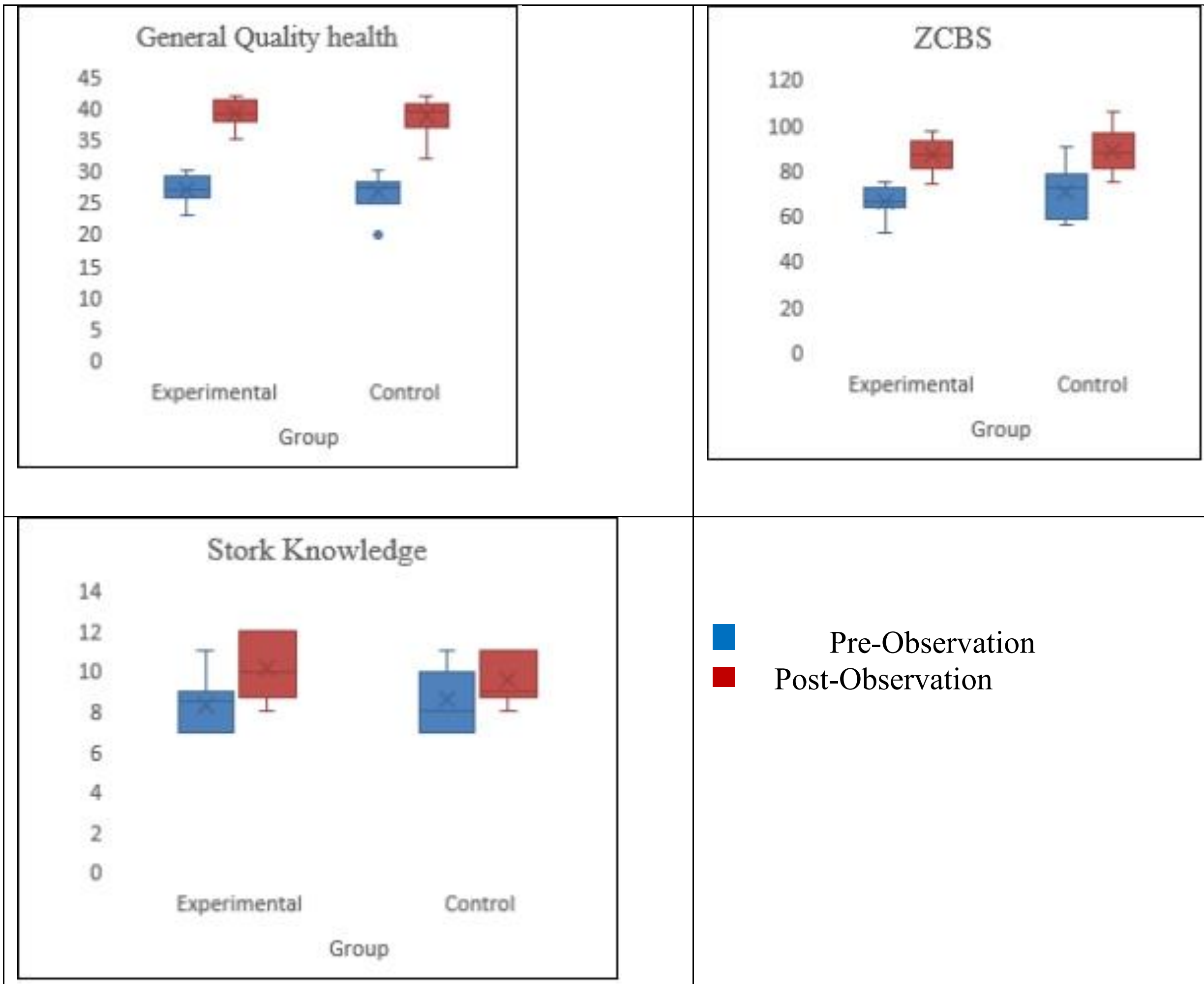

Figure 1: *Component total score for two groups, pre and post rehabilitation services*

5. DISCUSSION

According to a 2013 survey conducted by the Stroke Association, 64% of informal caregivers undergo emotional repercussions associated with stroke, indicating that providing informal care post-stroke may have adverse psychological effects on the caregiver. In a 2019 survey assessing the impact of post-stroke situations on informal caregivers, it was found that caregivers of spouses dealing with post-stroke experiences were significantly more likely to bear emotional burden (23). The majority of post-stroke patients, approximately 83.5%, in this study were categorized as having no depression. A meta-analysis of 50 studies concluded a prevalence of depression at 29%, remaining stable up to 10 years post-stroke, with a cumulative incidence ranging from 39% to 52% within 5 years of stroke (24). The recovery rates one year post-stroke showed a depression range of 15-57% in patients (24).

Caring for a family member after a stroke demands considerable effort and dedication, akin to a full-time job. Family caregivers face the challenge of balancing employment, education, friendships, social lives, family dynamics, and individual relationships. Family caregivers of stroke survivors dealing with post-stroke depression, as indicated in this study, expressed feelings of being overburdened and disappointed. The stress associated with this phenomenon stems from the everyday obligations of family caregivers, in addition to their personal commitments (25).

The investigation's results indicated a decline in the quality of life for both survivors and their caregivers. Stroke survivors and their family proxies agreed to participate in a functional assessment one to two months post-stroke, along with a quality of life (QOL) assessment. Factors such as age, work status, and the number of days spent in the hospital impacted the Quality of Life of survivors both at baseline and three months later (26). The study's findings suggest that caregivers of stroke survivors often experience moderate burden levels during the acute phase, and about 17% of these caregivers may have depression (27). Among caregivers, 26% reported mental health conditions such as anxiety disorders or depression. Other examined studies supported the finding that a higher caregiver burden was positively correlated with poorer post-stroke disabilities/complications (28).

In this research, it was observed that family member caregivers exhibited higher levels of anxiety and depression compared to their counterparts in the paid caregiver group. However, the paid caregiver group demonstrated anxiety and depression ratings superior to those observed in the healthy control groups of the study. Patients under the care of paid caregivers experienced more significant functional disabilities, attributed to a higher prevalence of ambulation disorders, aphasia, dysphagia, urinary and fecal incontinence, and sleep problems. Despite these challenges, anxiety and depression scores were comparatively lower in the paid caregiver group than in the family member caregiver group (29). Notably, the study found that a substantial 87.8% of caregivers did not experience depression. In contrast, previous studies reported varying percentages of caregivers experiencing depression, ranging from 18% (Balhara et al., 2012) to 71% (Guo & Liu, 2015), highlighting the complexity of this issue.

Depression emerges as a significant neuropsychiatric consequence post-stroke, characterized by increased incidence marked by feelings of sadness, anxiety, hopelessness, guilt, worthlessness, irritability, and restlessness. Sleep, appetite, initiative, and desire are often disrupted. The majority of post-stroke patients in this study fell into the category of no depression (83.5%). A systematic review and meta-analysis of 50 studies indicated a stable prevalence of depression at 29% up to 10 years post-stroke, with a cumulative incidence of 39–52% within 5 years (24).

The current study found a correlation between depressive symptoms and the severity of patients' functional disabilities, as those with more severe disabilities were more reliant on caregivers. Higher caregiver education levels were associated with fewer depressive symptoms, while the duration of care was proportional to depression, possibly due to increased stress levels associated with prolonged caregiving responsibilities. Partner caregivers faced significant challenges balancing work, childcare, and household issues, resulting in an inversely proportional relationship between care burden and depressive symptoms. Those with high care burden scores were also more likely to experience high depression levels (30). The study revealed that 49% of informal caregivers reported minimal or no caregiver burden, 34% reported mild to moderate burden, and 17% reported moderate to severe burden. Stroke survivor functional disability was linked to informal caregiver burden ($P = .0387$), and the presence of caregiver depressive symptoms was strongly correlated with caregiver burden ($P < .001$). Caregivers dealing with stroke survivors with functional disabilities and those experiencing depressive symptoms were more likely to face severe caregiver burden (31).

6. Conclusion:

Strengthening caregivers through focused training interventions proves to be a valuable approach to enhance their proficiency in managing the challenges associated with caring for individuals with dysarthria after a stroke. These programs, by addressing caregiver stress and enhancing their capabilities, not only contribute to the caregivers' well-being but also play a pivotal role in improving the overall quality of life for both caregivers and those under their care. Ongoing research and dedicated efforts in caregiver training initiatives can further advance our comprehension and implementation of effective strategies to support this crucial group within the healthcare continuum.

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