

Experiences of having lived with Broca's aphasia: a scoping review

Ana Frade¹

 orcid.org/0000-0002-0590-4290

Vanda Pinto²

 orcid.org/0000-0001-7047-1498

Luisa D'Espiney³

 orcid.org/0000-0002-9018-0134

¹PhD Student in Nursing, University of Lisbon, Nursing School of Lisbon (ESEL), Nursing Research, Innovation and Development Centre of Lisbon (CIDNUR)

²PhD, Nursing School of Lisbon (ESEL), Nursing Research, Innovation and Development Centre of Lisbon (CIDNUR).

³PhD, Nursing School of Lisbon (ESEL).

Abstract

Introduction

Broca's aphasia, a non-fluent aphasia, is a frustrating condition with extensive psychological, familial, and social impact. The reports of people who have already recovered or can express themselves are essential to increasing knowledge about the experience of living with Broca's aphasia. A-FROM is a framework designed to organize thinking about the impact of living with aphasia and includes four key domains: *Communication and language environment*; *Language and related impairments*; *Personal identity, attitudes and feelings*, and *Participation in life situations*. Nursing intervention is central to optimizing recovery and positively influencing the experience of successfully living with this clinical condition.

Objective

To map scientific evidence about the experience of people who lived through a period of Broca's aphasia.

Methods

A Scoping Review was performed following the Joanna Briggs Institute methodology. The review was based on the research question, "*How does the person report the experience of having lived through a period of Broca's aphasia?*", formulated according to the PCC strategy. The search was carried out in MEDLINE®, CINAHL®, *Psychology and Behavioral Sciences Collection*, and *Scopus* electronic databases in November 2022. Articles were selected based on the eligibility criteria. The review followed the PRISMA-ScR EQUATOR checklist.

Results

Seventeen articles published between 1961 and 2022 were included. Data obtained were grouped according to the key domains of the A-FROM tool. Information related to *Personal identity, attitudes and feelings*, and *Participation in life situations* were the most cited, followed by *Language and related impairments* and *Communication and language environment*.

Conclusion

It was identified that health professionals, therapeutic interventions, spirituality, hope, context, interactions, and psychosocial factors influence the experience of Broca's aphasia. It is essential to continue investigating how people report the experience of having lived through a period of Broca's aphasia to improve the quality of care and people's quality of life.

Keywords

Aphasia, Broca; Communication; Language Disorders; Life Change Events; Nursing; Review Literature as Topic.

Corresponding author

Ana Inês de Almeida Frade

E-mail: ana.ines.frade@esel.pt

Received: 14.11.22

Accepted: 02.02.23

How to cite this article: Frade A, Pinto V, D'Espiney L. Experiences of having lived with Broca's aphasia: a scoping review. *Pensar Enf* [Internet]. 2023 Mar; 27(1):16-29. Available from:

<https://doi.org/10.56732/pensarenf.v27i1.213>



Introduction

Aphasia, an acquired language disorder, can affect a person's ability to understand or formulate language¹. Stroke is the most common cause². Broca's aphasia is an expressive aphasia, a non-fluent aphasia, and currently, it is accepted that two main variants exist³. In one true Broca's aphasia, extensive damage involves the Broca's area, the surrounding frontal fields, the underlying white matter and basal ganglia⁴. In Broca's aphasia, a drastic loss of speech fluency occurs⁴. The ability to name and repeat is disturbed but listening comprehension is usually normal for colloquial language³. One of the most substantial changes is a loss of the ability to introduce some rules into the form of speech. The logic of sequencing the constituent elements may be correct and yet there are no linking particles or verb conjugations³. These changes create a communication impairment and impact the quality of life and well-being⁵. Broca's aphasia is a frustrating condition with extensive psychological, familial, and social impact, where the person is often aware of their communication difficulties^{2,5}. Because of each person's individuality, context, and injury etiology, Broca's aphasia is a unique and idiosyncratic experience⁶.

Living with aphasia: a framework for Outcome Measurement (A-FROM) is a structure designed to understand, guide, and organize thinking related to the impact of living with aphasia⁷. It was adapted from the World Health Organization International Classification of Functioning, Disability, and Health (ICF) and incorporated concepts from other models, such as the Canadian Disability Creation Process model⁸. It is a broad, non-prescriptive approach to outcome measurement that considers the impact of aphasia in important areas of life for the people with aphasia and their families. It is designed to help healthcare professionals and researchers think about the aphasia results, addressing several factors that affect the success of living with aphasia⁷. The A-FROM structure encompasses four key domains, which are dynamic, overlap, and interact with each other: *Communication and language environment* (any element outside the person who facilitates or acts as a barrier to communication, including individual/social attitudes, partner attributes or physical factors); *Language and related impairments*; *Personal identity, attitudes and feelings*, and *Participation in life situations* (involvement in relationships, functions, and daily activities)⁹.

Because of impaired communication, people with aphasia often face barriers in accessing health information¹⁰. Their capacity to transmit symptoms, question, request care, and express feelings, needs, wills, and decisions concerning their healthcare is compromised¹⁰. In nursing, understanding and being understood while communicating is crucial to quality of care and to meet the patient's care needs¹¹. Nursing interventions are central to promoting effective and therapeutic communication, optimizing recovery, and positively influencing the experience of successfully living with this clinical condition¹².

People experiencing Broca's aphasia cannot communicate changes at that moment. Due to this, reports of people who have recovered from aphasia or can express themselves are

vital to understanding Broca's aphasia experience¹³. Narrating the "internal world" is a vital source of information for understanding the experience of living without language¹³. Experience is what happens to us, what touches us, and when it reaches us, it shapes and transforms us¹⁴. In this context, knowledge of experience is about the meaning of what happened¹⁴, how the person interprets, understands and explains this experience, which presupposes an individual reflection¹⁵. Illness experiences are full of meanings¹⁶, which can only be understood through the meaning attributed by those who experienced them. Understanding the individual experience of the person who went through a period of Broca's aphasia from a retrospective perspective and not from an immediate lived experience, increases the comprehension of the phenomenon and reveals subjective truths. The experience is always subjective, individual and unique, including Broca's aphasia experience.

In a preliminary search, it wasn't found any literature review about the experience of having lived through a period of Broca's aphasia from the perspective of people who have experienced this clinical condition. Thus, the high prevalence of strokes, as the main cause of aphasia² and the impact of this language disorder on the person's life justified the need to develop this Scoping Review. Besides mapping and reporting the existing evidence, this review will clarify key concepts and identify gaps in the knowledge regarding the experience of having lived with Broca's aphasia¹⁷. It's crucial to decrease the gap between the people's perspective who have experienced this phenomenon and the external perspectives on aphasia¹⁸.

Aims

The main aim of this Scoping Review is to map the available scientific evidence about the experience of adults who lived a Broca's aphasia period according to their perspective, regardless of etiology. More specifically, the purpose of this review is to identify what people report about their Broca's aphasia experience, the impact and changes, the feelings and needs that emerged, factors that influenced the experience, which supports and resources they had and which they would have like to have had, always from the individual's perspective.

Exploring the experiences of people with aphasia can improve the quality of care¹⁹. Thus, the understanding gained in this review and the transferring this knowledge into practice can improve the health care provided to individuals with Broca's aphasia, including the quality of nursing care, by implementing more efficient nursing interventions addressing this population's needs. This knowledge can also be important for people with other language disorders and may contribute to improving health outcomes.

Methods

A Scoping Review was developed following the Joanna Briggs Institute methodology as a guide for transparent

research that allows understanding and replicating the entire path²⁰. The review was based on the research question: "How is reported by the person the experience of having lived a Broca's aphasia period?". It was formulated according to the PCC strategy: P=Population (adults who experienced Broca's aphasia); C=Concept (report of Broca's aphasia experience); C=Context (ambulatory and hospital). This study adheres to the PRISMA-ScR EQUATOR checklist (Supplementary File 1).

Eligibility criteria

Study inclusion criteria:

- Population: adults aged 19 years or over (according to the adult's definition of World Health Organization²¹) with no maximum age limit, who have lived a Broca's aphasia period (or expressive aphasia or a non-fluent aphasia), or that are still in recovery but are able to express themselves.
- Concept: Broca's aphasia experience from the participants' perspective regardless of Broca's aphasia etiology. What people report (e.g., direct quote, interview data) about Broca's aphasia experience, the impact, changes, feelings, specific needs, strategies and resources used, factors that influenced the experience, and which supports and resources they would like to have had.
- Context: ambulatory and hospital context.
- Primary studies, theoretical articles, literature reviews, and reports of experiences in English, Spanish and Portuguese, regardless of the year of publication, published in periodical journals, with access to the full text.

Study exclusion criteria:

- Population: children; participants who are diagnosed only with other types of aphasia; participants who have

chronic aphasia (chronic aphasia was defined as coexisting at least one year after the injury that caused it²²); participants who cannot express themselves; participants who have impaired communication resulting from sensory loss, dementia, delirium, or coma; participants who are diagnosed only with motor speech disorders resulting from muscle weakness or incoordination.

- Concept: experiences only from the perspective of caregivers, couples, friends, and healthcare professionals.

Sources of information and search strategy

The research was carried out in November 2022. A strategy that encompasses three stages was adopted²⁰. The first step included a search in the MEDLINE® (Medical Literature Analysis and Retrieval System Online Complete) and CINAHL® (Cumulative Index to Nursing and Allied Health Literature Complete) databases, using terms in natural language. Subsequently, the titles and abstracts' words were analyzed, as well as the indexed words used to describe the article, which allowed us to identify relevant search terms for this Scoping Review. In the second stage, a search was performed in the MEDLINE®; CINAHL®; Psychology and Behavioral Sciences Collection (via EBSCO) and in the Scopus database using search terms in natural language and DeCS and MeSH indexing terms in all fields of the articles without selecting a specific field, applying boolean operators "OR" and "AND", as explained in Table 1. The third phase of the research comprised the analysis of the references lists of the articles selected for this review to find important complementary studies to answer the research question.

CINAHL	MEDLINE	PSYCHOLOGY AND BEHAVIORAL SCIENCES COLLECTION	SCOPUS
(Narrati* OR (MH "Narratives") OR (MH "Narrative Medicine") OR (MH "Life Histories") OR (MH "Reports"))	(Narrati* OR (MH "Narration") OR (MH "Narrative Medicine") OR Life Histories OR Report*)	(Narrati* OR Life Histories OR Report*)	(Narrati* OR Life Histories OR Report*)
AND	AND	AND	AND
((Experience* OR (MH "Life Experiences") OR (MH "Life Change Events") OR (MH "Psychosocial Aspects of Illness") OR Psychosocial adjustment)	((Experience* OR Life Experience* OR (MH "Life Change Events") OR Psychosocial Aspects of Illness OR Psychosocial adjustment)	((Experience* OR Life experience* OR Life Change Events OR Psychosocial Aspects of Illness OR Psychosocial adjustment)	((Experience* OR Life experience* OR Life Change Events OR Psychosocial Aspects of Illness OR Psychosocial adjustment)
AND	AND	AND	AND
(Aphasi* OR (MH "Aphasia, Broca") OR (MH "Speech Disorders") OR Communicat* Disorders OR Communicat* Difficulties))	(Aphasi* OR (MH "Aphasia, Broca") OR (MH "Speech Disorders") OR Communicat* Disorders OR Communicat* Difficulties))	(Aphasi* OR Broca Aphasia OR Speech Disorders OR Communicat* Disorders OR Communicat* Difficulties))	(Aphasi* OR Broca Aphasia OR Speech Disorders OR Communicat* Disorders OR Communicat* Difficulties))

Table 1 – Search terms used in databases

Selection of sources of evidence

Following the search in databases, the articles identified were uploaded into the electronic tool Rayyan® to organize the results and remove duplicates. The selection of the studies was carried out according to the inclusion and exclusion eligibility criteria. It started with reading the titles and abstracts, followed by reading the full text of the studies identified for eligibility. Studies that did not meet the inclusion criteria were excluded. Two reviewers performed the selection of sources of evidence. The consensus of the independent reviewers resolved discrepancies in the inclusion or exclusion of articles.

Data collection and synthesis of results

To extract relevant information from the studies included in the review, an instrument (table) was built in Microsoft Excel®, based on Joanna Briggs Institute guidelines²⁰. This table includes information about the author(s), year of publication, country, aims, participants, methodology, aphasia etiology, concept (Broca's aphasia experience), and context.

Results

Selection of sources of evidence

A total of 1012 articles were obtained from the search in CINAHL®, MEDLINE®, Psychology and Behavioral Sciences Collection, and Scopus databases.

After removing duplicates, 961 articles were obtained. The selection of the studies was carried out according to the inclusion and exclusion criteria. After reading the title and abstract, 905 articles were excluded because they weren't related to the theme and didn't meet the inclusion criteria. 56 articles were sought for retrieval, but 2 could not be retrieved. 54 articles were assessed for eligibility. After analysis, 44 articles were excluded: 15 because the participants were people with chronic aphasia; 23 for not addressing the aphasia experience according to the participant's perspective; 2 because the focus was not the phenomenon under study, and 4 because they only address other types of aphasia. Of these articles, 10 were included in the review. From the analysis of the included studies' references 7 more articles were added, totaling 17 papers at the end. The PRISMA 2020 flow chart²⁰ (Figure 1) shows the study selection process.

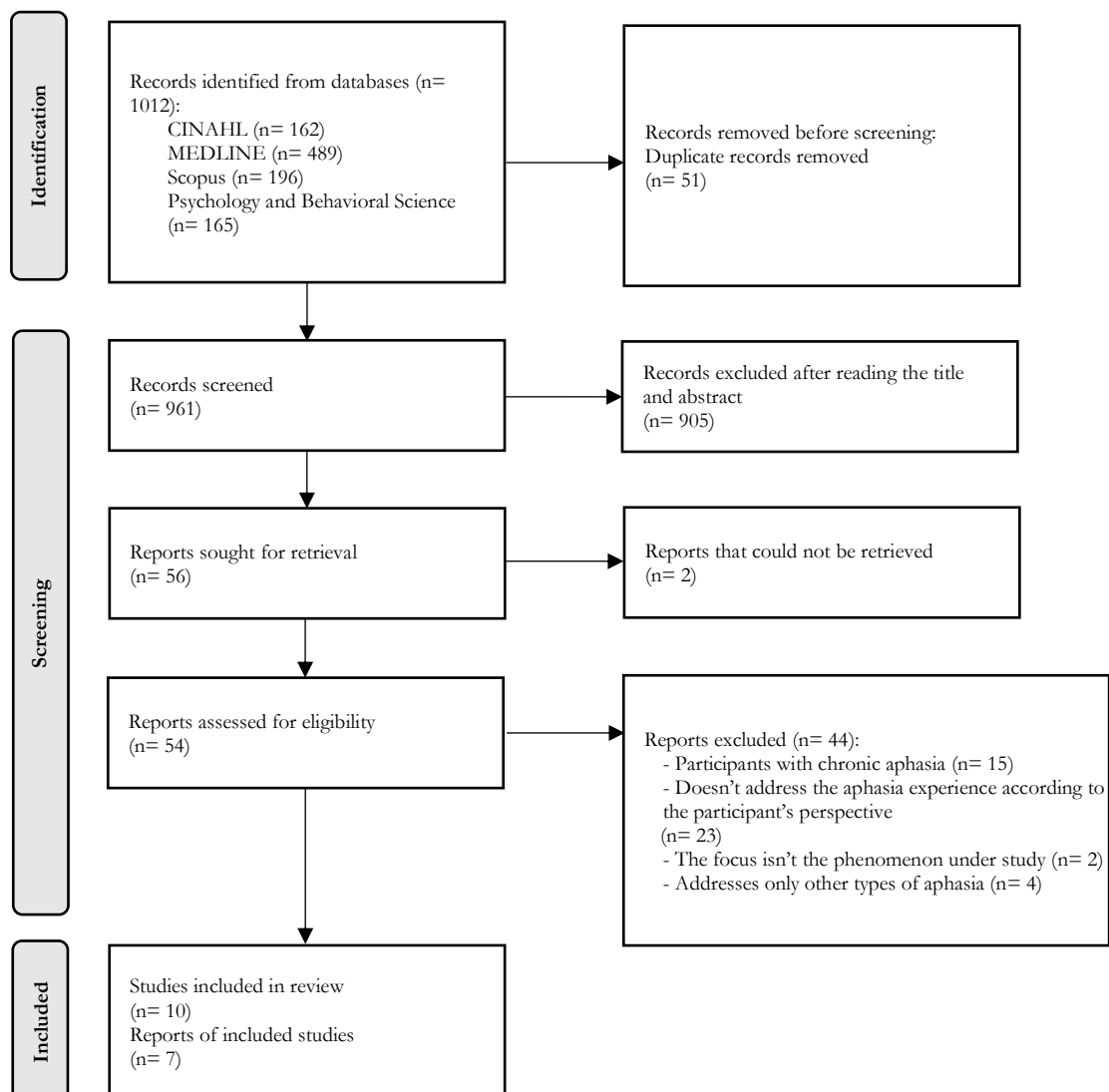


Figure 1 - PRISMA 2020 flow chart¹⁵

Characteristics of included studies

Seventeen articles published between 1961 and 2022 were identified. Seven studies were developed in Australia^{23,24,29,30,31,37,38}, five in United States of America^{26,32,33,34,35}, two in United Kingdom^{27,36}, one in Netherlands²⁸, one in New Zealand²⁵, and one in Argentina¹³. The methodology used in the selected articles varied from primary qualitative studies^{23,24,25,26,27,28,30,31,33,34,36,37,38}, experience reports^{29,32}, and theoretical articles that contain a first-person experience report^{13,35}. The aphasia etiology in the analyzed articles was, in its great majority, the stroke.

It is essential to state the difficulty in finding studies only with people diagnosed with Broca's aphasia. The justification probably is because, in most situations, the biggest problem occurs in expression, but often this is not unique, rigorous, specific and doesn't occur in isolation. In the search carried out, it wasn't found any article exclusively about the experience of Broca's aphasia with participants that only experienced Broca's aphasia and without other

associated language disorders. One article reports the experience of Broca's aphasia and speech apraxia³⁵. Still, all the selected articles for this review include participants diagnosed with Broca's aphasia, or expressive aphasia or non-fluent aphasia.

Only one study explicitly and specifically reports the impact of writing impairment in Broca's aphasia experience³⁶. All the other articles included in this review address mainly or only language disorders regarding oral communication.

Synthesis of results

The analysis of the selected studies allowed us to answer the research question. The results extracted from this Scoping Review varied between the impact of Broca's aphasia, which affects a person's different dimensions, inhibitory factors, and facilitating factors of living successfully with this clinical condition. The following Table 2 enables visualizing the results extracted from the analyzed articles and framing them with the review's question and objectives.

Table 2 – Results extraction

Author(s)/ year/ country	Aims	Methodology	Population	Concept: Broca's aphasia experience	Context
S1 - Ardila A and Rubio-Bruno S ¹³ 2017 Argentina	To analyze how people with aphasia experience the world and what they report about the experience of living without language	Theoretical article (contains a first-person experience report)	Adults with aphasia, including adults with Broca's aphasia	<ul style="list-style-type: none"> - People with aphasia live in an idiosyncratic cognitive world. The internal cognitive world is altered due to the lack of language. Cognitive strategies need to be reorganized ("I had to reinvent the world around me because this universe was only in words"); (verbal) intelligence is compromised; - In aphasia, only external stimuli are available. A particular dimension of the world is lost (language) and only the visual-perceptual information remains ("And suddenly the words disappeared"); - Nonverbal skills are sometimes affected in aphasia; - "It was no longer important to discover the beauty since it cannot be expressed in words". 	Not specified
S2 - Armstrong E et al. ²³ 2012 Australia	To present stories of living with aphasia	Qualitative	Two people with expressive aphasia who can already express themselves, and one person who had aphasia (not specified) but recovered quickly	<ul style="list-style-type: none"> - During hospitalization, it was important to meet people for not to feel isolated or the only one with a problem; - Frustration due to difficulties and failures, and with some therapeutic activities (difficulty or not being able to perform simple tasks); - Emphasis on using humor to help; - Importance of independence to direct their own communication recovery; - Reading the newspaper every day to help to recover language; - Talking with animals at home to practice speaking; - Feeling that could help himself more effectively than speech therapists; - It was important to feel connected to family and friends and talk to them. 	Ambulatory

<p>S3 - Baker C et al.²⁴</p> <p>2020</p> <p>Australia</p>	<p>To describe, from the perspective of people with aphasia, the experience of mood changes, depression, and current practice; to describe preferences within a stepped psychological care approach</p>	<p>Qualitative</p>	<p>Ten adults with aphasia, including adults with expressive aphasia</p>	<ul style="list-style-type: none"> - All participants experienced mood changes but didn't experience gradual psychological care in rehabilitation; - The onset is traumatic, with negative changes in mood and depression, with negative emotional, social, and behavioural consequences (social evasion, persistent low mood, sadness, and withdrawal from rehabilitation); - People try to overcome communication and mood difficulties with limited psychological support and rehabilitation services (low mood and depression are rarely addressed, and people aren't always supported to be independent or make decisions on rehabilitation with an impact on mood); - Positivity, supporting communication, and access to individualized therapeutic interventions would be essential through gradual psychological care to improve rehabilitation results. 	<p>Ambulatory and hospital context</p>
<p>S4 - Bright F et al.²⁵</p> <p>2013</p> <p>New Zealand</p>	<p>To explore how hope was experienced by people with aphasia and identify factors that influence it</p>	<p>Qualitative: interpretative description</p>	<p>Five people with aphasia: one with Broca's aphasia, three with anomic aphasia, and one with conduction aphasia</p>	<ul style="list-style-type: none"> - Hope is fluid, changes frequently and in a short period, and is important; - It seems to be related to how people get involved in rehabilitation and can be influenced; - Factors that influence hope: family, friends, health professionals (either supporting or reducing) and other patients; uncertainty about the future; see hope with a double face (positive and negative aspect) and a sense of disruption (in identity and/or involvement in meaningful activities). 	<p>Ambulatory</p>
<p>S5 - Carcello K and Susan M²⁶</p> <p>2020</p> <p>United States of America</p>	<p>To gain a greater understanding of the therapeutic use of blogs for stroke survivors with aphasia, from a psycho-socio-emotional perspective</p>	<p>Inductive qualitative content analysis</p>	<p>Five stroke survivors with aphasia: two with Broca's aphasia and three with an unknown type of aphasia</p>	<p>Participants used blogs to explore what living with aphasia was like:</p> <ul style="list-style-type: none"> - Difficulty in communicating, writing, and interacting with others by expressing their emotional responses and personal experiences; - Loss of words: "<i>I'm constantly trying to find the word I need.</i>"; the devastation of aphasia and emotional impact: "<i>the speech I used to rely on for a living was gone ...It hurts having to search for words.</i>" - Process of writing: "<i>sometimes I can't remember the word I want. Sometimes I leave out several words. My spelling is awful. But the thing that pains me most is the grammar ... this writing thing is hard</i>"; - Aphasia affects self-expression and often-times self-concept and identity: "<i>Before, I could talk intelligently and think straight. After this, I'm virtually mute (...)</i>" 	<p>Not specified</p>
<p>S6 - Clancy L et al.²⁷</p> <p>2018</p> <p>United Kingdom</p>	<p>To explore the experience of stroke survivors with aphasia, caregivers and healthcare professionals</p>	<p>Qualitative</p>	<p>Six stroke survivors with aphasia (including adults with expressive aphasia), ten caregivers and six health professionals</p>	<ul style="list-style-type: none"> - Aphasia has an emotional impact; - "Interactions" and "context" can help or hinder the process of making sense, the emotional burden and the involvement in rehabilitation; - Three broad themes were identified: "<i>being in a foreign country</i>", "<i>finding a voice</i>", and "<i>being just a number</i>". 	<p>Ambulatory and hospital context</p>
<p>S7 - Dalemans RJ et al.²⁸</p> <p>2010</p> <p>Netherlands</p>	<p>To explore how people with aphasia, perceive their participation in society and investigate the factors that influence it, focusing on individual experiences and perspectives</p>	<p>Qualitative</p>	<p>Thirteen adults with aphasia (including adults with expressive aphasia) and twelve caregivers</p>	<ul style="list-style-type: none"> - The involvement and feeling of belonging in social activities (the quality of the activities is more important than the quantity); - People with aphasia feel isolated, but want to feel involved; - Feeling of being a burden to others, wanting to function normally; - Inability to work often, wishing to contribute in other ways; - Feeling stigmatized, wishing to be respected; - Factors that influence involvement in social participation: <ul style="list-style-type: none"> • Personal factors: motivation, physical and psychological condition, and communication skills; • Social factors: the role of the central caregiver and the characteristics of the communication partner (s), namely will, skills and knowledge; • Environmental factors: home peace and familiarity. 	<p>Ambulatory</p>
<p>S8 - Green C and Waks L²⁹</p> <p>2008</p> <p>Australia</p>	<p>Share the language recovery (expression ability) of a person with aphasia</p>	<p>Experience report</p>	<p>Adult with expressive aphasia who has greatly recovered</p>	<ul style="list-style-type: none"> - "<i>I had no words to express myself</i>"; "<i>In the hospital, they do not deal well with aphasia or language problems. If a person cannot communicate, the whole system collapses</i>"; "<i>I had to rebuild my life</i>"; "<i>Progress has been very slow</i>"; "<i>I found that even the simplest things were difficult</i>"; "<i>Contacting with a person who went through a similar situation in rehab gave me a glimpse of hope</i>"; - When he got home, he didn't want to go in and felt like he didn't belong there anymore, like a stranger in his own home. Although he was loved, life changed; 	<p>Ambulatory</p>

				- "Four months later, I only had a handful of words"; "I felt that I had lost the most important thing in my life. I didn't see the future"; "I wish I wasn't alive"; Nine months after the stroke he had to resign his position; "I was recovering the language over time, but I couldn't see it"; "I felt that the language was stuck"; "I learned to enjoy life again"; "Recovery is extremely difficult and people feel that they lost something and lament; "We lost our dreams, hope, and planned future"; "We lost our confidence".	
S9 - Grohn B et al.³⁰ 2012 Australia	To describe the experience of the first three months post-stroke; to identify factors that facilitate the success of living with aphasia	Qualitative: a prospective longitudinal study	Fifteen people with aphasia, including adults with expressive aphasia	- Factors that facilitate the success of living with aphasia: <ul style="list-style-type: none"> • Be involved in recovery, be independent, feel to be in control of life and have a purpose in life; • Carry out activities to improve communication: reading, sudoku, Scrabble, writing a shopping list, using the computer and the phone, homework prescribed by therapists; • Social support and involvement of family and friends (including using communication strategies) to help restore confidence and feel competent; • Meet people in the hospital and group therapy (source of support, courage, and motivation); • Importance of rehabilitation, speech therapy, and health professionals (important in the recovery of language, for social interactions, source of information, motivation, courage, and confidence); • Adaptation (using strategies to improve communication); • Have a positive outlook (optimism, hope, determination, and gratitude); - Inability to participate in activities that define the role and previous identity leads to anguish about the future and has and impacts identity/self.	Ambulatory and hospital context
S10 - Grohn B et al.³¹ 2014 Australia	To describe the insider's perspective of what is important to living successfully with aphasia and the changes in the first year	Qualitative: longitudinal prospective study	Fifteen people with aphasia, including adults with expressive aphasia	- The perception of communication improvements; - Moving forward actively through positive actions and involvement in meaningful activities; - Social support, family, and friends; - Maintaining positivity about the future.	Ambulatory
S11 - Hall WA³² 1961 United States of America	Not mentioned	Experience report	An adult who has experienced expressive aphasia	- Inability to communicate feelings; - Not accepting the inability to speak; - Feelings of pity and pity of the family and others; - Feeling of self-rejection and worthlessness received with comforting words instead of rejection; - Visits invaded the private world; - Anxiety; - Speaking and writing were incompatible with simultaneous thought processes; - The speech was inappropriate for competition and success in the job market; - Importance of speech therapy and psychotherapy in speech rehabilitation.	Hospital context
S12 - Holland AL et al.³³ 2010 United States of America	To provide ideas on topics/content for treatment that are meaningful to people with aphasia	Qualitative	Thirty-three adults with aphasia (twenty-nine with non-fluent aphasia)	- Talk about their life experiences, reconnect with families and focus on communicating on the following topics: <ul style="list-style-type: none"> • Life's history; • Prayers, testimonies, speeches, and palestras; • External interests; • Making plans; • Talking to family and other people and talking about work; • Search or provide information (about strangers, about the family; asking and answering questions); • Making an order at a restaurant; • Telephone. 	Not specified

S13 - Laures-Gore JS et al.³⁴ 2018 United States of America	To explore the spiritual experience of adults with aphasia, to understand the role of spirituality in recovery	Qualitative	Thirteen adults with aphasia, including adults with expressive aphasia	<ul style="list-style-type: none"> - Spirituality can contribute to the recovery, understanding, and acceptance of life changes (coping strategy): as a greater power in controlling events and as an auxiliary; - Other people are essential for aphasia recovery (social relationships imbued with spiritual meaning), which offer a better quality of life, the opportunity to practice language, and motivation for communication, that are important in the search for meaning; - Other forms of spiritual coping can amplify negative reactions to stress and cause people to engage in inappropriate behavior. 	Not specified
S14 - Simmons-Mackie N and Kagan A³⁵ 2007 United States of America	To describe aphasia using the World Health Organization ICF; address the impact of contextual factors on the aphasia experience and participation in life activities	Theoretical article (contains a first-person experience report)	An adult reporting their experience of Broca's aphasia and apraxia of speech	<ul style="list-style-type: none"> - Experience of severe activity limitations and participation restrictions; - Protection of the family, removing responsibilities, and avoiding activities create barriers to participation in life situations. - Feelings of incompetence and dependence (levels of confidence, optimism, and personal identity are influenced by the social environment and performance. When confidence and self-esteem decrease, personal barriers to participation are created). - Therapy focused on (1) improving expressive speech and language, (2) obtaining the necessary communicative skills to perform household chores (3) learning compensatory strategies to engage in interactions, (4) returning to activities (5) reducing barriers to participation (training of the partners to help eliminate attitudinal barriers and group therapy to develop conversational skills and confidence). 	Not specified
S15 - Thiel L and Conroy P³⁶ 2022 United Kingdom	To explore the experiences of people with aphasia living with language-related writing difficulties and the impact on their lives	Qualitative	Eight people with post-stroke aphasia and writing difficulties (including adults with Broca's aphasia)	<ul style="list-style-type: none"> - Participation in society, self-esteem and confidence was impacted by writing difficulties. 	Ambulatory
S16 - Worrall L et al.³⁷ 2011 Australia	Understand what people with aphasia want from services; to describe the goals of people with aphasia; code objectives according to the ICF	Qualitative: Descriptive	Fifty adults with post-stroke aphasia, including adults with expressive aphasia	<ul style="list-style-type: none"> - Desire to return to the previous life, communicate basic needs and opinions (feelings of frustration, hopelessness, isolation, and depression); - Aphasia was a higher priority than physical disabilities; - The need for communication rehabilitation to be connected to real life and to foster trust; - Desire for information about aphasia (impaired communication made it difficult to obtain adequate information), available services, prognosis, therapy and rehabilitation stages (having information allowed to take control and participate in decisions about therapy and rehabilitation); - Wanting more speech therapy, greater autonomy, dignity and respect; - Importance of involvement in social, leisure, and work activities, as well as the recovery of physical health; - Wanting to help others; - The goals are mostly linked to Activities and Participation, Environmental Factors, Body Functions, and Structures, and Personal Factors. 	Ambulatory
S17 - Worrall LE et al.³⁸ 2017 Australia	To determine factors that contribute to living well with aphasia in the first twelve months after a stroke	Qualitative: prospective longitudinal cohort study	Fifty-eight adults with aphasia, including adults with expressive aphasia	<ul style="list-style-type: none"> - Higher family income, greater social network size, being female, and having milder aphasia were positively associated; - Graduate or postgraduate educational levels, low mood, and poor physical functioning were negatively associated with participation; - Psychosocial aspects were the most significant predictors; - Professionals can help spouses communicate effectively with the person with aphasia, help to return to work by ensuring that the person with aphasia is safe and well cared for, and ensure that they have access to information. 	Ambulatory and hospital context

Legend: S – Study

These results were grouped according to the A-FROM structure dimensions⁹ and are presented in Table 3, for easier data visualization and interpretation. In the *Communication and language environment* field, all elements external to the person that positively and negatively affect

communication and language were included, such as other people's services and attitudes. The *Language and related impairments* domain include changes in the language and communication process and facilitating and inhibiting factors that influence the recovery. The *Personal identity, attitudes and feelings* dimension comprises information related to how the patients see themselves, how they see aphasia

and face the future, feelings, and attitudes, as well as facilitating and inhibiting factors. The *Participation in life situations* area includes data about relationships, roles, responsibilities, participation in activities, and facilitating and inhibiting conditions⁹. Data associated with personal identity, attitudes, and feelings, and participation in life

situations, were most often mentioned in this literature review, followed by the language and related impairments and the communication and language environment, respectively.

Table 3 – Results presentation (adapted from A-FROM)⁷

BROCA'S APHASIA EXPERIENCE	
COMMUNICATION AND LANGUAGE ENVIRONMENT	<p>Facilitating factors - Support and communication strategies; individualized therapeutic interventions; interactions and context; family and caregivers; speech therapy and health professionals; "<i>Finding a voice</i>" (the voice of a loved one); social support^{S3,S6,S9}.</p> <p>Inhibitory factors - Limited rehabilitation services; hospital environment (noisy, fast-paced, constantly changing, not conducive to effective communication; inconsistent use of communication strategies); interactions and the context; difficulty in the hospital to deal with people with aphasia^{S3,S6,S8}.</p>
LANGUAGE AND RELATED IMPAIRMENTS	<p>Experience - Difficulty or inability in communicating through words (including expressing feelings and personal experiences); difficulty in writing; the internal cognitive world is altered; non-verbal skills can be affected; only external stimuli and visual-perceptual information remained, which acquire particular importance; (verbal) intelligence is compromised; "<i>Had the language stuck?</i>"; need to use strategies to improve communication; speech and hand were incompatible with simultaneous thought processes; blocks or hinders access to information and services^{S1,S5,S8,S9,S11,S16}.</p> <p>Facilitating factors - Read the newspaper every day; talk to the animals; independence to direct recovery; Feeling of being able to help yourself; positivity; individualized therapeutic interventions; hope; communication strategies; reading, sudoku, Scrabble, writing a shopping list, using the computer, phone, homework prescribed by therapists; rehabilitation, speech therapy, and health professionals; spirituality^{S2,S3,S4,S9,S11,S13}.</p> <p>Inhibitory factors - Recovery is extremely difficult and progress is very slow^{S8}.</p>
PERSONAL IDENTITY, ATTITUDES AND FEELINGS	<p>Experience - Devastation and emotional impact; need to reinvent the world around and rebuild life, which has completely changed; changes in the world emotional interpretation; feeling of frustration due to difficulties, failures and with some of the therapeutic activities; negative mood changes and depression, with negative emotional, social and behavioral consequences (social evasion, low mood, persistent sadness and withdrawal from rehabilitation); feeling of "<i>Being in a foreign country</i>" (uncertainty, unknown, confusion) and the shock of being sick; sensation of disruption; experience of a biographical rupture with the need to make sense of this new reality; feeling that it is just a number, without being seen as a unique individual and feeling of isolation; feeling of being a burden to others; often feel stigmatized, but wish to be respected; feeling like a stranger in your own home (feeling of not belonging); feeling of having lost the most important thing and regret it; inability to envision a future; feeling of not wanting to be alive; loss of dreams, hope, the planned future and confidence; feelings of anguish about the future; impact on identity/self; not accepting the inability to speak; feelings of pity and pity from others, self-rejection and feeling of uselessness; anxiety; feelings of incompetence and dependence; decrease of confidence, optimism and self-esteem; feelings of frustration, hopelessness, isolation; desire to return to the previous life and communicate their needs and opinions^{S1,S2,S3,S5,S6,S7,S8,S9,S11,S14,S15,S16}.</p> <p>Facilitating factors - Use of humor; meeting people in the hospital, in group therapy and the relationship established with the therapists (source of support, courage, and motivation); family and friends; access to individualized therapeutic interventions through gradual psychological care; having a positive vision (optimism, hope, determination, and gratitude); hope; interactions and the context; caregivers; feeling of being heard by the team; recovery; "<i>Finding a voice</i>" (your own voice); contact with a person who has gone through a similar situation; feeling loved; perception of improvements in communication, involvement in significant activities; maintaining positivity about the future; speech therapy and psychotherapy; spirituality; higher family income, self-assessment of successfully living with aphasia and having lighter aphasia^{S2,S3,S4,S6,S8,S9,S10,S11,S13,S17}.</p> <p>Inhibitory factors - Some therapeutic activities (difficulty or inability to perform simple tasks); psychological support and limited rehabilitation services (low mood and depression are rarely addressed in rehabilitation); interactions and context; procedures are done for people instead of being done with people; the focus of health professionals were on their physical condition, contributing to the lack of attention to psychological needs and social objectives; be infantilized and depersonalized; visits that invade the private world^{S2,S3,S6,S11}.</p>
PARTICIPATION IN LIFE SITUATIONS	<p>Experience - Dependence on others; frequent inability to work; the wish to contribute to the community in other ways; need to give up employment; severe activity limitations, difficulty in performing tasks, needing more time to perform activities; participation restrictions; inability to compete and succeed in the job market; impact on society participation^{S5,S6,S7,S8,S9,S11,S14,S15}.</p> <p>Facilitating factors - Having a positive vision (optimism, hope, determination and gratitude); recovery; independence; interactions and context; "<i>Find a voice</i>"; degree of involvement, commitment and sense of belonging in social activities (the quality of activities is more important than the quantity), leisure and work; motivation, physical and psychological condition and communication skills; caregiver and the characteristics of the communication partner (s) (will, skills and knowledge); home peace and familiarity; feeling of being in charge or in control of life and having a purpose in life; talk about life experiences, reconnect with the family and focus on communicating on topics that are meaningful to them; speech therapy and compensatory communication strategies; reducing barriers to participation (partner training and counseling and group therapy); information about aphasia, available services, prognosis and rehabilitation stages; dignity and respect; higher family income, greater social network, being female and having mild aphasia^{S2,S3,S6,S7,S9,S10,S12,S14,S16,S17}.</p> <p>Inhibitory factors - People are not always supported to be independent or make decisions; interactions and context; physical functioning and fatigue; protection of the family, removing responsibilities; internal personal barriers (fear of failure, feelings of incompetence and dependence, low confidence, low self-esteem, and negativism); undergraduate or graduate schooling levels, depressed mood^{S3,S6,S9,S14,S17}.</p>

Legend: S – Study

S1 - Ardila A and Rubio-Bruno S, 2017¹³; S2 - Armstrong E et al., 2012²³; S3 - Baker C et al., 2020²⁴; S4 - Bright F et al., 2013²⁵; S5 - Carcello K and Susan M, 2020²⁶; S6 - Clancy L et al., 2018²⁷; S7 - Dalemans RJ et al., 2010²⁸; S8 - Green C and Waks L, 2008²⁹; S9 - Grohn B et al., 2012³⁰; S10 - Grohn B et al., 2014³¹; S11 - Hall WA, 1961³²; S12 - Holland AL et al., 2010³³; S13 - Laures-Gore JS et al., 2018³⁴; S14 - Simmons-Mackie N and Kagan A, 2007³⁵; S15 - Thiel L and Conroy P, 2022³⁶; S16 - Worrall L et al., 2011³⁷; S17 - Worrall LE et al., 2017³⁸

Personal identity, attitudes and feelings

The need to reinvent the world and rebuild life has emerged, as well as the negative impact of aphasia on^{S1;S2;S3;S5;S6;S7;S8;S9;S11;S14;S15;S16;}

- Emotional level: frustration, depression, feeling of isolation and stigmatization, of "Being in a foreign country", of being a burden to others, not accepting the inability to speak and not wanting to be alive, decreased confidence and self-esteem, anguish, feelings of self-rejection and worthlessness, anxiety, feelings of incompetence, decreased optimism and hopelessness;

- Social and behavioural level: social evasion and disconnection from rehabilitation;

- Identity: feeling of disruption and experience of a biographical rupture with the need to make sense of their new reality.

The facilitating factors that influence this dimension encompass^{S2;S3;S4;S6;S8;S9;S10;S11;S13;S17;}

- Internal conditions: use of humour, hope, language recovery, optimism, determination and gratitude, spirituality, and having mild aphasia;

- External conditions: interactions and context, family, friends, and caregivers, contact with a person who has gone through a similar situation, speech therapy and psychotherapy.

The inhibiting factors that emerged include therapeutic interventions: disability or difficulty in performing some therapeutic activities, limited psychological support and rehabilitation services, the procedures being done for people and not with people, health professionals focus on physical condition, which contributes to the lack of attention to psychological needs and depersonalization^{S2;S3;S6;S11;}

Participation in life situations

Information related to this dimension was the second most mentioned. The negative impact was evident in roles (dependence on others), responsibilities, and activities (inability to work, with the need to give up employment, difficulty in performing tasks, and participation restrictions)^{S5;S6;S7;S8;S9;S11;S14;S15;} One study specifically addresses the impact of writing difficulties on social participation^{S15;}

In this domain, facilitating factors include^{S2;S3;S6;S7;S9;S10;S12;S14;S16;S17;}

Internal conditions: recovery, a feeling of control, independence, involvement, commitment and sense of belonging in social activities, motivation, physical and psychological condition, having a purpose in life, learning

compensatory communication strategies, being female and having milder aphasia;

External conditions: the context, interactions, caregiver, speech therapy, clinical condition, recovery information, greater family income, and greater social network.

The inhibiting factors comprehend^{S3;S6;S9;S14;S17;}

Internal barriers: fear of failure, feelings of incompetence and dependence, low confidence, low self-esteem and optimism, graduate or postgraduate educational levels, low mood, and physical malfunction;

External elements: interactions and context, people weren't always supported to be independent or to make decisions and family protection.

Language and related impairments

It was the third most mentioned dimension. In this context, were identified: difficulty or inability to communicate through words, mostly orally but also in writing; difficulty in expressing feelings and personal experiences; changes in the internal cognitive world; non-verbal skills affected sometimes; (verbal) intelligence was compromised, and speech and hand were incompatible with simultaneous thought processes^{S1;S5;S8;S11;} This makes accessing adequate information and services complex, and the need to use other strategies to improve communication^{S1;S8;S9;S11;S16;} Only one study explicitly addresses writing difficulties and refers to their impact on social participation, self-esteem and confidence^{S15;}

As facilitating factors for aphasia recovery, the performing activities emerged (talking with the animals, reading, sudoku, scrabble, writing a shopping list, using the computer and the phone, and the homework prescribed by the therapists); the internal forces (hope, spirituality, feeling of being able to help oneself), and the external aids (rehabilitation, speech therapy, and health professionals)^{S2;S3;S4;S9;S11;S13;} As negative aspects, recovery is complicated, and progress is plodding^{S8;}

Communication and language environment

Finally, data within the scope of this domain was the least mentioned. As positive factors emerged: communication support and access to individualized therapeutic interventions; interactions and context; the family and caregivers; "find a voice" through the voice of a loved one; feeling heard by the team; social support; use of communication strategies and the role of speech therapy and health professionals^{S3;S6;S9;}

Factors that have a negative influence were identified, namely: limited rehabilitation services; the hospital environment (noisy, fast-paced, constantly changing, not

conducive to effective communication and the inconsistent use of communication strategies); the interactions and context, and the inability at the hospital to deal with the person with aphasia^{S3,S6,S9}.

Discussion

Summary of evidence

The results of this Scoping Review are aligned with the impact of aphasia on the fundamental needs described by Thompson (2014)¹. Corresponding to *personal identity, attitudes and feelings*, Thompson (2014)¹ defends that aphasia impacts identity; affection (by the difficulty in expressing emotions and affection), and people feel perceived as a physical presence rather than a person. Regarding *Participation in life situations*, Thompson (2014)¹ states that aphasia impacts freedom (it is a threat to autonomy, and people have difficulty in expressing choices and claiming rights), participation (with feelings of isolation) and subsistence (by the inability to communicate verbally). Related *Language and related impairments*, aphasia affects protection (because of the difficulty in asking for support and the inability to alert)¹.

Broca's aphasia has a tremendous negative effect, and the psychosocial impact of this clinical condition was clear. It was also clear that therapeutic interventions^{S3}, context and interactions^{S6}, health professionals^{S9,S11,S17}, hope^{S4}, spirituality^{S13}, and psychosocial factors influence the experience of Broca's aphasia.

According to Thompson and McKeever (2014)³⁹, aphasia has a negative impact on relationships by denying access to support networks, which leads to isolation. Aphasia also results in a 'loss of self', intensified by inadequate healthcare communication strategies³⁹.

Concerning the influence of therapeutic interventions and health professionals, a study developed to explore the factors influencing the satisfaction and dissatisfaction of people with aphasia regarding their health care identified seven areas of care¹⁹. Two of these areas are Manner and Methods of Service Delivery (related to the individual behaviour of health professionals, health professionals' approach to health care, a health professional's personality, the level of inclusion of the person with aphasia, understanding shown to the person, the level of involvement in decision-making, goal-setting and therapy activities) and Information, Communication and Knowledge¹⁹.

About hope, a study carried out concluded that hope could be important for people with aphasia, and the authors identified it being experienced in two ways: *Simply "having" hope* (broad feeling, but passive, which seems to be the main form of hope) and *Actively hoping* (an active and future-oriented form of hope)^{S4}. In that same study, hope seems related to how people get involved in rehabilitation and how it can influence it. The factors that influence hope were identified as: family; friends; health professionals (either supporting or reducing) and other patients; uncertainty about the future; seeing hope with a double face (positive

and negative aspect) and a sense of disruption (in identity and/or involvement in meaningful activities)^{S4}. These factors are influenced by past experiences, present reality, and perceived future^{S4}. In line with this, a study developed more recently concluded that social support, a sense of progress, and engagement in meaningful activities and interactions seem essential in supporting people (re)develop hopes for their future⁴⁰.

On the sphere of spirituality, according to a study^{S13}, it could be seen in two ways: as a higher power that is important for the understanding of oneself, for recovery, communication improvement, being in control of events, and directing recovery, which does not involve much personal activity; and/or as a relationship with a higher power as a source of help and strength, with more frequent religious and spiritual practices (seeking the Sacred for comfort, support and to understand the aphasia meaning). Other people can also be essential for aphasia recovery (social relationships imbued with spiritual meaning), which offer a better quality of life, an opportunity to practice language, motivation for communication and are essential in search of meaning^{S13}. Still, other forms of spiritual coping can be associated with severe existential suffering in this context. They can amplify adverse reactions to stress and cause people to engage in inappropriate behaviours^{S13}.

Regarding interactions and context^{S6}, it can help or hinder making sense of the experience, the emotional burden, and how the patient gets involved in rehabilitation. In a study carried out, three broad themes were identified: "*being in a foreign country*", "*finding a voice*", and "*being just a number*"^{S6}. "*Being in a foreign country*" includes uncertainty and confusion regarding the condition, the hospital, dependence on others, and the shock of being ill aggravated by the ward environment (noisy, fast-paced, constantly changing, not conducive to effective communication and the inconsistent use of communication strategies); "*Finding a voice*" was fundamental to make sense of what happened and for adaptation^{S6}. Feeling like "*Just being a number*" instead of being seen as a unique individual is related to the perspective that the focus of health professionals is the physical condition, contributing to the lack of attention to psychological needs and social goals, with the perception that the team focuses in the technical procedures of rehabilitation and not in the person^{S6}.

Limitations of the study

The search was conducted in only four databases and only articles written in English, Portuguese and Spanish were included, which may have limited access to other articles with relevant contributions to this review. Another limitation is that it was not possible to access two full-text articles. It is important to point out that not including theses, dissertations and "grey" literature in this review may have contributed to not getting important scientific evidence, which can also represent a limitation.

Conclusion

This review aimed to map the available scientific evidence on the experience of people who have gone through a Broca's aphasia period. The Scoping Review enabled us to answer the research question and deepen the understanding of the phenomenon under study. More precisely, it allowed recognizing the negative impact and changes resulting from Broca's aphasia, the feelings associated, the specific needs, factors that influenced the experience, what support and resources people would like to have had, from the perspective of those who experienced this clinical condition. In this study, data related to *Personal identity, attitudes, feelings, and Participation in life situations* were the most often mentioned in the literature, followed by the *Language and related impairments* and the *Communication and language environment*, respectively, regarding Broca's aphasia experience.

The importance of health professionals, therapeutic interventions, spirituality, hope, context, interactions, and psychosocial factors became clear in caring for patients with Broca's aphasia.

The knowledge gained in this Scoping Review allows health professionals to better understand the needs of people with Broca's aphasia and to implement appropriate improvements to health care and service delivery¹⁹. This includes improvements in nursing care, which will promote well-being, enhancing safety, reducing harm, and improving satisfaction with the care provided.

This review shows that it is essential to continue investigating how people report the experience of having lived a period of Broca's aphasia to comprehend better the experience and the needs of this population and continually improve the assistance of people with this clinical condition. Considering the difficulty in this review in finding studies only with people diagnosed with Broca's aphasia, as a suggestion for future research, it would be pertinent to investigate how people report the experience of having lived a period of Broca's aphasia, focusing only on participants who have fully recovered from this specific type of aphasia. Besides that, it would be pertinent to investigate the current practice regarding teaching about the experience of Broca's aphasia in health-related professions, including nursing. It would also be helpful to study the impact of what is already known about the experience of this clinical condition in the management of health care in contexts that provide care to people with Broca's aphasia.

References

- Thompson J, McKeever M. Improving support for patients with aphasia. *Nursing Times* [Internet] 2014 [cited 2022 Nov 7]; 110(25):18-20. Available from: <https://cdn.ps.emap.com/wp-content/uploads/sites/3/2014/06/180614-Improving-support-for-patients-with-aphasia.pdf>
- Sundin K, Jansson L, Norberg A. Communicating with people with stroke and aphasia: understanding through sensation without words. *J Clin Nurs*. 2000;9(4):481-8. doi.org/10.1046/j.1365-2702.2000.00379.x.
- Caldas A. A herança de Franz Joseph Gall: o cérebro ao serviço do comportamento humano. Amadora: McGraw-Hill; 1999.
- Damásio A. Aphasia. *The New England Journal of Medicine*. 1992;326:531-539. doi: [10.1056/NEJM199202203260806](https://doi.org/10.1056/NEJM199202203260806).
- Pallavi J, Perumal RC, Krupa M. Quality of communication life in individuals with broca's aphasia and normal individuals: a comparative study. *Ann Indian Acad Neurol*. 2018;21(4):285-289. doi.org/10.4103/aian.AIAN_489_17
- Frade AI, Pinto VM, d'Espiney L. O valor das estratégias aumentativas e alternativas de comunicação para os adultos com afasia de Broca: uma revisão narrativa da literatura. *Cadernos de Saúde*. 2022;14(1):12-20. doi.org/10.34632/cadernosdesaude.2022.11483
- Kagan A, Simmons-Mackie N, Rowland A, Huijbregts M, Shumway E, McEwen S, Threats T, Sharp S. Counting what counts: a framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*. 2008;22(3):258-280. doi.org/10.1080/02687030701282595
- Noreau L, Fougereyrollas P, Vincent C. The LIFE-H: assessment of the quality of social participation. *Technology and Disability*. 2002;14(3):113-118. doi.org/10.3233/TAD-2002-14306
- Kagan A. A-FROM in Action at the Aphasia Institute. *Seminars in Speech and Language*. 2011;32(3):216-228. doi.org/10.1055/s-0031-1286176
- Frade AIA, d'Espiney L, Pinto VM. Vulnerability, health information right and the contributions of augmentative and alternative communication for people with aphasia. *Clinical Ethics* [Internet] 2022 [cited 2022 Nov 7]; doi.org/10.1177/14777509221105397 Epub ahead of print
- Sundin K, Jansson L. 'Understanding and being understood' as a creative caring phenomenon--in care of patients with stroke and aphasia. *J Clin Nurs*. 2003;12(1):107-16. doi.org/10.1046/j.1365-2702.2003.00676.x
- Poslawsky IE, Schuurmans MJ, Lindeman E, Hafsteinsdóttir TB. A systematic review of nursing rehabilitation of stroke patients with aphasia. *J Clin Nurs*. 2010;19(1-2):17-32. doi.org/10.1111/j.1365-2702.2009.03023.x

13. Ardila A, Rubio-Bruno S. Aphasia from the inside: the cognitive world of the aphasic patient. *Appl Neuropsychol Adult*. 2018;25(5):434-440. doi.org/10.1080/23279095.2017.1323753
14. Bondía JL. Notes on the experience and the knowledge of experience. *Braz J Educ*. 2002;19:20-28. doi.org/10.1590/S1413-24782002000100003
15. Amatuzzi MM. Experiência: um termo chave para a psicologia. Memorandum [Internet] 2007 [cited 2022 Nov 4]; 13:8-15. Available from: <https://periodicos.ufmg.br/index.php/memorandum/article/view/6699>
16. Lira GV Nations MK, Catrib AMF. Cronicidade e cuidados de saúde: o que a antropologia da saúde tem a nos ensinar?. *Texto & Contexto Enfermagem* 2004;13(1):147-155.
17. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc*. 2015;13(3):141-146. doi.org/10.1097/XEB.0000000000000050
18. Parr S. Psychosocial aspects of aphasia: whose perspectives? *Folia Phoniatr Logop*, 2001;53:266-288. doi.org/10.1159/000052681
19. Tomkins B, Siyambalapatiya S, Worrall L. What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology*, 2013;27(8):972-991. doi.org/10.1080/02687038.2013.811211
20. Peters M, Godfrey C, McInerney P, Munn Z, Tricco A, Khalil H. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z, editors. *JBIM manual for evidence synthesis*. The Joanna Briggs Institute; 2020. doi.org/10.46658/JBIMES-20-12
21. World Health Organization. World Health Organization Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Geneva, Switzerland; 2013. Available from <https://www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/>
22. Luck AM, Rose ML. Interviewing people with aphasia: insights into method adjustments from a pilot study. *Aphasiology*. 2007;21(2):208-224. doi.org/10.1080/02687030601065470
23. Armstrong E, Hersh D, Hayward C, Fraser J, Brown M. Living with aphasia: three indigenous Australian stories. *Int J Speech Lang Pathol*. 2012;14(3):271-80. doi.org/10.3109/17549507.2011.663790
24. Baker C, Worrall L, Rose M, Ryan B. It was really dark: the experiences and preferences of people with aphasia to manage mood changes and depression. *Aphasiology*. 2020;34(1):19-46. doi.org/10.1080/02687038.2019.1673304
25. Bright FAS, Kayes NM, McCann CM, McPherson KM. Hope in people with aphasia. *Aphasiology*. 2013;27(1):41-58. doi.org/10.1080/02687038.2012.718069
26. Carcello K, McLennon S. Personal road map for recovery: examining the therapeutic use of weblogs by stroke survivors with aphasia. *Disabil Rehabil*. 2022;44(10):1933-1938. doi.org/10.1080/09638288.2020.1812122
27. Clancy L, Povey R, Rodham K. Living in a foreign country: experiences of staff-patient communication in inpatient stroke settings for people with post-stroke aphasia and those supporting them. *Disabil Rehabil*. 2020;42(3):324-334. doi.org/10.1080/09638288.2018.1497716
28. Dalemans RJ, Witte L de, Wade D, van den Heuvel W. Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord*. 2010;45(5):537-50. doi.org/10.3109/13682820903223633
29. Green C, Waks L. A second chance: recovering language with aphasia. *Int J Speech Lang Pathol*. 2008;10(3):127-31. doi.org/10.1080/17549500801971517
30. Grohn B, Worrall LE, Simmons-Mackie N, Brown K. The first 3-months post-stroke: what facilitates successfully living with aphasia? *Int J Speech Lang Pathol*. 2012;14(4):390-400. doi.org/10.3109/17549507.2012.692813
31. Grohn B, Worrall L, Simmons-Mackie N, Hudson K. Living successfully with aphasia during the first year post-stroke: a longitudinal qualitative study. *Aphasiology*. 2014;28(12):1405-1425. doi.org/10.1080/02687038.2014.935118
32. Hall WA. Return from silence - a personal experience. *J Speech Hearing Disord*. 1961;26(2):174-177. doi.org/10.1044/jshd.2602.174
33. Holland AL, Halper AS, Cherney LR. Tell me your story: analysis of script topics selected by persons with aphasia. *Am J Speech Lang Pathol*. 2010;19(3):198-203. [doi.org/10.1044/1058-0360\(2010/09-0095\)](https://doi.org/10.1044/1058-0360(2010/09-0095))
34. Laures-Gore JS, Lambert PL, Kruger AC., Love J, Davis Jr DE. Spirituality and post-stroke aphasia recovery. *J Relig Health*. 2018;57:1876-1888. doi.org/10.1007/s10943-018-0592-4

35. Simmons-Mackie N, Kagan A. Application of the ICF aphasia. *Semin Speech Lang.* 2007;28(4):244-253. doi.org/10.1055/s-2007-986521
36. Thiel L, Conroy P. I think writing is everything: an exploration of the writing experiences of people with aphasia. *Int J Lang Commun Disord.* 2022;57(6):1381-1398. doi.org/10.1111/1460-6984.12762
37. Worrall L, Sherratt S, Rogers P, Howe T, Hersh D, Ferguson A, et al. What people with aphasia want: their goals according to the ICF. *Aphasiology,* 2011;25(3):309-322. doi.org/10.1080/02687038.2010.508530
38. Worrall L, Hudson K, Khan A, Ryan B, Simmons-Mackie N. Determinants of living well with aphasia in the first year poststroke: a prospective cohort study. *Arch Phys Med Rehabil.* 2017;98(2):235-240. doi.org/10.1016/j.apmr.2016.06.020
39. Thompson J, McKeever M. The impact of stroke aphasia on health and well-being and appropriate nursing interventions: an exploration using the theory of human scale development. *J Clin Nurs.* 2014;23(3-4):410-20. doi.org/10.1111/j.1365-2702.2012.04237.x
40. Bright FAS, McCann CM, Kayes NM. Recalibrating hope: a longitudinal study of the experiences of people with aphasia after stroke. *Scand J Caring Sci.* 2019;34(2):428-435. doi.org/10.1111/scs.12745