JOURNAL REHABILITÁCIA
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LCRH
ISSN 0375 – 0922 www.journal.rehabilitacia.sk

Patient-Reported Impact of Aphasia After Stroke on Activities, Participation, and Emotional Well-Being: Results from the Aphasia Impact Questionnaire (AIQ-21)

[1]Zsolt CSÉFALVAY, [1] Viktória ČIERNIK KEVICKÁ, [2]Marta HORŇÁKOVÁ

[1]Univerzita Komenského v Bratislave. Pedagogická fakulta, Katedra logopédie, Bratislava, Slovensko.
[2]Univerzita Komenského v Bratislave. Pedagogická fakulta, Katedra liečebnej pedagogiky, Bratislava, Slovensko

**Corresponding author: csefalvay@fedu.uniba.sk*

SUMMARY/ABSTRACT

Background
Aphasia, a neurogenic language disorder often caused by stroke, affects about one-third of stroke survivors, impairing speech production and comprehension. Besides language deficits, aphasia significantly impacts psychosocial functioning, quality of life, emotional well-being, and social participation.

Participants
This study involved 53 Slovak-speaking individuals with various clinical aphasia types. Ages ranged from 28 to 89 years (M = 59), with the 50–59 age group most prevalent. The sample included 29 women and 24 men with diverse educational backgrounds. Anomic aphasia was most common (n = 21), followed by Broca's (n = 14) and conduction aphasia (n = 11). The average time since aphasia onset was 15.3 months (range 1–60 months).

Methods
Aphasia severity was assessed using DgAAA, a comprehensive language battery. The subjective impact on quality of life was measured with the Slovak adaptation of the Aphasia Impact Questionnaire–21 (AIQ-21), covering Activities, Participation, and Emotional State. Associations between AIQ-21 scores and aphasia severity, age, sex, education, and time since onset were analyzed using appropriate statistical methods for non-normally distributed data.

Results
A correlation analysis revealed a significant moderate negative association between aphasia severity (DgAAA scores) and self-reported impact (AIQ-21), with rho = -0.39, p = 0.024. Better language performance was linked to a lower perceived impact of aphasia. The effect size indicates a small to moderate clinically relevant relationship, highlighting a meaningful connection between objective language ability and patients' subjective experience. In contrast, demographic factors—age, sex, education, and time since aphasia onset—did not significantly influence any aphasia impact domains.

Conclusion
The study concludes that aphasia severity is the primary factor influencing the perceived impact of aphasia on quality of life, with milder cases reporting less burden across activities, participation, and emotional well-being. Demographic variables such as age, sex, education, and time since onset do not significantly affect these subjective assessments. Additionally, the AIQ-21 is confirmed as a

KEYWORDS:

Aphasia, Activities, Participation, Aphasia Impact Questionnaire (AIQ-21)

DOI: 10.61983/lcrh.v62i3.117

valuable tool for capturing important information about the lived experiences of people with aphasia, highlighting the need to explore psychosocial factors alongside clinical severity in rehabilitation.

Súhrn

Pacientami hodnotený dopad afázie po mozgovej príhode na aktivity, participáciu a emocionálnu pohodu: Výsledky z dotazníka Aphasia Impact Questionnaire (AIQ-21)

Východisko
Afázia je neurogénna porucha reči, ktorá často vzniká po mozgovej príhode a postihuje približne jednu tretinu tých, ktorí mozgovú príhodu prežili. Zasahuje produkciu aj porozumenie reči. Okrem jazykových deficitov má afázia výrazný vplyv na psychosociálne fungovanie, kvalitu života, emocionálnu pohodu a spoločenskú participáciu.

Účastníci
Štúdie sa zúčastnilo 53 slovensky hovoriacich osôb s rôznymi klinickými typmi afázie. Vek účastníkov sa pohyboval od 28 do 89 rokov (priemer = 59), pričom najpočetnejšia bola veková skupina 50–59 rokov. Vzorka zahŕňala 29 žien a 24 mužov s rôznorodým vzdelaním. Najčastejším typom bola anomická afázia (n = 21), nasledovaná Brocovou afáziou (n = 14) a kondukčnou afáziou (n = 11). Priemerný čas od vzniku afázie bol 15,3 mesiaca (rozsah 1–60 mesiacov).

Metódy
Závažnosť afázie bola hodnotená pomocou DgAAA, komplexného jazykového testu. Subjektívny dopad na kvalitu života sa meral slovenskou adaptáciou dotazníka Aphasia Impact Questionnaire–21 (AIQ-21), ktorý zahŕňa oblasti Aktivít, Participácie a Emocionálneho stavu. Vzťahy medzi skóre AIQ-21 a závažnosťou afázie, vekom, pohlavím, vzdelaním a časom od vzniku afázie boli analyzované pomocou štatistických metód vhodných pre ne-normálne distribuované dáta.

Výsledky
Analýza korelácie ukázala významný stredne silný negatívny vzťah medzi závažnosťou afázie (skóre DgAAA) a subjektívne vnímaným dopadom (AIQ-21), s hodnotou rho = -0,39, p = 0,024. Lepší jazykový výkon súvisel s nižším vnímaným dopadom afázie. Veľkosť efektu naznačuje klinicky relevantný vzťah, ktorý poukazuje na významné prepojenie medzi objektívnou jazykovou schopnosťou a subjektívnou skúsenosťou pacientov. Naopak, demografické faktory – vek, pohlavie, vzdelanie a čas od vzniku afázie – nemali významný vplyv na žiadnu z oblastí dopadu afázie.

Záver
Štúdia dospela k záveru, že závažnosť afázie je hlavným faktorom ovplyvňujúcim vnímaný dopad afázie na kvalitu života – miernejšie prípady hlásia menšiu záťaž v oblastiach aktivít, participácie a emocionálnej pohody. Demografické premenné ako vek, pohlavie, vzdelanie a čas od vzniku afázie nemajú významný vplyv na tieto subjektívne hodnotenia. Navyše sa potvrdilo, že AIQ-21 je cenný nástroj na zachytenie dôležitých informácií o prežívaní ľudí s afáziou, čím sa zdôrazňuje potreba skúmať psychosociálne faktory popri klinickej závažnosti v rámci rehabilitácie.

1 INTRODUCTION

Aphasia is a profound neurogenic communication disorder characterized by impairments in speech production and comprehension, with an estimated prevalence affecting approximately one-third of stroke survivors (Engelter et al., 2006; Flowers et al., 2016). For rehabilitation professionals managing post-stroke populations, a comprehensive understanding of both the neurological and psychosocial sequelae of aphasia is imperative, given their significant influence on patients' quality of life, social participation, and therapeutic outcomes.

Empirical evidence consistently demonstrates that aphasia adversely impacts health-related quality of life (HRQoL), with affected individuals reporting diminished subjective well-being and increased incidence of depressive symptoms relative to stroke survivors without language impairments (Cruice et al., 2011;

Kauhanen et al., 2000; Hilari et al., 2012). Social participation is frequently compromised (Dalemans et al., 2010), and even when physical health status and social support are comparable, those with aphasia experience reduced engagement in daily activities and lower life satisfaction (Hilari & Byng, 2009).

The majority of extant literature assessing the psychosocial impact of aphasia has relied heavily on proxy reports from caregivers or clinicians, which may inadequately represent the patient's subjective experience (Hilari et al., 2012). Systematic reviews identify key determinants adversely affecting quality of life in aphasia, including severity of language impairment, co-occurring depression, comorbid medical conditions, and restricted social participation. Consequently, enhancing quality of life, particularly with respect to communication-related domains—has emerged as a primary goal within speech-language pathology and aphasia rehabilitation. Quality of life is conceptualized as an individual's subjective appraisal of their life circumstances, shaped by cultural and personal values (Rangmani & Judovsky, 2020).

Communication difficulties constitute one of the most salient contributors to diminished quality of life in aphasia, correlating with reduced self-esteem, psychological distress, and social isolation (Carleto & Caldana, 2014; Filipska-Blejder et al., 2023; Lima et al., 2020). Notwithstanding these challenges, a majority of individuals with aphasia retain a strong motivation to engage in communicative interactions.

Contemporary rehabilitation frameworks, such as the Life Participation Approach to Aphasia (LPAA), emphasize reintegration into meaningful life roles through individualized goal setting, social inclusion, and active family involvement (Chapey et al., 2000). The integration of standardized quality-of-life measures into clinical protocols is critical to inform personalized intervention strategies that address patients' real-world priorities.

Our study, the first of its kind conducted in Slovakia (Cséfalvay et al., 2024), investigated the relationship between the severity of aphasia and the self-perceived impact of the disorder on daily communication, participation, and emotional well-being. In a sample of 32 individuals with chronic post-stroke aphasia, no significant correlation was found between overall language impairment and the subjective impact of aphasia. However, a moderate and statistically significant association was identified between better language comprehension and a lower perceived impact, suggesting that comprehension plays a pivotal role in shaping individuals' experiences of living with aphasia.

These findings are consistent with our previous research (Horňáková & Cséfalvay, 2024), which established a strong association between communicative comprehension, social integration, and overall quality of life. Additionally, younger individuals with aphasia reported higher levels of emotional distress. Quality of life in this population appears to be influenced by a multifactorial constellation, including social support, motor impairments, and the ability to maintain meaningful social roles, dimensions that merit integrated clinical attention in aphasia rehabilitation.

Building upon these findings, the present study seeks to provide a more comprehensive analysis by examining a larger and more diverse sample of individuals with aphasia. The aim is to identify and explore additional factors that shape patients' subjective experiences of how aphasia affects their everyday functional abilities, social engagement, and emotional health. Through this broader investigation, the study endeavors to deepen the understanding of the multifaceted personal and psychosocial consequences of aphasia. Drawing on extensive clinical experience and longitudinal observation, we hypothesize that

demographic and clinical variables such as age, educational attainment, and time since onset may significantly modulate self-reported outcomes. This rationale forms the foundation of the current investigation.

2 GROUP AND METHODS

The study sample comprised 53 Slovak-speaking individuals diagnosed with aphasia, each meeting the clinical criteria for one of the recognized aphasia syndromes. Participants' ages ranged from 28 to 89 years (mean age = 59 years), with the largest subgroup aged between 50 and 59 years. The cohort included 29 females and 24 males. Educational attainment was categorized into three levels (primary, secondary, and higher education).

Clinically, the most frequently diagnosed aphasia type in the sample was anomic aphasia (n = 21), followed by Broca's aphasia (n = 14) and conduction aphasia (n = 11). Less common diagnoses included Wernicke's aphasia (n = 3), transcortical motor aphasia (n = 2), mixed transcortical aphasia (n = 1), and transcortical sensory aphasia (n = 1). The mean time since aphasia onset was 15.3 months, with a range of 1 to 60 months, reflecting significant heterogeneity in the chronicity of the condition.

All participants were assessed using the *Diagnostic Assessment of Aphasia, Alexia, and Agraphia* (DgAAA; Cséfalvay, Wiedenmann, & Egerová, 2018), a comprehensive Slovak test battery designed to evaluate language impairments across a broad spectrum of functional domains.

The Aphasia Impact Questionnaire – 21 (AIQ-21) (Swinburn etl al, 2018; Slovak adaptation by Mackulin, 2021) is a validated patient-reported outcome measure specifically developed to assess the perceived impact of aphasia on everyday functioning and psychosocial well-being (Mackulin, Cséfalvay, 2022).

The instrument consists of 21 items organized into three key domains: activities (6 items), participation (4 items), and emotional state (11 items). The activities domain evaluates communication-related tasks such as speaking with close others and strangers, understanding speech from both close others and strangers, writing a message to a friend, and reading a newspaper article (1-6). The participation domain assesses social engagement and involvement in meaningful activities by evaluating an individual's ability to carry out necessary daily tasks, engage in enjoyable work-related activities, maintain friendships, and interact with family members (7-10). The emotional state and personal well-being domain encompass a wide range of affective experiences commonly associated with aphasia, including feelings of tension, worry, unhappiness, helplessness, boredom, shame, anger, loneliness, and perceived cognitive inadequacy, as well as positive emotions such as confidence and hopefulness about the future (11-21).

Each item is evaluated using a 5-point Likert scale, reflecting the individual's self-perceived communicative ability or emotional experience. Individuals with aphasia are instructed to indicate, either nonverbally or verbally, the ease with which they were able to communicate with a close person over the past week. Responses are recorded on a self-assessment scale ranging from 4 (very difficult) to 0 (no difficulty) (see Figure 1).

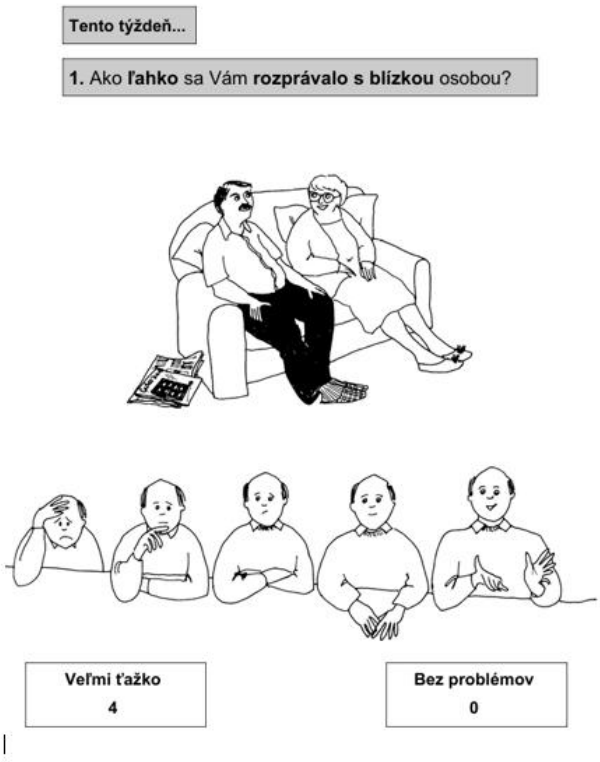

Figure 1. An illustration of an item from the AIQ21sk, where the patient's task is to indicate how easy it was for them to communicate with a close person (4 – very difficult, 0 – no difficulty).

This comprehensive approach allows the AIQ-21 to capture both the functional and psychosocial consequences of aphasia from the patient's perspective. Typically administered via an assisted interview lasting approximately 20 to 30 minutes, the AIQ-21 facilitates individualized therapeutic planning by identifying patient-specific challenges and rehabilitation priorities. For the present study, participants were recruited from specialized rehabilitation centers providing care for individuals with post-stroke aphasia, with informed consent obtained before data collection.

Following a comprehensive evaluation of aphasia, alexia, and agraphia, the AIQ-21 was administered in its Slovak version (*AIQ-21sk*), with interviewers providing clarification and support as needed to promote accurate and reliable responses. For each participant, domain-specific and total AIQ-21 scores were calculated. These were subsequently analyzed in relation to demographic variables (age, gender, education level), clinical characteristics (aphasia type, time since onset), and indicators of overall quality of life.

3 STARTING POINT, OBJECTIVE, TASKS

Building upon the theoretical framework of the International Classification of Functioning, Disability, and Health (ICF), which differentiates between the constructs of Activities and Participation, the present study was initiated to explore how individuals with aphasia perceive the impact of their condition across multiple quality-of-life dimensions, as assessed by the Aphasia Impact Questionnaire-21 (AIQ-21).

The research specifically aimed to examine the extent to which clinical severity of aphasia, operationalized using the Comprehensive Aphasia Test Battery (DgAAA), and selected demographic variables—including age, sex, educational level, and time since onset—are associated with self-reported outcomes in the AIQ-21 domains: Activities, Participation, Emotional State, and the overall Total Score.

Therefore, the overarching objective of this study was to clarify the relative contributions of clinical and demographic factors to subjective quality of life, to inform a more individualized and holistic approach to aphasia rehabilitation. Future research tasks will involve the integration of multidimensional predictors—such as communicative participation, social support, and mood state into predictive models of quality-of-life outcomes, thereby advancing our understanding of aphasia as not merely a linguistic impairment but a lived biopsychosocial condition.

4 RESULTS

This section delineates the empirical findings from analyses investigating the associations between the domains of the Aphasia Impact Questionnaire-21 (AIQ-21) specifically Activities, Participation, Emotional State, and the Total Score and selected demographic and clinical variables, including age, educational attainment, time since aphasia onset, and sex. It is critical to preliminarily distinguish the conceptual frameworks of *Activities* and *Participation*: *Activities* pertain to the individual's capacity to perform discrete tasks, whereas *Participation* encompasses broader engagement within social contexts such as occupational, social, and leisure activities. Thus, *Activities* primarily reflect individual functional abilities, while *Participation* captures the extended societal impact of communication impairments.

4.1. Relationship between aphasia severity and subjective impact on activities, participation, and emotional state

To investigate the association between aphasia severity and its perceived impact, a Spearman rank-order correlation analysis was conducted between scores obtained from the Comprehensive Aphasia Test Battery (DgAAA) and self-reported impact measures from the AIQ-21. The adoption of a non-parametric statistical method was warranted due to the non-normal distribution of the variables. A statistically significant negative correlation was observed between the total score on the comprehensive language battery (DgAAA) and the Aphasia Impact Questionnaire (AIQ), with Spearman's rho = 0.39 and $p = 0.024$. This indicates that better performance on language tasks is moderately associated with a lower perceived impact of aphasia (assuming lower AIQ scores reflect better outcomes or less impact). The effect size, expressed as Fisher's z = 0.319, corresponds to a small to moderate effect, supporting the clinical relevance of the association. Although the strength of the correlation is modest, it suggests a meaningful link between objective language ability and the subjective experience of living with aphasia.

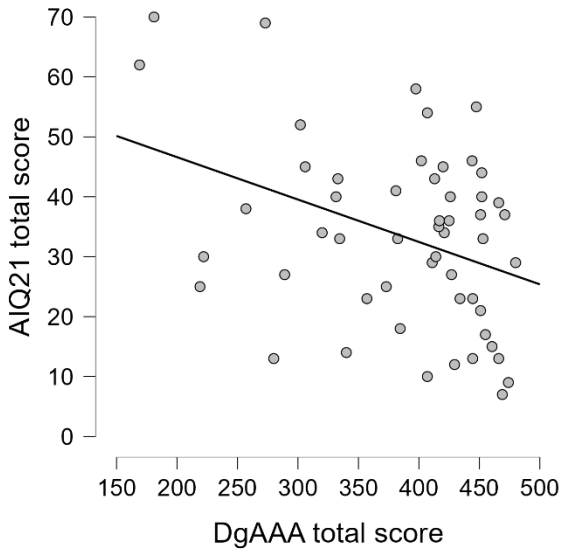

Figure 2: *Scatter plot illustrating the relationship between aphasia severity (DgAAA total scores) and the impact of aphasia on activities, participation, and emotional state (AIQ-21 scores).*

4.2. Relationship between time since aphasia onset and perceived impact on activities, participation, and emotional state

The correlation between time post-onset and AIQ-21 scores was not statistically significant, with Spearman's rho = –0.15 and $p = 0.285$. This weak negative correlation suggests a slight trend in which individuals with a longer time since aphasia onset tend to report lower AIQ-21 scores, indicating less perceived impact of aphasia. However, the relationship is small and statistically non-significant. The corresponding Fisher's z = –0.151 confirms a very small effect size, reinforcing the interpretation that time since onset is not meaningfully associated with the perceived impact of aphasia in this sample. While the direction of the correlation hints at possible gradual adaptation or improvement in psychosocial adjustment over time, the evidence is insufficient to draw firm conclusions.

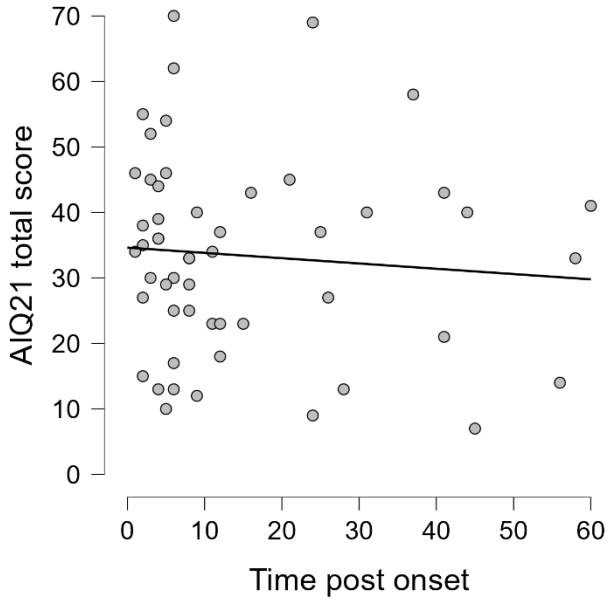

Figure 3. *Scatter plot showing the relationship between time post-onset (in months) and the perceived impact of aphasia on activities, participation, and emotional well-being, as measured by AIQ-21 scores.*

4.3. Relationship between age and perceived impact of aphasia on activities, participation, and emotional state

The correlation between age and AIQ-21 scores was not statistically significant, with Spearman's rho = 0.115 and p = 0.41. This very weak positive correlation suggests that older individuals may report slightly higher AIQ scores, which would correspond to a greater perceived impact of aphasia. However, given the small magnitude of the correlation and the lack of statistical significance, this trend is not meaningful in the current sample. The associated Fisher's z = 0.116 reflects a very small effect size, supporting the conclusion that age is not reliably associated with self-reported impact of aphasia. These findings suggest that age alone does not substantially influence how individuals perceive the psychosocial consequences of their language disorder.

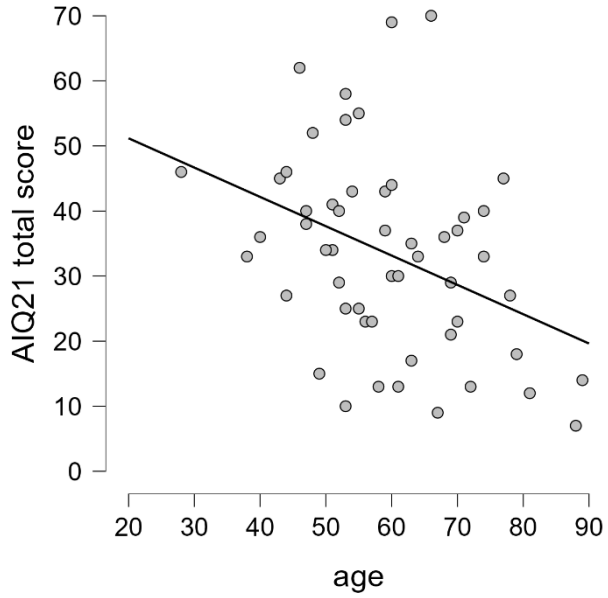

Figure 4. *Scatter plot illustrating the relationship between age (in years) and the perceived impact of aphasia on activities, participation, and emotional well-being, as assessed by AIQ-21 scores.*

4.5. Gender differences in the perceived impact of aphasia on activities, participation, and emotional state

Comparative analyses between male and female participants on AIQ-21 domain scores revealed no statistically significant differences across any domain (total scores were 58 versus 59, $p = 0.658$). These results indicate that sex does not exert a significant influence on patients' subjective evaluations of aphasia-related quality of life impact.

4.6. Impact of educational level on quality of life in the perceived impact on activities, participation, and emotional state

The correlation between level of education and AIQ-21 scores was not statistically significant, with Spearman's rho = 0.145 and p = 0.301. This weak positive correlation suggests that individuals with more years of education tend to report slightly higher AIQ-21 scores, which would indicate a greater perceived impact of aphasia. However, due to the small magnitude of the correlation and the lack of statistical significance, this relationship is not meaningful in the current sample.The corresponding Fisher's z = 0.146 reflects a very small effect size, supporting the conclusion that level of education is not reliably associated with the self-reported impact of aphasia. These findings imply that educational attainment does not substantially influence how individuals perceive the psychosocial consequences of aphasia in this group.

5 CONCLUSIONS

In conclusion, our study provides a detailed examination of the relationship between aphasia severity, demographic factors, and the self-perceived impact of aphasia on quality of life, as assessed by the AIQ-21. Among the variables investigated, only aphasia severity measured by the standardized Comprehensive Aphasia Test Battery (DgAAA)—showed a statistically significant association with subjective quality-of-

life outcomes. Individuals with milder aphasia reported a lower perceived burden across domains such as everyday activities, social participation, emotional well-being, and overall impact.

In contrast, demographic factors including age, sex, educational level, and time since aphasia onset did not show meaningful relationships with patients' self-assessed impact. Correlation analyses consistently revealed negligible to weak non-significant associations, indicating these variables do not systematically influence how individuals with aphasia perceive their social participation, communication abilities, emotional state, or overall quality of life.

These findings emphasize that the subjective experience of aphasia-related disability is primarily determined by clinical severity rather than demographic characteristics or chronicity. The lack of significant associations with demographic factors challenges assumptions about their predictive value in post-stroke rehabilitation outcomes.

This results underscores the need for future research to focus on additional determinants particularly psychosocial, environmental, and neurocognitive factors that may better explain the variability in quality-of-life outcomes among people with aphasia. Such multidimensional investigations are crucial for developing individualized, context-sensitive interventions that address both clinical symptoms and broader influences on psychosocial well-being and resilience.

6. ZUSAMMENFASSUNG

Hintergrund
Aphasie, eine neurogene Sprachstörung, die häufig durch einen Schlaganfall verursacht wird, betrifft etwa ein Drittel der Schlaganfallüberlebenden und beeinträchtigt die Sprachproduktion und das Sprachverständnis. Neben den Sprachdefiziten wirkt sich Aphasie auch erheblich auf die psychosoziale Funktion, die Lebensqualität, das emotionale Wohlbefinden und die soziale Teilhabe aus.

Teilnehmer*innen
An der Studie nahmen 53 slowakischsprachige Personen mit verschiedenen klinischen Aphasieformen teil. Das Alter lag zwischen 28 und 89 Jahren (M = 59), wobei die Altersgruppe 50–59 Jahre am häufigsten vertreten war. Die Stichprobe umfasste 29 Frauen und 24 Männer mit unterschiedlichen Bildungsabschlüssen. Am häufigsten war die anomische Aphasie (n = 21), gefolgt von Broca-Aphasie (n = 14) und Leitungsaphasie (n = 11). Die durchschnittliche Zeit seit dem Aphasie-Beginn betrug 15,3 Monate (Spanne 1–60 Monate).

Methoden
Der Schweregrad der Aphasie wurde mit dem umfassenden Sprachtest DgAAA erfasst. Die subjektive Auswirkung auf die Lebensqualität wurde mit der slowakischen Adaptation des Aphasia Impact Questionnaire–21 (AIQ-21) gemessen, der die Bereiche Aktivitäten, Teilhabe und emotionaler Zustand abdeckt. Die Zusammenhänge zwischen AIQ-21-Werten und Aphasie-Schweregrad, Alter, Geschlecht, Bildung sowie Zeit seit Beginn wurden unter Verwendung geeigneter statistischer Verfahren für nicht-normalverteilte Daten analysiert.

Ergebnisse
Eine Korrelationsanalyse zeigte eine signifikante moderate negative Beziehung zwischen dem Aphasie-Schweregrad (DgAAA-Werte) und dem selbstberichteten Einfluss (AIQ-21) mit rho = -0,39, p = 0,024. Bessere Sprachleistungen waren mit einem geringeren wahrgenommenen Einfluss der Aphasie verbunden. Die Effektstärke weist auf einen kleinen bis moderaten klinisch relevanten Zusammenhang hin und betont die bedeutsame Verbindung zwischen objektiver Sprachfähigkeit und subjektiver Erfahrung der Betroffenen. Demgegenüber hatten demografische Faktoren – Alter, Geschlecht, Bildung und Zeit seit Aphasie-Beginn – keinen signifikanten Einfluss auf die verschiedenen Bereiche des Aphasie-Impacts.

Schlussfolgerung
Die Studie zeigt, dass der Schweregrad der Aphasie der entscheidende Faktor für die wahrgenommene Auswirkung der Aphasie auf die Lebensqualität ist, wobei mildere Fälle eine geringere Belastung in den Bereichen Aktivitäten, Teilhabe und emotionales Wohlbefinden berichten. Demografische Variablen wie Alter, Geschlecht, Bildung und Zeit seit Beginn beeinflussen diese subjektiven Einschätzungen nicht signifikant. Zudem bestätigt sich der AIQ-21 als wertvolles Instrument zur Erfassung wichtiger Aspekte der gelebten Erfahrungen von Menschen mit Aphasie und unterstreicht die Notwendigkeit, psychosoziale Faktoren neben der klinischen Schwere in der Rehabilitation zu berücksichtigen.

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