

Communication Breakdown in Patients with Aphasia - A Bird View of Indian Context

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DOI: <https://doi.org/10.52403/ijhsr.20240838>

ABSTRACT

Introduction: Aphasia is defined as a language disorder that results from damage to the parts of the brain responsible for language processing. It occurs as a result of stroke or brain injury. The linguistic deficit in aphasia can lead to communication breakdown in caregiver-patient interactions. Aphasia caregivers face relationship conflict, social isolation, and despair due to communication breakdown. This study examines the extent of this breakdown.

Method: Twelve caregivers of individuals with aphasia participated in the study. Six of these caregivers were caring for a person with Broca's aphasia, and four had been caring for someone with transcortical motor aphasia. A semi-structured interview questionnaire was developed based on three domains (Caregiver perspective - Speaker, Environmental, Caregiver perspective - Listener). Self-report questionnaires were provided. Carers were questioned in semi-structured interviews. Conversations were audio-recorded in order to be transcribed and analyzed.

Results: Overall, activities in daily life were affected due to communication breakdown. Conversations involving personal life were the most affected. In the caregiver-speaker perspective domain, almost half of the caregivers faced problems in conversing in long and complex sentences with aphasic patients. Breakdown occurs most with unknown people. Clarity and slurred speech cause communication breakdown. Broca's aphasia caregivers experience more breakdown than those caring for individuals with transcortical motor aphasia.

Conclusions: The results of the study indicated that communication problems are a major challenge for many caregivers, especially in conversations about personal life. At least a third of caregivers also struggle with communication in routine tasks.

Keywords: Communication breakdown, Caregiver perspective, Broca's aphasia, Transcortical motor aphasia.

INTRODUCTION

Aphasia can be defined as the loss or impairment of language caused by brain damage [1]. Aphasia is a sequela of focal brain injury in adulthood, that disrupts the

intricate neural architecture subserving language processing. This disruption manifests as a group of impairments encompassing comprehension, production, reading, and writing, effectively

compromising an individual previously established communicative competence. Aphasia usually occurs suddenly, often following a stroke or head injury, but it may also develop slowly, as the result of a brain tumor or a progressive neurological disease. The disorder impairs the expression and understanding of language as well as reading and writing. There are 180,000 new cases of aphasia each year in the United States, with 1 in every 272 Americans affected. Approximately one-third of these cases result from cerebrovascular accidents (CVAs). Global aphasia is the most common type. The incidence of aphasia due to CVA is equal between men and women but increases with age. Individuals younger than 65 have a 15% chance of being affected, while those older than 85 have a 43% chance. Additionally, 25% to 40% of stroke survivors develop aphasia due to damage to the brain's language-processing regions [2].

Apart from language deficits experienced by people with aphasia, they also often experience significant negative emotional and psychosocial changes, some of which are related to the nature of their brain damage and some of which are natural reactions to disability [3]. A person with aphasia may confront communication breakdowns and barriers, leading to significant frustration and potential conflicts with their communication partners. Losing the ability to communicate can be devastating, and can have a long-lasting effect. Communication breakdown refers to the failure or significant difficulty in conveying or understanding messages due to impairments in language abilities. This disruption can occur in various forms, affecting both expressive and receptive language functions.

The effects of communication breakdown in aphasia are extensive, influencing emotional, social, occupational, daily living, cognitive, and therapeutic areas of life. Emotionally, individuals often face frustration, anxiety, depression, and diminished self-confidence. Socially, they

may experience isolation, strained relationships, and reduced social engagement. In the workplace, communication difficulties can lead to job performance issues, unemployment, and limited career advancement. Daily living challenges include reduced independence and potential safety risks. Cognitively, the effort to communicate can cause mental fatigue and hinder problem-solving abilities.

Various factors related to the individuals themselves, their conversation partners, the nature of the conversation, and the physical environment influenced their conversational experiences. There is huge importance that their communication partner's knowledge and understanding of aphasia, as well as their use of supportive conversation strategies. They will express a strong desire to regain their former language abilities and roles as active societal participants. Psychological support may be of paramount importance to help individuals cope with the consequences of aphasia [4]. Communication breakdowns, especially in therapy sessions, often manifest as lexical errors where individuals struggle to find the right word. These breakdowns can also include mispronunciations and semantic errors that affect the meaning of the conversation. Responses to these errors vary. Clinicians might overlook minor lexical errors during task-oriented activities, while spouses or close partners are more likely to engage in conversational repair to maintain understanding. The frequency and severity of breakdowns are influenced by the speaker's goals, the topic of conversation, and the listener's knowledge. Unfamiliar topics tend to increase the likelihood of errors, and listeners who are well-versed in the subject are better equipped to assist in repairing communication. Thus, both the context and the participants' familiarity with the subject matter play critical roles in managing and mitigating communication breakdowns [5].

A study investigated the experiences of seven men and four women with aphasia (n = 11), with a mean age of 65.4 years,

ranging from 48 to 79 years, and a mean time since stroke onset of 38 months. All participants lived at home with a partner and were no longer working. The analysis of the data revealed 38 subcategories grouped into 14 categories. Findings include a reduction in conversation opportunities, with informants having fewer conversations and partners, and limiting discussions to practical issues. Communication difficulties, such as word-finding problems, were common, and both the individuals with aphasia and their conversation partners (CPs) faced challenges in understanding each other. Conversations often became unbalanced, with the CP taking on a dominant role, leading to increased exhaustion and frustration for the informants. Despite these challenges, experiences varied, with some informants maintaining more conversation topics similar to pre-aphasia levels, while others had minimal interaction. The study highlights the complexity of communication dynamics for individuals with aphasia and the significant impact on their emotional well-being^[4].

A study had explored the subjective communication difficulties experienced by individuals with very mild aphasia, who despite scoring within normal ranges on standardized aphasia assessments, continue to face significant challenges in everyday communication. Through semi-structured interviews with five participants, the study highlights several key issues. Participants reported persistent communication difficulties, such as the need for increased preparation and focused attention, and the struggle with word retrieval and complex language tasks. These challenges have led to reduced social participation, difficulties in returning to work, and a heightened awareness of their impairments. The study underscores that even very mild aphasia still impacts various aspects of life, including personal identity and social interactions^[6]. Communication partners and caregivers of individuals with aphasia often face significant constraints and challenges. The

frustration of communication breakdown can lead to emotional tolls like guilt, anxiety, and burnout. Lack of understanding and limited communication strategies can further exacerbate the situation, making it time-consuming and emotionally draining. Caregivers may feel helpless and struggle to cope with the changes in their relationship and the individual's abilities, leading to grief and loss. Moreover, they may not have access to adequate resources, training, or support, making it essential to provide them with education and training to develop effective communication strategies. By acknowledging these challenges, we can better support caregivers and communication partners, enabling them to provide the best possible support for individuals with aphasia. Hence, they can engage in meaningful conversations with loved ones, maintain relationships, and connect with their community. Improved communication abilities also enable individuals with aphasia to pursue their educational and professional goals, make informed decisions, and maintain autonomy and independence.

Research on the influence of conversation partner familiarity on communication, particularly in people with aphasia (PWA), reveals mixed results. Familiar partners, defined by shared past experiences and knowledge, often communicate more accurately and efficiently due to better perspective-taking and reliance on shared information. However, studies show varying outcomes depending on task complexity, relationship type, and motivation. In PWA, limited research indicates that while lower-level linguistic measures like verb and sentence production may remain stable, higher-level strategies such as gesture use and repair of conversational trouble can vary with partner familiarity. Familiar partners often provide more collaborative and supportive communication, aiding in effective repair of conversational breakdowns, whereas unfamiliar partners may gloss over breakdowns or take on the repair responsibility. Additionally,

familiarity with aphasia and communication strategies among conversation partners, along with a sense of comfort and support during interactions, significantly enhance communication effectiveness and reduce effort for PWA [7].

Aphasia therapy should not solely focus on linguistic deficits but should consider the broader social, psychological, and emotional effects of aphasia. A holistic approach is essential, as it acknowledges that aphasia affects multiple aspects of a person's life, ultimately influencing their overall quality of life. By addressing not only the linguistic but also the social and psychological challenges, therapists can provide more comprehensive support. Studies on communication breakdown in aphasia is sparse, and the scenario of communication breakdown is different in persons with Aphasia based on geographical region and socio-cultural context, this fact necessitated the current study. The necessity of analyzing the communication breakdown of PWA in Indian population emerges at this point as there are no studies available on the same. Hence, this study calls for further research to develop better assessment methods and interventions tailored to person with aphasia and their caregivers experiencing these subtle but impactful difficulties.

MATERIALS & METHODS

The study involving twelve caregivers of persons with aphasia (8 with Broca's aphasia and 4 with global aphasia) was structured into two phases. Most caregivers were spouses. The process involved creating and validating a semi-structured interview questionnaire based on three domains: Caregiver-Speaker Perspective, Environmental factors, and Caregiver-Listener Perspective.

Phase 1: Questionnaire Development and Administration The questionnaire was designed to gather insights from caregivers regarding their communication experiences with persons with aphasia (PWA), focusing

on three primary domains: the caregiver's perspective as a speaker, environmental factors affecting communication, and the caregiver's perspective as a listener. The questionnaire comprises a total of 15 questions, with 5 questions dedicated to each domain. These questions aim to understand the challenges and dynamics of communication with PWA from various angles, ensuring a comprehensive understanding of the caregiver's experiences and the factors influencing effective communication. A semi-structured interview format was developed and validated, with a self-report format chosen to allow caregivers the freedom to express their thoughts in-depth. The validated questionnaire was then administered to caregivers, enabling them to share their perspectives and experiences comprehensively.

Phase 2: Semi-Structured Interviews To gather additional information about communication issues that might have been missed in the questionnaire, caregivers were interviewed using semi-structured interviews to identify their communication challenges. All interviews were audio-recorded for accuracy. One researcher transcribed the audio files verbatim, while a second researcher reviewed the transcriptions for accuracy. The transcribed data were coded and examined to identify key themes and insights.

This two-phase approach ensured a thorough understanding of the caregivers' experiences and communication challenges, enhancing the validity and depth of the collected data.

RESULT

The study revealed that communication breakdown significantly affected the activities of daily living in individuals with aphasia, leading to noteworthy challenges in routine interactions and activities, particularly impacting personal and social domains. Conversation was most evidently affected as a consequence of communication breakdown, and this skill is

crucial for maintaining relationships and emotional well-being, causing frustration and isolation for both patients and caregivers. Nearly half of the caregivers faced difficulties when conversing with aphasic patients, especially with long and complex sentences, indicating a substantial challenge in maintaining effective and meaningful communication essential for caregiving and emotional support for the PWAs. Communication breakdowns were most frequent when interacting with unknown people, suggesting that unfamiliar environments and new social interactions posed significant challenges for aphasic patients, possibly due to increased anxiety and the need for more cognitive resources. From the caregiver-listener perspective, clarity and slurred speech were the main factors leading to communication breakdown, hindering caregivers' ability to understand and respond appropriately, exacerbating communication difficulties. In the aspect of environmental factors, communication breakdowns are often observed by caregivers when individuals interact with unknown people. The lack of familiarity with the individual's specific communication style, preferences, or needs can lead to misunderstandings, as strangers may not know how to interpret nonverbal cues or unique speech patterns. Increased anxiety during these interactions can further hinder effective communication, making the individual less clear or more hesitant.

Additionally, misinterpretation of the individual's communication attempts and differences in communication expectations between the individual and the stranger also contribute to these challenges.

In the caregiver-speaker perspective domain, nearly half of the caregivers faced challenges when conversing with aphasic patients, particularly with long and complex sentences. This difficulty arises because aphasia often impairs an individual's ability to understand or produce complex language structures. Caregivers struggle to effectively communicate intricate or lengthy information due to the patient's reduced comprehension and expressive language abilities. Aphasic patients may find it challenging to process the multiple components of long sentences, leading to misunderstandings or an incomplete grasp of the information conveyed. As a result, caregivers may need to simplify their language, break down information into shorter segments, or use alternative communication strategies to ensure effective interaction and understanding.

Additionally, caregivers of patients with Broca's aphasia experienced more frequent communication breakdowns compared to those with transcortical motor aphasia, highlighting the more severe impact of Broca's aphasia on communication abilities and the necessity for more intensive and specialized intervention strategies.

Key Findings on Communication Breakdown and Its Impact on Communication

Aspect	Key Findings
Overall Impact on Daily Life	Significant disruption due to communication breakdown
Personal Life Conversations	Most affected area; high impact on personal interactions
Caregiver-Speaker Perspective	Difficulties with long and complex sentences
Environmental Factors	Most breakdowns when interacting with unknown people
Caregiver-Listener Perspective	Main factors: clarity and slurred speech
Broca's vs. Transcortical Motor Aphasia	More breakdowns with Broca's aphasia

Table 1: Highlighting the key factors related to breakdown

DISCUSSION

The study findings highlight the significant disruption due to communication breakdowns on the daily lives of individuals

with aphasia. Communication breakdown in aphasia has a strong impact, extending beyond the individual's quality of life to also affect their communication partners, who

often experience significant emotional and psychological distress. In the existing literature, a study-specific questionnaire about self-reported changes in the everyday life and health of significant others (SOs) of people with aphasia was administered to 173 significant others of people with aphasia (PWAs) living in Sweden, yielding a response rate of 67.8%. The perceived severity of the PWA's physical, cognitive, and language impairments had a profound influence on the SOs' daily lives [8].

Our study found that communication breakdowns significantly disrupt the daily lives of individuals with aphasia. This finding aligns with previous research, which has demonstrated ongoing difficulties even six months post-stroke in activities of daily living (ADL) and communication for many stroke survivors. The persistence of these limitations underscores the critical need for continued rehabilitation and support services well beyond the acute phase of stroke recovery. Participation limitations were stark, with 79% of individuals scoring ≤ 30 on the Frenchay Activities Index (FAI), indicating restricted engagement in extended ADL. Quality of life was notably compromised, with 54% of individuals scoring ≤ 4 on the Stroke and Aphasia Quality of Life Scale-39g (SAQOL-39g) [9]. Personal life conversations were identified as the most affected area, highlighting the high impact on personal interactions. Aphasia severely impacts personal relationships and the ability to engage in meaningful conversations. Our results further emphasize the need for targeted interventions aimed at improving conversational skills in personal settings.

From the caregiver-listener perspective, clarity and slurred speech were the main factors leading to communication breakdown, hindering caregivers' ability to understand and respond appropriately, exacerbating communication difficulties. Lexical breakdown occurred when the individual struggled to retrieve specific words or used a word with a similar meaning instead of the targeted word,

disrupting the flow of communication. Breakdowns were also seen when the participants mispronounced words, leading to corrective feedback from the caregiver. This was observed more in persons with non-fluent aphasia considered for the study [5]. Communication breakdowns often occur when individuals with aphasia interact with unfamiliar people. Caregivers frequently observe these breakdowns, which can be attributed to the stranger's lack of understanding of the individual's unique communication style, preferences, and needs. Additionally, misinterpretation of nonverbal cues and speech patterns can lead to misunderstandings. The individual's increased anxiety during these interactions can further hinder effective communication, causing them to become less clear or more hesitant. Moreover, differences in communication expectations between the individual and the stranger can also contribute to these challenges, ultimately leading to communication breakdowns.

Communication partners of individuals with Broca's aphasia experienced more frequent communication breakdowns compared to those with transcortical motor aphasia. The communication between caregivers and individuals with aphasia varies even within similar types of aphasia. For instance, although both Broca's and transcortical motor aphasia are non-fluent types, the communication challenges faced by caregivers differ. Additionally, there are no existing studies in the literature that compare these specific communication challenges between Broca's aphasia and transcortical motor aphasia.

CONCLUSION

Traditional research has focused on linguistic deficits in people with aphasia (PWA), but recent studies emphasize broader effects like frustration, anxiety, and reduced self-confidence. Addressing these requires therapeutic approaches considering emotional and social aspects. Educating and training communication partners (CPs) and caregivers is crucial, as they manage

communication breakdowns. Tailored interventions based on individual and cultural needs can improve outcomes for PWA.

This study aims to improve the lives of PWA and caregivers, addressing a critical gap in the literature. In the Indian context, it provides culturally specific data for effective interventions. Results showed that communication breakdowns significantly impact daily activities, causing frustration and isolation. Caregivers struggled with long sentences, particularly with unfamiliar people. Issues included clarity, slurred speech, lexical breakdowns, and mispronunciations, especially in non-fluent aphasia. Environmental factors like misinterpretations by strangers also contributed. Caregivers of patients with Broca's aphasia faced more frequent breakdowns, highlighting the need for specialized interventions.

Understanding communication breakdowns in aphasia is vital for comprehensive support. Addressing linguistic, emotional, social, and cognitive challenges can lead to better interventions and support systems, improving the quality of life for PWA. This study offers valuable insights and paves the way for tailored, culturally appropriate interventions. To facilitate social approach, recovery, and treatment, and to improve the quality of life for both caregivers and patients, addressing these comprehensive challenges is essential.

Declaration by Authors

Acknowledgement: None

Source of Funding: None

Conflict of Interest: The authors declare no conflict of interest.

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How to cite this article: Ayana Das R, Samritha Sanjay, Serene Sarah Shyju, Akshay P Vibin, Abhishekh B P. Communication breakdown in patients with aphasia - a bird view of Indian context. *Int J Health Sci Res*. 2024; 14(8):330-336. DOI: [10.52403/ijhsr.20240838](https://doi.org/10.52403/ijhsr.20240838)
