

Exploring the Role of Caregiver Quality Of Life in the Recovery Pattern of Patients With Severe Non-Fluent Aphasia – Case Series

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ABSTRACT

Background: Aphasia is a condition that leads to partial or total loss of ability to speak, understand, read or write a language. When a person was affected by chronic disorder or disability their families were often faced with the responsibility of providing care to the individual leading to a new title of caregiver. It is widely accepted that the caregivers of individual with aphasia can have a significant impact in the rehabilitation of interpersonal communication.

Aim: To analyze the role of caregiver's quality of life in the recovery of severe non –fluent aphasia patients along with speech and language stimulation.

Methods and procedure: Six unpaid caregivers of patients with aphasia were women with experience of one to three months of caregiving were selected. The language assessment was done using the Western Aphasia Battery. A structured interview was carried out to assess the attitude of the participants and the material 'Questionnaire to Evaluate the Extent of Burden on Caregivers of Person with Aphasia - Malayalam version' by Swathi B and S. P. Goswami was administered to analyze the burden level of caregiver. Speech and language intervention was provided and the therapy goals were based on the Manual of Adult Aphasia Therapy – Malayalam.

Outcomes and results: The patients of caregivers who had low burden level shows better recovery compared to those with higher burden level.

Conclusion: The caregivers' positive attitude towards person with aphasia corresponds with the active facilitation of communication can make the rehabilitation more efficacious.

Keywords: Aphasia, Caregiver Burden, Recovery

Introduction

Aphasia is an acquired communication disorder caused by brain damage, characterized by impairments of language modalities such as speaking, listening, reading and writing. It is not the result of a sensory or motor deficit, general intellectual deficit, confusion or a psychiatric disorder (Hallowell and Chappey,2008)^[6]. Aphasia is a multimodality physiological inefficiency with [greater than loss of] verbal symbolic manipulations (e.g. association, storage, retrieval, and rule implementation). In isolated form it is

caused by focal damage to cortical and/or sub cortical structures of the hemisphere(s) dominant for such symbolic manipulations. It is affected by and affects other physiological information processes to the degree that they support, interact with, or are supported by the symbolic deficits (McNeil, 1982)^[7].

Aphasia is usually resulting from Cerebro - vascular accident/ stroke (CVA). CVA occurs when the blood supply to a certain region of the brain is greatly diminished or stopped due to an ischemic event (embolism or thrombosis) or from a hemorrhagic event (i.e., intra cerebral hemorrhage, subarachnoid hemorrhage). Other etiologies of aphasia include; Traumatic brain injury, brain tumors, infections, and degenerative conditions such as Alzheimer's and progressive aphasia(Alfredo Ardila, 2014)^[11].

According to the National Institute on Deafness and other Communication Disorders (NIDCD), in the United States, there are 180,000 new aphasia cases a year, and one of every 272 Americans are affected with aphasia. In India, the community incidence is 43/100,000 per year and prevalence is 3000 per million (Engelter et al.,2006)^[2].The Global rate of post –stroke aphasia from seventy-five articles published between 2000 and 2021 reported the presence of aphasia in 7% - 77% of all the individuals with stroke (Frederick et al., 2022)^[3]. According to Benson 1964, aphasia is classified as fluent and non- fluent type. Both these types are created by cortical lesions to or within the language dominant hemisphere specifically at or near Broca's area, Wernicke's area and the arcuate fasciculus. Aphasia symptoms vary in severity of impairment and impact on functional communication, depending on factors such as the location and extent of damage and the demands of the communication environment.

Most individuals who experience aphasia after a stroke recover to some extent, with the majority of gains taking place in the first year. The recovery arc varies significantly from person to person. Some patients with stroke – induced aphasia experience some improvement in speech and language processing in weeks and months following onset, regardless of whether or not they receive aphasia therapy (Pederson et al.,1995). This is typically referred as Spontaneous Recovery. While in some other cases the person may continue to improve the language abilities for many years. Characteristically in the course of recovery, one type of aphasia may evolve in to another type- Global into severe Broca's, Wernicke's, Transcortical and Conduction in to Anomic aphasia. However, the nature of recovery mechanism will vary depends up on several factors. Some of the established predictors of possible levels of recovery are – Age, lesion size, lesion location, and aphasia severity and type (Basso,1992)^[5]. In addition, the environmental factors particularly, caregiver support and motivation also influence the recovery process of patient with aphasia.

In case of aphasia, its onset itself brings spectrum of changes in personal, familial and various social domains of patient with aphasia and they need assistance in managing their day-to-day activities therefore care-partner inclusion is identified as part of best practice in aphasia recovery. The caregivers are considered individuals who have the function of helping and / or providing the appropriate attention to people who present limitations to the basic activities of daily living, stimulating their independence and respecting their autonomy (Nakatani AYK, Souto CCS et al., 2003)^[8]. Caregiver undertakes various responsibilities including aiding with personal activity, offering medical support, providing emotional encouragement, preparing meals, maintaining a clean and organized household environment and assisting with transportation. But the caregiving can be challenging and demanding for individual, taking a toll on their mental and physical health, and leading to increased stress and strain in their lives. Most often, the caregiver has to take the role without warning. This sudden shift in identity and responsibility leaves little time for psychological adjustment (Agard et al, 2015).

The extent to which the caregivers perceive their mental and physical health, social life and financial status as suffering is known as 'caregiver burden'. The level of burden varies with age, gender, severity

of aphasia, dependency and socio-economic status, and can be manifested as “fatigue, emotional discomfort, limited social life, changes in family life, marital difficulties, balancing tasks and accessing resources”. This can negatively impact on recovery mechanism of patient with aphasia.

Caregiver burden research in the area of speech- language pathology has increased over the past few years. It has been studied by examining the presence of burden in family members who caring for individuals with speech, language and swallowing impairments across the lifespan. There is a wide agreement that family and friends of people with aphasia can play a crucial role in the rehabilitation of interpersonal communication. Highly supportive environment improves the outcome of patient with aphasia. Stroke patients who receive good support show more motivation and more likely to have better outcome. Hence the study aimed to assess the role of caregiver burden in the recovery of person with aphasia) PWA and thereby disseminate knowledge about the significance of evaluating caregiver burden and offering caregiver training together with aphasia therapy.

Review of literature

Aphasia is a language disorder that is characterized by communication difficulty, which changes family and social life as well as decreased quality of life of people with aphasia and their caregivers. Caregivers’ views of aphasia and its impact on daily interactions and activities are also valuable for treatment planning. There are several studies which back up the research question. In a study by Jennifer et al. (2019), they propose that the roles assumed by the caregiver evolve over time as both caregiver and person with aphasia adjust to life with a chronic disability. According to McGurk and Kneebone (2013), disability for the caregiver includes poorer social adjustment, decreased social life and leisure activities, and relationship stress. In the perspective of Visser-Meily, (2006) by focusing intervention goals solely on the person with aphasia, there is risk of missing a key link in ensuring that people with aphasia and their caregivers are able to successfully reintegrate into the community and receive appropriate outpatient rehabilitative care. Based on the study conducted by Maneetpal Badesha et al. (2023), they suggest that SLPs can be effective at reducing caregiver burden through interventions involving caregivers across the lifespan and continuum of care. Emerging evidence indicates that caregivers of person with aphasia respond positively to education and wellness programs (Boles, 2011; Boles and Area, 2010). Howe and colleagues (2012) found that caregiver education programs result in positive changes in dealing with the everyday communication problems and barriers that accompany aphasia and found that such education programs lower caregiver distress. Gillepsie et al. (2010) interviewed caregivers and people with aphasia and found that caregivers being included in therapy sessions as an active participant offers a teachable moment for the caregiver which encourages the therapy progress at home. In conclusion, the literature reviewed highlights the critical role of caregivers in the therapy and recovery process of individuals with aphasia. Understanding and addressing caregiver burden is crucial not only for enhancing caregiver well-being but also for optimizing patient outcomes in aphasia therapy. Thus, integrating comprehensive caregiver support and training into aphasia therapy remains crucial for optimizing care and achieving meaningful rehabilitation goals.

Need for the study

Up to 40% of the stroke survivors who acquired aphasia require long term caregiver assistance after discharge from the hospital. Caregivers play a crucial role in the rehabilitation journey of individuals with aphasia, helping them to reintegrate into the community after hospitalization. While services for the

person with aphasia (PWA) are becoming more person-centered, support for caregivers remains lacking due, in part, to the specific focus on the aphasia as an individual problem. The speech-language pathologist would be able to advise caregivers with appropriate coping mechanisms if they were aware of their struggles. Also helps the caregiver to understand the condition of person with aphasia in a better way that would develop a positive attitude and facilitate better communication. This study highlights the role, (Quality of life)QOL and personality of caregiver in the recovery of severe Non –Fluent Aphasia patients along with Speech and Language Stimulation.

Aim and objectives

- Analyze the role of caregiver’s QOL and personality in the recovery of severe Non –Fluent Aphasia patients along with Speech and Language Stimulation.
- Assess the impact of caregiver burden on recovery of patients with Severe Non fluent aphasia

Method

Materials

- Western Aphasia battery
- Structured Interview Consist of 5 questionnaires through telephonic mode.
- ‘Questionnaires to evaluate the extent of burden on caregivers of persons with aphasia-Malayalam (Swathi B & S. P Goswami)

Participants of the study:

The study included a total of six unpaid caregivers of patients with aphasia, all of whom were women aged over 25. These caregivers, who were either the wives or daughters of the patients, were selected from the Kasaragod district in Kerala. Each participant had between one to three months of caregiving experience prior to the study. They were required to be literate in Malayalam. Caregivers with any mental or physical challenges (such as sensory loss, motor deficits) or emotional and psychological disorders were excluded from participation.

Procedures

The study was conducted in three phases. In Phase 1, demographic details of the patients were collected, and a language assessment was performed using the Western Aphasia Battery. This evaluation revealed that all six patients had severe non-fluent aphasia, either Global or Broca’s type. In Phase 2, a structured interview consisting of five questions was conducted via telephone to analyze the caregivers' attitudes towards their situation. In Phase 3, a questionnaire titled 'Questionnaire to Evaluate the Extent of Burden on Caregivers of PWA - Malayalam version' by Swathi B and S. P. Goswami was administered to measure the caregivers' burden levels across the domains of Psychosocial, Emotional, Personal relationship, Care-responsibility, Caregiver’s health related problems, Communication expectation, and Caregiver’s communication style. The results are shown in Table1. Participant data.

Result

The study involved six stroke survivors, both male and female, aged between 50 and 60 years, all diagnosed with severe non-fluent aphasia one-month post-stroke. The caregivers selected for the study were all Malayalam-speaking women. Based on their carer burden, participants were divided in to two categories (Low level & High level) for the purpose of analysis and comparison. Analysis revealed that

three caregivers experienced high levels of burden, while the other three experienced low levels of burden. All patients received speech and language intervention for 3-4 weeks, with sessions conducted three days per week. Therapy goals were based on the Manual of Adult Aphasia Therapy – Malayalam (MAAT-M).

Following the speech therapy period, the recovery patterns were assessed using the MAAT-M therapy goals. The results indicated that patients whose caregivers had low burden levels showed better recovery patterns compared to those whose caregivers had high burden levels. Additionally, caregivers with low burden levels were more actively involved in the sessions and their positive attitudes contributed to a better prognosis for the patients.

TABLE 1. Participant Data

Patient	Age/Gender	Diagnosis	Caregiver	Age	Burden level
P1	66/M	Global	C1(Wife)	60	81
P2	50/M	Brocas	C2(Daughter)	29	78
P3	62/F	Brocas	C3(Wife)	55	87
P4	55/F	Global	C4(Wife)	50	156
P5	57/M	Brocas	C5(Daughter)	32	159
P6	61/M	Brocas	C6(Wife)	58	156

NOTE: P-Patient, M-Male, F-Female, C-Caregiver

Discussion

Providing education and training can improve the communication between the caregiver and the person with aphasia, while also improving quality of life and psychosocial well-being for both members of the dyad, (Simmons -Mackie, 2004)^[4]. Among the three phases of the study, collecting demographic details and language assessment using WAB were done in the first phase. In second phase, a structured interview between the clinician and the caregiver was done through telephonic medium to inspect the caregiver’s attitude towards the situation. The burden level of caregivers was estimated using the material 'Questionnaire to Evaluate the Extent of Burden on Caregivers of PWA - Malayalam version' by Swathi B and S. P. Goswami in the third phase. The questionnaire comprises seven domains, such as Psychosocial, Emotional, Personal relationship, Care-responsibility, Caregiver’s health related problems, Communication expectation, and Caregiver’s communication style. By evaluating these domains for assessment, caregivers were classified as having a higher or lower burden level. The individuals with aphasia participated in speech and language interventions lasting three to four weeks, with sessions held three days a week which were followed by MAAT-M. The therapy goals were more focused on the MAAT-M domains such as functional communication, comprehension and expression, and repetition. After the speech and language intervention phase, patients with caregiver experiencing lower burden tend to recover more rapidly compared to those with caregivers facing higher burden. The study investigated the impact of caregiver burden and caregiver's QOL, and personality in the recovery of

patients with severe non fluent aphasia. The more positive the caregiver's attitude towards PWA and the lower their burden level, the more pronounced the recovery observed in PWA. The results of the current study are conformable with the previous research highlighting the role of caregivers in the recovery of PWA. That is, an empathetic caregiver can enhance the rehabilitation process by creating a supportive environment that encourages communication and engagement.

This study has enlightened the fact that the burden level of caregiver would limit their participation in the therapy sessions of PWA. Lower burden level would promote the active participation of caregivers in the therapy thereby increasing the pace of recovery pattern in PWA. This certainly indicates the significance of caregiver education and training that should be ensured as an important step in aphasia management.

There are certain limitations in the study. For instance, the research objective did not take into account the education and socio-economic status of patients or caregivers. Additionally, the cognitive status of patients was not considered in this study. Since the study had only a small sample size of 6 participants, with 3 facing high caregiver burden and 3 with low burden, future research should aim to be conducted with a larger sample size to enhance the study's reliability and generalizability. In addition, further studies could be conducted by comparing the recovery patterns before and after caregiver training.

Conclusion

Aphasia caused changes in the carers' lives including "decreased social life and leisure activities, relationship stress, poor psychological adjustment etc." The analysis on caregiver burden and its influence in PWA reveals that Caregiver's positive attitude towards PWA correlated with the active facilitation of communication which can lead to more effective rehabilitation. Findings emphasizes that individuals who have a lower level of caregiver burden tend to exhibit a better recovery pattern in the PWA. Also, the results of the study indicate that neither the age nor the relationship of the caregiver had a significant effect on the recovery pattern. The study highlights the role of caregiver and the analysis of caregiver burden that need to be considered during the therapy of PWA. The emphasis should be extended to the counseling and training of the caregivers along with their participation in the therapy. Speech and language pathologists may be able to use the experience to help the family members of PWA to provide proper care and they may also be able to develop and execute PWA's Caregiver-Focused Programs. Therefore, caregiver training not only alleviates the burden on caregivers but also enhances the overall quality of care and the recovery outcomes for individuals with aphasia.

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