UNIVERSIDADE DE LISBOA
Faculdade de Medicina

Study of subjective cognitive complaints and their relation to cognitive impairment in stroke survivors

Margarida Garcia Monereo Areias

Orientador: Professora Doutora Maria Isabel Segurado Pavão Martins Catarino Petiz
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Dissertação especialmente elaborada para obtenção do grau de Mestre em Neurociências

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ABSTRACT

Stroke, a leading cause of long-term disability globally, affects millions of individuals every year. It often results in physical and mental changes that significantly impact daily functioning. The mental effects of stroke encompass cognitive, emotional, behavioural and social domains, with cognitive impairments ranging from 10% to 82% in prevalence, depending on assessment criteria and timing. Cognitive impairment can be evaluated either objectively, using global cognitive screening tests or neuropsychological tests covering one or more domains (e.g. memory, attention, processing speed, executive functions), or subjectively, using self-report measures or interviews. To date, most studies investigating post-stroke cognition have focused on objective assessment. Detection of cognitive impairment in the chronic phase is essential to better define rehabilitation and functional adaptation strategies, as marked improvements in cognitive function can occur in the first months after stroke, and recovery can be facilitated by rehabilitation programs.

Subjective cognitive complaints, reflecting the cognitive and emotional difficulties reported by stroke survivors, play a crucial role in understanding the experiences of stroke patients. By examining the nature of those complaints and the various factors that may influence self-perception, healthcare professionals can gain further insights into the subjective experiences of patients, their impact in social, family and work life, and provide more effective care.

The current study aimed to investigate the frequency and types of subjective cognitive complaints after stroke and their relationship with objective cognitive impairment.

The study was designed as a prospective observational study of stroke survivors, observed in a stroke outpatient clinic of the Department of Neurology, Hospital de Santa Maria, CHULN, Lisbon, Portugal. After informed consent, patients undertook a brief cognitive evaluation and the following tests and scales were applied: Cognitive and Language Complaints Evaluation - 24 (CLCE-24), Addenbrooke's Cognitive Examination scale, National Institutes of Health Stroke Scale (NIHSS), Modified Rankin Scale, Geriatric Depression Scale. The NIHSS and the Modified Rankin Scale were applied during the consultation by the patient's neurologist. The CLCE-24 scale was also applied once to the family member or caregiver accompanying the patient. Demographic information was collected (age, education, gender, laterality, living at home or in a rehabilitation clinic) as well as clinical features provided by the patient physician

(hemorrhagic or ischemic stroke); first or recurrent stroke; stroke territory; lesion volume; stroke severity, as assessed by the NIHSS.

A total of 50 patients were included. Thirty-one patients were male (62%), with a median age of 70 years (interquartile range: 60.75–79 years). The majority (38%) had 1 to 4 years of formal education (primary education), were retired (74%), lived at home (98%), and were right-handers (98%). The median duration since stroke was 12 months (interquartile range = 5–21 months). The most frequent type of stroke was ischemic (84%), with the left middle cerebral artery as the most common location (32.6%) followed by the right middle cerebral artery (18.4%). Hemorrhagic strokes were less frequent (16%), with the right thalamus being the most common location (4.1%).

Cognitive complaints, assessed in the CLCE-24 scale, were common after stroke (median score = 8.5 points, out of 22) and both patients and their family members agreed on the existence of these complaints ($p < 0.01$), which suggests that family members can provide valuable information about the patient's condition and may be able to help identify cognitive and emotional problems that the patient may not be aware of.

Objective cognitive impairment, assessed in the Addenbrooke's Cognitive Examination scale, was predominant after stoke (median score = 76 points, out of 100). The results of this scale showed that most patients (62%) have Mild Cognitive Impairment and that only 38% of the patients scored above the established norma-based cut-off values for cognitive impairment. Cognitive complains related to language (i.e., patient-reported difficulty in reading, writing, and speaking) seemed to be more prevalent (median score = 21.0, out of 26). Cognitive complaints and objective cognitive impairment were not correlated (r = -0.199, p = 0.170). However, objective cognitive impairment was correlated with the *cognitive* category of the CLCE-24 scale (r = -0.322, p = 0.023), which indicates that the more cognitive complaints patients reported, the more objective cognitive impairment they have. Patient family members' scores on the CLCE-24 scale were correlated with the patients' scores on the Addenbrooke's Cognitive Examination scale (r = -0.496, p = 0.006), showing that relative's perception is related to patients' objective scores.

Cognitive complains were correlated with functional independence (r = 0.407, p = 0.003), depression (r = 0.693, $p < 0.001$) but not with cognitive performance (r = -0.221, p = 0.126), and were independent from age, gender, literacy, professional situation, lesion location and type of stroke, suggesting that the cognitive state, mainly depression, is more correlated with the patient's complaints than the objective performance.

The multivariate model integrated the modified Rankin scale and Geriatric Depression Scale variables as predictors of post-stroke cognitive complaints, suggesting their potential as significant predictors of post-stroke cognitive complaints. This model highlighted the association between these complaints, functional disability and depression, suggesting that mitigating depressive symptoms could lead to a decrease in patients' reported complaints.

These findings underscore the importance of emotional factors when evaluating cognitive complaints in stroke patients, even if they do not align with objective measures of cognitive functioning. This study provides information on the complex relationship between subjective complaints, cognitive impairment and emotional factors after stroke. The present findings may contribute to the development of tailored treatment programs to improve the quality of life and cognitive outcomes in this population.

Overall, this study deepens our understanding of the intricate relationship between cognitive complaints, objective cognitive impairment, emotional factors, and functional disability in stroke patients. It emphasizes the multifaceted nature of these issues and the necessity of comprehensive assessments that encompass patient and family perspectives, emotional aspects, and objective cognitive performance.

Additionally, in order to address the emotional challenges faced by stroke patients, we propose a holistic approach that integrates neurological monitoring with emotional and social support. We propose: Implementation of cognitive rehabilitation programs designed to equip patients with coping strategies tailored to their cognitive challenges; Emotional and social worker monitoring, alongside neurological monitoring, to address patients' mental health needs and provide emotional support; A socio-behavioural support group, led by professionals, to offer a safe space for patients to share experiences and receive guidance; Involving family members or care takers in consultations, to provide more accurate information about the patient's condition; Establishing a multidisciplinary neuroscience group, comprising neurologists, psychologists, social workers, and other relevant professionals, to oversee the integration of neurological, emotional, and social support services, ensuring a comprehensive approach to patient care. With this approach, we aim to enhance the overall care and well-being of stroke patients by acknowledging and addressing their emotional needs, contributing to their successful rehabilitation and recovery.

Keywords: Stroke, subjective cognitive complaints, cognitive impairment.

RESUMO

O acidente vascular cerebral (AVC), uma das principais causas de incapacidade a longo prazo a nível mundial, afeta milhões de pessoas todos os anos. Resulta, frequentemente, em alterações cognitivas e comportamentais que afetam significativamente o funcionamento diário. Os efeitos do AVC abrangem os domínios cognitivo, emocional, comportamental e social, com uma prevalência de deficiências cognitivas que varia entre 10% e 82%, dependendo dos critérios de avaliação e do momento em que ocorre. O défice cognitivo pode ser avaliado objetivamente, utilizando testes de rastreio cognitivo global ou testes neuropsicológicos que abrangem um ou mais domínios (por exemplo, memória, atenção, velocidade de processamento, funções executivas), ou subjetivamente, utilizando medidas de auto-relato ou entrevistas. Até à data, a maioria dos estudos que investigam a cognição pós-AVC tem-se centrado na avaliação objetiva. A deteção do défice cognitivo na fase crónica é essencial para definir melhor as estratégias de reabilitação e adaptação funcional, uma vez que podem ocorrer melhorias acentuadas na função cognitiva nos primeiros meses após o AVC e a recuperação pode ser facilitada por programas de reabilitação.

As queixas cognitivas subjetivas refletem as dificuldades cognitivas relatadas pelos doentes, e desempenham um papel crucial na compreensão das suas experiências cognitivas e emocionais. Ao examinar os vários fatores que podem influenciar a perceção subjetiva, os profissionais de saúde podem obter informações sobre as experiências subjetivas dos doentes e prestar cuidados mais eficazes.

O presente estudo teve como objetivo investigar a frequência e o tipo de queixas cognitivas subjetivas após o AVC, bem como a sua relação com o comprometimento cognitivo objetivo.

O estudo foi concebido como um estudo observacional prospetivo de sobreviventes de AVC observados num ambulatório de AVC do Departamento de Neurologia do Hospital de Santa Maria, CHULN, Lisboa, Portugal. Após consentimento informado, os doentes responderam a escalas e foram submetidos a uma breve avaliação cognitiva, que consistiu na aplicação dos seguintes testes e escalas: Cognitive and Language Complaints Evaluation - 24 (CLCE-24), Addenbrooke's Cognitive Examination scale, National Institutes of Health Stroke Scale (NIHSS), Modified Rankin Scale, Escala de Depressão Geriátrica. O NIHSS e a Modified Rankin Scale foram aplicados durante a consulta pelo

neurologista do doente. A escala CLCE-24 foi também aplicada uma vez ao familiar ou cuidador que acompanhava o doente. Foram recolhidas informações demográficas (idade, escolaridade, sexo, lateralidade, residência no domicílio ou em clínica de reabilitação) e caraterísticas clínicas fornecidas pelo médico do doente (AVC hemorrágico ou isquémico); primeiro ou recorrente AVC; território do AVC; volume da lesão; gravidade do AVC, avaliada pela NIHSS.

Foram incluídos 50 doentes. Trinta e um pacientes eram do sexo masculino (62%), com mediana de idade de 70 anos (intervalo interquartil: 60.75-79 anos). A maioria tinha 1 a 4 anos de educação formal (ensino primário) (38%), era reformada (74%), vivia em casa (98%) e era dextra (98%). A mediana da duração entre a data do AVC e a data de realização do teste foi de 12 meses (intervalo interquartil = 5-21 meses). O tipo de AVC mais frequente foi o isquémico (84%), sendo a artéria cerebral média esquerda a localização mais comum (32,6%), seguida da artéria cerebral média direita (18,4%). O AVC hemorrágico foi menos frequente (16%), sendo o tálamo direito a localização mais comum (4,1%).

Os resultados revelaram que as queixas cognitivas subjetivas, avaliadas através da escala CLCE-24, eram comuns após o AVC (mediana = 8.5 pontos, em 22). Adicionalmente, os doentes e os seus familiares concordaram com a existência destas queixas ($p < 0.01$), o que sugere que os familiares podem fornecer informações relevantes sobre o estado do doente, e podem ajudar a identificar problemas cognitivos e emocionais de que o doente pode não estar consciente.

O comprometimento cognitivo objetivo, avaliado pela escala Addenbrooke's Cognitive Examination, foi predominante após o AVC (mediana = 76 pontos, em 100). Os resultados desta escala mostraram que a maioria dos doentes (62%) tem um défice cognitivo ligeiro e que apenas 38% dos doentes obtiveram pontuações acima dos valores de corte estabelecidos para o défice cognitivo com base na norma. As queixas cognitivas relacionadas com a linguagem (ou seja, dificuldade de leitura, escrita e fala relatada pelo doente) parecem ser mais prevalentes (mediana = 21,0, em 26). As queixas cognitivas e o défice cognitivo objetivo não estavam correlacionados (r = -0,199, p = 0,170). No entanto, o défice cognitivo objetivo foi correlacionado com a categoria cognitiva da escala CLCE-24 (r = -0,322, p = 0,023), o que indica que quanto mais queixas cognitivas os doentes referem, mais défice cognitivo objetivo têm. As pontuações dos familiares dos doentes na escala CLCE-24 estavam correlacionadas com as pontuações dos doentes na

escala Addenbrooke's Cognitive Examination (r = -0,496, p = 0,006), mostrando que a perceção dos familiares está relacionada com as pontuações objetivas dos doentes.

As queixas cognitivas correlacionaram-se com a independência funcional (r = 0,407, p = 0,003), depressão (r = 0,693, p < 0,001) mas não com o desempenho cognitivo (r = -0,221, p = 0,126), e foram independentes da idade, sexo, literacia, situação profissional, localização da lesão e tipo de AVC, sugerindo que o estado cognitivo, principalmente a depressão, está mais correlacionado com as queixas do doente do que o desempenho objetivo.

O modelo de análise multivariada integrou as variáveis Modified Rankin Scale e Escala de Depressão Geriátrica como preditores das queixas cognitivas pós-AVC, evidenciando o seu potencial como preditores significativos das queixas cognitivas pós-AVC. Este modelo realçou a associação entre estas queixas, a incapacidade funcional e a depressão, sugerindo que a atenuação dos sintomas depressivos poderia levar a uma diminuição das queixas relatadas pelos doentes.

Estes resultados sublinham a importância de considerar os fatores psicológicos quando se avaliam as queixas cognitivas subjetivas em doentes com AVC, mesmo que não se alinhem com medidas objetivas do funcionamento cognitivo. Este estudo fornece informações sobre a complexa relação entre as queixas subjetivas, o défice cognitivo e os fatores emocionais após o AVC. Os presentes resultados podem contribuir para o desenvolvimento de programas de tratamento adaptados para melhorar a qualidade de vida e os resultados cognitivos nesta população.

De um modo geral, este estudo aprofunda a nossa compreensão da intrincada relação entre queixas cognitivas, défice cognitivo objetivo, fatores emocionais e incapacidade funcional em doentes com AVC. Salienta a natureza multifacetada destas questões e a necessidade de avaliações abrangentes que englobem as perspetivas do doente e da família, os aspetos emocionais e o desempenho cognitivo objetivo.

Além disso, a fim de abordar os desafios emocionais enfrentados pelos doentes com AVC, propomos uma abordagem holística que integra a monitorização neurológica com o apoio emocional e social. Propomos: Implementação de programas de reabilitação cognitiva concebidos para equipar os doentes com estratégias adaptadas aos seus desafios cognitivos; Monitorização emocional e de assistentes sociais, paralela à monitorização neurológica, para abordar as necessidades de saúde mental dos doentes e fornecer apoio emocional; Um grupo de apoio sócio-comportamental, liderado por profissionais, para

oferecer um espaço seguro para os doentes partilharem experiências e receberem orientação; Criação de um grupo multidisciplinar de neurociências, composto por neurologistas, psicólogos, assistentes sociais e outros profissionais relevantes, para supervisionar a integração dos serviços de apoio neurológico, emocional e social, assegurando uma abordagem abrangente aos cuidados do doente. Com esta abordagem, pretendemos melhorar os cuidados globais e o bem-estar dos doentes com AVC, reconhecendo e respondendo às suas necessidades emocionais, contribuindo para o sucesso da sua reabilitação e recuperação.

Palavras-chave: AVC, queixas subjetivas cognitivas subjetivas, défice cognitivo

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I. INTRODUCTION

Stroke is a major cause of long-term disability affecting almost 17 million people worldwide and approximately 1.1 million people per year in Europe alone, with significant consequences for survivors' daily functioning and quality of life. In Portugal, around 23,000 patients are discharged from hospitals with a stroke diagnosis each year. (Direcção Geral de Saúde, 2014; Bejot, Bailly, Durier & Giroud, 2016; Feigin et al. 2017). About 80% of strokes are ischemic, 15% are caused by a parenchymal bleeding (intracerebral hemorrhage) and 5% result from a bleeding in the subarachnoid space (subarachnoid hemorrhage) (Go et al., 2013; Caplan, 2016;). Depending on the location and severity of brain damage, temporary or permanent loss of functions in the physical, cognitive and behaviour and/or emotional domain occurs (Cumming, Brodtmann, Darby & Bernhardt, 2014; Bramlett & Dietrich, 2015). Most patients survive their stroke, and after hospitalization, stroke patients may be discharged either to their homes, to rehabilitation facilities (e.g., inpatient rehabilitation facility or skilled nursing facility) for additional therapy, or to nursing homes for long-term care and support, depending on the severity of their condition, family support and medical needs (Hong, 2018; Jackson & Chari, 2019). Therefore, stroke survivors comprise a large spectrum of patients requiring long term management (Bejot, Bailly, Durier & Giroud, 2016).

The improved post-stroke survival over the past decades has, in turn, shifted research and clinical attention towards the long-term physical and mental consequences of stroke, not only in objective measures but also in terms of subjective perception, personal impact and quality of life. In fact, understanding the subjective cognitive complaints reported by stroke survivors is to be essential to address their needs adequately (Chohan, Venkatesh & How, 2019; Bavikatte, Subramanian, Ashford, Allison & Hicklin, 2021; Kainz et al., 2021).

This chapter provides an overview of the impact of stroke on cognitive function and introduces the importance of studying subjective cognitive complaints in stroke survivors.

A. IMPAIRMENTS AFTER STROKE

The impairments after stroke can affect different domains of functioning and autonomy: cognitive, non-cognitive or psychological.

A1. NON-COGNITIVE IMPAIRMENTS

Regarding the non-cognitive domain, stroke survivors frequently experience one or more physical impairments. The most prominent are motor deficits (e.g., muscle weakness, spasticity, and movement disorders), sensory disturbances (e.g., pain, increased or decreased sensation and sensory impairments), seizures and sleep disorders (e.g., insomnia) (Davis, Billings, Longstreth & Khot, 2013; Caplan, 2016; Bavikatte, Subramanian, Ashford, Allison & Hicklin, 2021). All of these may cause loss of autonomy and contribute to dependency.

A2. COGNITIVE IMPAIRMENTS

Neurocognitive consequences of stroke refer to the impairments and changes in cognitive function that can occur as a result of a stroke. Depending on the location and severity of the stroke, these cognitive impairments may affect different cognitive domains and have an impact in daily living, autonomy, and the ability to return to work. The cognitive profile after stroke typically includes impairments in the domains of processing speed, attention and executive function. Less frequently it may involve memory, language and visuospatial functions (Cumming, Marshall & Lazar, 2013; Aam et al., 2020; Lo et al., 2022). Cognitive disorders due to stroke can be included in different syndromes:

1. Vascular mild cognitive impairment (VaMCI): refers to a cognitive decline that is greater than expected for an individual's age and education level but does not meet the criteria for dementia. It is commonly associated with vascular risk factors and is considered a prodromal stage of vascular dementia. Often involves deficits in executive functions, processing speed, attention, and memory (Pendlebury et al., 2012; Sachdev et al., 2014);
2. Vascular dementia (VaD): a type of dementia caused by cerebrovascular disease, including stroke. It is characterized by a decline in cognitive function that interferes with daily activities. Typically presents with impairments in executive functions, attention, memory, and language. The specific pattern of cognitive impairment may vary depending on the location and extent of cerebrovascular damage (Pendlebury et al., 2012);
3. More isolated impairments such as:
    a. Processing Speed Reduction: Many stroke survivors experience a reduction in processing speed, affecting the efficiency of cognitive processing. This can

result in slowed thinking, responding, and information processing, which can impact overall cognitive performance (El Husseini et al., 2023);

b. Visuospatial Dysfunction: Stroke can result in visuospatial impairments, impacting spatial perception, visual attention, and navigation abilities. This can manifest as difficulties in judging distances, recognizing objects, or mentally manipulating and representing spatial information or in inattention to one side of the space, or neglect (Nijboer, Winters, Kollen & Kwakkel, 2018; Ye et al., 2019; Zebhauser, Vernet, Unterburger & Brem, 2019; Alves, Silva, Fonseca & Martins, 2021);

c. Memory Impairment: Stroke survivors may experience difficulties in acquiring, retaining, or retrieving information from memory. These impairments can affect both short-term and long-term memory processes the latter more associated to temporal infarcts (Maeshima & Osawa, 2021; El Husseini, et al., 2023);

d. Attention and Concentration Deficits: Stroke can also lead to attention and concentration difficulties. Stroke survivors may struggle to focus, sustain attention, or divide attention between multiple tasks (Aam et al., 2020; Lo et al., 2022);

e. Executive Dysfunction: Executive functions involve higher-level cognitive processes such as planning, problem-solving, decision-making, and cognitive flexibility. Stroke can disrupt these functions, leading to difficulties in organizing, initiating, and completing tasks, as well as impaired judgment and problem-solving abilities (Skidmore, Eskes, & Brodtmann, 2023). These are common when stroke involves the frontal subcortical networks;

f. Language and Communication Impairments: Depending on the location of the stroke, language and communication abilities can be affected specially following lesions of the left hemisphere. Aphasia, which involves difficulties in understanding or producing language, is a common consequence. It can manifest as difficulties in speaking, finding words, understanding written or spoken language, or reading and writing (Fridriksson & Hillis, 2021);

The prevalence of cognitive impairment ranges from 10% to 82%, depending on the criteria used to define impairment, the time interval of assessment chosen after stroke and the patient sample evaluated (Sexton et al., 2019).

Cognitive impairment can be evaluated either objectively, using global cognitive screening tests or neuropsychological tests covering one or more domains (e.g. memory, attention, processing speed, executive functions), or subjectively, using self-report measures or interviews. To date, most studies investigating post-stroke cognition have focused on objective assessment (van Rijsbergen, Mark, de Kort, & Sitskoorn, 2014).

Detection of cognitive impairment in the chronic phase is essential to better define rehabilitation and functional adaptation strategies, as marked improvements in cognitive function can occur in the first months after stroke, and recovery can be facilitated by rehabilitation programs (Cumming, Marshall & Lazar, 2013; Levine et al., 2015; Mellon et al., 2015; Pinter et al., 2019). Longitudinal studies show that approximately 70% of the patients remain cognitively stable over time, about 10% deteriorate and develop dementia, and 20-30% will partially recover in terms of cognitive function (Levine et al., 2015; Brainin et al., 2015).

A3. NEUROPSYCHIATRIC IMPAIRMENTS

In addition to the mentioned impairments, neuropsychiatric disorders are also prevalent after stroke, with nearly 31% of patients experiencing depression and approximately 25% of patients reporting anxiety (Ferro, Caeiro & Figueira, 2016; Medeiros, Roy, Kontos & Beach, 2020).

Predictors of post-stroke depression and anxiety include pre-stroke depression or anxiety, post-stroke cognitive impairment (e.g. aphasia), history of insomnia, dependence to perform activities of daily living, inability to work, lack of social support and maladaptive coping mechanisms in difficult personal situations (Ferro, Caeiro & Figueira, 2016; Medeiros, Roy, Kontos & Beach, 2020).

Fatigue and apathy are also among the most common sequelae of stroke. Fatigue is reported by more than 50% of stroke survivors, even when stroke is relatively mild and there is little disability. The onset of fatigue often occurs immediately after stroke. About one-third of the patients recover over time, but fatigue tends to persist in the majority of patients. The factors found to be most strongly associated with the prevalence of fatigue after stroke include physical disability and depression. (Kutlubaev & Mead, 2013; Wu, Mead, Macleod & Chalder, 2015; Cumming, Packer, Kramer & English, 2016).

Apathy affects around a third of post-stroke patients. The prevalence of apathy increases over time, especially in patients who show evidence of cognitive and functional decline (Tay, Morris & Markus, 2021). Post-stroke apathy is characterized by a lack of motivation and interest in daily activities. Husain and colleagues point out that post-stroke apathy can significantly impact patients' rehabilitation and quality of life, as it interferes with participation in rehabilitation therapies and engagement in activities that promote functional recovery, as well as affecting psychological well-being and adaptation to post-stroke changes. Understanding this relationship is fundamental to developing effective rehabilitation and psychosocial support strategies for these patients (Chong & Husain, 2016; Heron, Apps & Husain, 2018).

This post-stroke emotional disorders are associated with a lower quality of life (QoL) in both patients and their caregivers, more dependency in activities of daily living, more institutionalization, higher health-care costs, and a higher mortality rate (Cumming, Brodtmann, Darby & Bernhardt, 2014; Levine, 2015; Medeiros, Roy, Kontos & Beach, 2020).

B. SUBJECTIVE COGNITIVE COMPLAINTS

The consequences of stroke can negatively affect the subjective experience of cognitive abilities after a stroke. Despite the multiple recent studies on post-stroke objective cognitive performance, less scientific attention has been paid to subjective cognitive complaints. These refer to the cognitive and behavioral difficulties stroke patients experience and report.

The prevalence of post-stroke subjective cognitive complaints vary widely, depending on the measurement tools, ranging between 28.6% and 92% of the patients worldwide (van Rijsbergen, Mark, de Kort & Sitskoorn, 2014; van Rijsbergen, Mark, Kop, de Kort & Sitskoorn, 2019; Nijsse et al., 2021). Of the few domains that were assessed in these studies, complaints related to the domains mental speed, concentration and memory found to be the most common (Duits, Munnecom, van Heugten & van Oostenbrugge, 2008; Wendel et al., 2008; Lamb, Anderson, Saling & Dewey, 2013; van Rijsbergen, Mark, de Kort & Sitskoorn, 2014; Nijsse et al., 2021).

However, the cognitive tests and scales for the assessment of objective and subjective cognitive complaints do not accurately measure the engagement of patients in their daily activities, so there may be a mismatch between what is assessed by neuropsychological tests and the actual performance of the patient.

In addition to the subjective cognitive complaints reported by patients, caregivers often report other behavioral changes in stroke survivors. These may include irritability, aggression, indifference, unpredictable mood swings, and difficulty controlling anger or frustration. These changes can lead to social and emotional difficulties, damaging relationships and affecting overall well-being. (Naghavi, Koffman, Lin & Du, 2019; Kootker et al.,2019; Zhang et al., 2020; Hazelton et al., 2022).

B1. SUBJECTIVE COGNITIVE COMPLAINTS AND OBJECTIVE COGNITIVE PERFORMANCE

The association between subjective cognitive complaints with objective cognitive impairment in stroke patients is unclear, as research studies have produced mixed results.

Some studies found subjective cognitive complaints to be associated with objective cognitive impairment (Lincoln & Tinson,1989; Davis, Cockburn, Wade & Smith, 1995; Keller, Schlenker & Pigache, 1995; Van Heugten et al., 2007; Wendel et al., 2008; Xiong, et al., 2011; Narasimhalu, Wiryasaputra, Sitoh & Kandiah, 2013), while others have not found a significant association (Martin et al., 2002; Duits, Munnecom, van Heugten & van Oostenbrugge, 2008; Winkens, Van Heugten, Fasotti & Wade 2009; Aben et al., 2011; Pendlebury, Mariz, Bull, Mehta & Rothwell, 2012; Lamb, Anderson, Saling & Dewey, 2013). Studies suggests that there is not a one-to-one relationship between objective cognitive performance, based on neuropsychological tests, and the patient-reported subjective cognitive complaints (van Heugten et al., 2007; Duits, Munnecom, van Heugten & van Oostenbrugge, 2008; Winkens, Van Heugten, Fasotti & Wade, 2009; Aben et al., 2011; Nijsse et al., 2017; Ji et al., 2022; Zanin, Reinholdsson & Abzhandadze, 2023).

When there is a relationship between subjective cognitive complaints and objective cognitive performance, its degree is variable and is influenced by various factors. Some individuals may report cognitive difficulties despite performing within the normal range on standardized cognitive tests, while others may not perceive any cognitive difficulties

despite objective cognitive impairments (van Rijsbergen, Mark, de Kort & Sitskoorn, 2014).

Several factors contribute to the discrepancy between subjective cognitive complaints and objective performance. On one hand, objective cognitive tests do not cover the wide range of activities, multitasking and cognitive demands that individuals face in daily living and in their professional life. On the other hand, cognitive tests can vary in their degree of difficulty and sensitivity, which may influence test results. Additionally, emotional factors, such as depression and anxiety, can amplify subjective cognitive complaints even in the absence of significant cognitive impairment.

The association between cognitive complaints and objective performance can also vary based on the specific cognitive domain being assessed and the tools utilized for evaluation, as well as whether symptoms are self-reported spontaneously or in response to a scale. For example, some studies have found that cognitive complaints of memory are more closely associated with objective memory performance, while other cognitive domains, such as attention or executive functions, may show weaker correlations (Zlatar et al., 2014; Miley-Akerstedt et al., 2018). Davis, Cockburn, Wade & Smith (1995), Wendel et al. (2008) and Xiong et al. (2011) add that patients with subjective cognitive complaints would show impairment in objective cognitive function, in a domain specific manner. Duits, Munnecom, van Heugten & van Oostenbrugge (2008) evaluated the patient perceived impact of subjective cognitive complaints, using the CLCE-24 scale (Checklist for cognitive and emotional consequences following stroke), that assesses the cognitive domains of memory, visual-spatial function, attention, and language by indicating the presence or absence of each complain (this scale is further detailed in the chapter *methods*, sub-chapter *tests and scales*), and concluded that post-stroke subjective cognitive complaints were unrelated to objective cognitive impairment. However, this study had several limitations. First, the patients were retrospectively included and selected by living only at home after discharge from the stroke unit. As a result, they do not represent the general stroke population. Moreover, a selection bias was included as this selection was made with intention, based on the assumption that cognitive and emotional changes might be more easily neglected in patients discharged home than in those referred to a nursing home or rehabilitation centre. Second, the sample size was relatively small (n = 61), thereby reducing statistical power. Third, the CLCE-24 scale was used, but performance was based only on global screening measures (Mini-Mental

State Examination[1] and the Cambridge Cognitive Examination[2]), hence no patterns of cognitive performance. Furthermore, patients' cognitive performances in test situations do not always correspond to performances in daily life activities (Winkens, Van Heugten, Fasotti & Wade, 2009; Lamb, Anderson, Saling & Dewey, 2013).

Reduced awareness of cognitive deficits or a tendency to underreport difficulties due to denial or social desirability bias can lead to a discrepancy between subjective cognitive complaints and objective performance (van Rijsbergen, Mark, Kop, de Kort, Sitskoorn, 2020). When comparing subjective cognitive complaints of patients with stroke to informant reports (e.g., family members), there can be moderate agreement on the prevalence and severity of patients' subjective cognitive complaints, but also discrepancies (Tinson & Lincoln, 1987; Lincoln & Tinson, 1989; Martin et al., 2002; Visser-Keizer et al., 2002; Hochstenbach, Prigatano & Mulder, 2005; Wendel et al., 2008; Pendlebury & Rothwell, 2009; van Rijsbergen et al., 2014; van Rijsbergen, Mark, Kop, de Kort, Sitskoorn, 2020). The differences in perception between individuals and their informants may be because, according to social psychology, people who share the same event do not perceive it in the same way, and stroke patients may have a distorted perception of their problems (Hochstenbach, Prigatano, & Mulder, 2005; van Rijsbergen, Mark, de Kort, & Sitskoorn, 2014), and/or because of the patients' reduced awareness (i.e., anosognosia[3]), denial, or emotional distress of patients and/or their partners (van Exel et al., 2005; Wendel et al., 2008; Barrett, 2021). Thus, the relatives of the patients with right-sided injuries may report more difficulties in daily life activities than the relatives of patients with left-sided injuries, since patients with right-sided injuries may have anosognosia and therefore have reduced awareness or complete rejection of the disabling consequences of brain dysfunction (Barrett, 2021).

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[1] The Mini-Mental State Examination (MMSE) is a brief screening tool to detect the presence of cognitive impairment and to provide a quantitative evaluation of cognitive impairment and to record cognitive changes over time. The MMSE measures orientation to time and place, immediate recall, short-term verbal memory, calculation, language, and construct ability. (Folstein, Folstein, & McHugh, 1975; Folstein, Robins, & Helzer, 1983).

[2] The Cambridge Cognition Examination (CAMCOG) is the cognitive and self-contained part of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX). The CAMCOG is a standardized instrument used to measure the extent of dementia, and to assess the level of cognitive impairment. The measure assesses orientation, language, memory, praxis, attention, abstract thinking, perception and calculation (Roth et al., 1986).

[3] Anosognosia means "without knowledge of disease." People with neurologic disorders can demonstrate reduced awareness, or complete disavowal, of disabling consequences of brain dysfunction. After right brain stroke, patients can appear unaware of left hemiparesis (Heilman, Barrett & Adair, 1998; Fowler, Sala, Hart & McIntosh, 2018).

Many of the previous studies to date have evaluated objective cognitive performance without exploring the impact of subjective cognitive complaints on daily life. It is essential to consider and establish a relationship between both, as well as to characterise how these influence the patients' psychological state, in order to provide a more comprehensive understanding of the individual's cognitive profile and to understand whether these complaints are relevant warning signs of impairment and to develop appropriate treatment programs (van Rijsbergen, Mark, Kop, de Kort, & Sitskoorn, 2018).

B2. SUBJECTIVE COGNITIVE COMPLAINTS AND EMOTIONAL FACTORS

In addition to a possible link with objective cognitive impairment, studies suggest an association between subjective cognitive complaints and post-stroke emotional factors, with higher levels of depressive symptoms associated with an increase in subjective cognitive complaints, regardless of objective cognitive performance (Ayerbe et al., 2013; Narasimhalu et al., 2013; Cumming et al., 2013; Nijsse et al., 2017; Lamb, Anderson, Saling & Dewey, 2013; Medeiros, Roy, Kontos & Beach, 2020). However, this relationship is not always found (Narasimhalu, Wiryasaputra, Sitoh & Kandiah, 2013).

It is important to study the relationship between cognitive complaints and depression in order to know if they are indeed related and to what extent, and to be able to provide more appropriate forms of treatment.

C. OBJECTIVES AND HYPOTHESES

The current study aimed to identify the frequency and type of subjective cognitive complaints after a stroke, their agreement between patients and families, and how they are related to the objective cognitive and functional impairment.

The specific objectives were:

1) To analyse the frequency and type of post-stroke subjective cognitive complaints, covering various cognitive domains;
2) To compare the cognitive complaints reported by stroke patients with those reported by their family members;
3) To assess the correlation between cognitive complaints and objective cognitive impairment after stroke;
4) To assess the correlation between cognitive complaints and neurological deficits and functional disability after stroke;
5) To evaluate the existence of a correlation between the degree of depression and cognitive complaints.

The main hypothesis is that cognitive complaints reflect cognitive impairment in stroke patients.

Additionally we also hypothesized that:

a) The frequency of complaints is related to the severity of stroke (Davis, Cockburn, Wade & Smith, 1995; van Exel et al., 2005; Wendel et al., 2008; Xiong et al., 2011; Barrett, 2021);
b) There would be a weak agreement between the complaints reported by patients and those reported by family members, since family may be aware of symptoms that patient may underestimate (Hochstenbach, Prigatano, & Mulder, 2005; van Rijsbergen, Mark, de Kort, & Sitskoorn, 2014);
c) Patients with subjective cognitive complaints would show impairment in objective cognitive function, in a domain (cognitive and emotional) specific manner (Davis, Cockburn, Wade & Smith, 1995; van Exel et al., 2005; Wendel et al., 2008; Xiong et al., 2011; Barrett, 2021);

d) Cognitive complaints would be correlated to functional disability in stroke patients, since they are part of a spectrum of disability felt by the patients and related to the severity of stroke;

d) Cognitive complaints are exacerbated by depressive symptomatology.

II. METHODS

A. STUDY DESIGN AND PATIENT SELECTION

We performed an observational, prospective, cohort study that included patients in the chronic phase of stroke, recruited from the outpatient stroke clinic of the Department of Neurology, Hospital de Santa Maria, CHULN, Lisbon, Portugal. The assessment took place at the site and on the date of the appointment, after the patients signed the written informed consent. Recruitment lasted from October 2021 to May 2022.

We consecutively included adult patients with the following inclusion criteria: a) stroke with hemispheric, cerebellar and/or thalamic involvement; b) chronic phase of stroke (at least 3 months after stroke); c) vascular lesion documented in imaging exam (CT or MRI); d) be able to participate in the cognitive assessment of pen and paper cognitive batteries. Patients with either ischemic or hemorrhagic strokes were considered. The exclusion criteria were as follows: a) evidence of cognitive impairment prior to stroke, according to the clinical history provided by the patient's relatives and/or to the patient's medical records in the hospital electronic health platform; b) severe aphasia, precluding the application of the assessment tests.

The study was approved by the Joint Ethics Committee of the Lisbon Academic Medical Centre, and patient informed consent was obtained for acquisition and publication of individuals' data. After informed consent, demographic information was collected (age, education, gender, laterality, living at home or in a rehabilitation clinic) as well as clinical features provided by the patient physician (hemorrhagic or ischemic stroke); first or recurrent stroke; stroke territory; lesion volume; stroke severity, as assessed by the NIHSS (*National Institutes of Health Stroke Scale*).

B. ASSESSMENT MEASURES

The tests and scales applied to each patient were chosen considering their psychometric properties, validity, reliability and sensitivity.

The following battery of tests was applied:

- Cognitive and Language Complaints Evaluation - 24 (CLCE-24): A self-report measure assessing subjective cognitive complaints in stroke patients, comprising cognitive (domains of memory, visual-spatial function, attention, and language) and

emotional categories by a brief checklist composed of 24 questions: 22 closed questions about cognitive and emotional complaints, and 2 open questions to allow the patient to express additional cognitive complaints not included in the checklist. Each item is assessed by indicating the presence or absence (score 1 or 0, respectively) of each complain. The higher the score, the more complaints the individual has. In addition, if a complaint is present, the interviewer asks about the influence it has on the patient's daily life (hindering daily life severely or not) (van Heugten, Rasquin, Winkens, Beusmans & Verhey, 2007);

- Addenbrooke's Cognitive Examination scale: An objective cognitive assessment scale used to measure cognitive impairment in stroke patients. In this study it was used the third version of this scale (ACE-III), validated for the Portuguese population. It consists of 24 tasks, with a maximum score of 100 points, divided in five domains: Attention/Orientation (18 points), Memory (26 points), Fluency (14 points), Language (26 points) and Visuospatial functions (16 points). The total score is obtained by adding the sub-scores in the five domains. Higher scores are indicative of better cognitive functioning (Mioshi et al., 2006; Baeta, Pimentel & Peixoto, 2015). The cut-off point values for Mild Cognitive Impairment (MCI) are 79 and for Dementia 68 points (Simões et al., 2015);

- National Institutes of Health Stroke Scale (NIHSS): A measure of neurological post-stroke deficits. The scale, consisting of 15 items, assesses the level of consciousness, visual fields, ocular movements, facial palsy, limb strength, sensory function, coordination, language, speech (dysarthria) and hemi-attention (Lyden, Lu, & Jackson, 1999; Lyden, Lu, & Levine, 2001; Balakrishnan et al., 2014). The overall score ranges from 0 to 42, with higher scores representing more severe neurological deficits (Adams & Davis, 1999);

- Modified Rankin Scale: A measure of functional independence with reference to the pre-stroke activities. This scale is composed of 7 disability grades (0, 1, 2, 3, 4, 5 and 6), with grade 0 corresponding to the asymptomatic state, grade 5 corresponding to the severe disability, and grade 6 to death (Wilson et al., 2002; Kasner, 2006). A total score of 2 or below indicates that the patient is functionally independent, and a total

score above 2 indicates that the patient is functionally dependent (Sulter, Steen & Keyser, 1999);

- Geriatric Depression Scale, 15 item version: A measure of depressive symptomatology. This 15 items version was developed by Sheikh & Yesavage (1986) and is a short version of the original scale, formulated by Yesavage et al. (1982), that has 30 items. This scale was developed to detect depression mainly in the elderly population and can be applied to geriatric patients who have suffered a stroke. The 15 items were chosen out of the original 30 items based on the items which most strongly correlated with the diagnosis of depression. Sheikh & Yesavage (1986) suggest that, in order to quantify the results, the following classification should be used: scores of 0-5 points indicates the absence of depression; scores higher than 5 are depression indicators.

The NIHSS and the Modified Rankin Scale were applied during the consultation by the patient's neurologist. The CLCE-24 scale was also applied once to the family member or caregiver accompanying the patient.

C. STATISTICAL ANALYSIS

First, a descriptive statistical analysis of the demographic and clinical characteristics and of the vascular territories and haemorrhage was performed. Categorical variables were presented as frequencies. Continuous variables were presented as mean (standard deviation) or median [interquartile range], according to their distribution.

Then, regarding the 1st specific objective, in order to determine post-stroke cognitive complaints, covering various cognitive domains, we applied the CLCE-24 scale (Checklist for cognitive and emotional consequences following stroke), and the frequency and type of post-stroke cognitive complaints were assessed through a descriptive analysis.

In addition, the following sub-analysis were performed:

- Test the hypothesis that the distribution of patients' CLCE-24 scores was the same in the stroke type category.
- Test the hypothesis that the distribution of patients' CLCE-24 score was the same in the lesion location category.

- Compare the scores obtained in the *cognitive* and *emotional* categories of the CLCE-24 test.
- Correlate the *cognitive* and *emotional* scores of the CLCE-24 test in each patient.

Concerning the 2nd specific objective, which consisted of comparing the patient's perception with the family member's perception, the CLCE-24 scale was applied to the patient and the family member, in a pairwise comparison to compare the patient's report with the family's report.

Due to the hypothesis that the patient-family complains discrepancy is greater in patients with right lesions than in left lesions, a sub-analysis was performed correlating the CLCE-24 score of the patient and family member, according to the laterality of the injury, to infer if the difference between the score of the relative and the score of the patient with right-sided injury will be greater compared to the difference between the score of the relative and the score of the patient with left-sided injury.

With regard to the 3rd specific objective, which aimed to study the correlation between cognitive complaints and objective cognitive impairment, we applied, the Addenbrooke's Cognitive Examination scale.

In order to evaluate in which CLCE-24 categories there is a greater correlation with the Addenbrooke's Cognitive Examination, a 1st and 2nd sub-analysis were performed correlating the score obtained in the *cognitive* category with the Addenbrooke's Cognitive Examination, and the score obtained in the *emotional* category with the Addenbrooke's Cognitive Examination, respectively. A 3rd sub-analysis was performed to assess whether there was a correlation between the scores of the CLCE-24 test applied to the family members and the scores of the Addenbrooke's Cognitive Examination applied to the patients of these family members.

Regarding the 4th specific objective, which aimed to study the correlation of cognitive complaints with the neurological deficit and post-stroke functional disability, we correlated the score obtained in the NIHSS scale (National Institutes of Health Stroke Scale) with the results obtained in the CLCE-24 scale. To study the correlation between cognitive complaints and post-stroke functional disability, the modified Rankin Scale was applied and correlated with the CLCE-24 scale score.

With regard to the 5th specific objective, we assessed depressive symptoms, with the Geriatric Depression Scale, and correlated its results with the CLCE-24 scale score.

Owing to the hypothesis that there might be a strong correlation between the scores of the Geriatric Depression Scale and the scores obtained in the *emotional* category of the CLCE-24 scale, a 1st sub-analysis was performed correlating these two scores. We also calculated the partial correlation between CLCE-24 scale and the scores in the Addenbrooke's Cognitive Examination, controlling for the level of depression.

Univariate analysis was performed using the nonparametric tests Wilcoxon test, Mann-Whitney U-test or Kruskal-Wallis test. Continuous variables were correlated using a Spearman correlation coefficient for ordinal variables, or using a partial correlation coefficient, or compared with control correlations using the Cocor software package (Diedenhofen & Musch, 2015), as appropriate.

To evaluate the interactions and mutual influences of these variables, a multivariable model was constructed. This model included variables that exhibited significant effects in the univariate analysis and were selected based on clinical and statistical rationale, particularly those with previously demonstrated clinical associations and statistical correlations with the dependent and independent variables, such as the covariates modified Rankin Scale and Geriatric Depression Scale.

For the multivariate analysis, an ordered logistic regression was computed. The multivariate logistic regression model was built including variables with a statistically significant association in the bivariate analysis or those that were considered clinically relevant, using a step-up approach.

Statistical analysis was performed using SPSS (*Software Statistical Package for the Social Sciences*) version 20.0 (IBM SPSS, Chicago, IL). Alpha levels were set at 0.05 for statistical significance, and the *p*-value was corrected for multiple comparisons whenever appropriate.

III. RESULTS

A. DEMOGRAPHIC AND CLINICAL FEATURES

Fifty patients from the stroke outpatients' clinic at Santa Maria Hospital were evaluated after informed consent. Patient's demographic and clinical features are presented in Table 1. The majority of patients were male (62%), with a median age of 70 years and 1 to 4 years of formal education (primary education) (38%). The majority were retired (74%), lived at home (98.0%) and were right-handers (98.0%). The median duration between the stroke date and the test run date was 12 months.

The most frequent type of stroke was ischemic (84%). The median NIHSS score on admission was 7, the median NIHSS score on discharge was 2, the median NIHSS score on the day of testing was 1, the median Modified Rankin Scale (mRanking) score on the day of testing was 2, and the median Geriatric Depression Scale (GDS) score on the day of testing was 5.

Table 1 - Demographic and clinical features of the patients

		Cases (n = 50)
Demographic features	Age (years), median [IQR]	70 [60,75 – 79]
	Gender (F/M), n(%)	19 (38%) / 31 (62%)
	Literacy n(%)	
	1-4 years n(%)	19 (38%)
	5-6 years n(%)	7 (14%)
	7-9 years n(%)	9 (18%)
	10-12 years n(%)	8 (16%)
	More than 13 years n(%)	7 (14%)
	Professional situation (Rt/W), n(%)	37 (74%) / 13 (26%)
	Residency (LC/LH), n(%)	1 (2.0%) / 49 (98.0%)
	Handedness (L/R), n(%)	1 (2.0%) / 49 (98.0%)
	Period between stroke date and test run date (months), median [IQR]	12 [5-21]
Clinical features	Lesion location, n(%)	
	Left hemisphere*, n(%)	24 (48%)
	Right hemisphere*, n(%)	25 (50%)
	Left cerebellum, n(%)	1 (2%)
	Type of stroke (H/I), n(%)	8 (16%) / 42 (84%)
	Recurrency (N/Y), n(%)	47 (94%) / 3 (6%)

NIHSS on the day of stroke**, median [IQR]	7 [4 – 11,5]
NIHSS on the day of discharge***, median [IQR]	2 [1 – 4,5]
NIHSS on the day of testing, median [IQR]	1 [0 – 2]
mRankin on the day of testing, median [IQR]	2 [1 – 2]
GDS on the day of testing, median [IQR]	5 [4 – 9]

* thalamic involvement is aggregated with hemispheric involvement
**4 missing data (due to hospitalization and collection of this data at another hospital)
*** 5 missing data (due to hospitalization and collection of this data at another hospital)
Values are presented as the median [interquartile range], unless otherwise specified. F, female; M, male; Rt, retired; W, worker; LC, living in a rehabilitation clinic; LH, living at home; L, left; R, right; H, haemorrhagic; I, ischemic; N, no; Y, yes; NIHSS, National Institutes of Health Stroke Scale; mRankin, modified Rankin scale; GDS, Geriatric Depression Scale.

Table 2 presents vascular territories involved, indicating that the most frequent type of stroke was ischemic in the left middle cerebral artery (32.6%) followed by stroke in the right middle cerebral artery (18.4%). Hemorrhagic strokes were less frequent, with the right thalamus being the most common location (4.1%).

Table 2 - Territories of ischemia and haemorrhage lesion after stroke

Ischemic stroke	
Arterial territory	**N (%)**
Right middle cerebral artery	9 (18.0%)
Right middle cerebral artery and vertebrobasilar territory	2 (4.0%)
Left middle cerebral artery	17 (34%)
Right internal carotid artery	3 (6.0%)
Left internal carotid artery	2 (4.0%)
Left posterior carotid artery	1 (2.0%)
Right anterior cerebral artery	1 (2.0%)
Right posterior inferior cerebellar artery (PICA)	1 (2.0%)
Right posterior cerebral artery	2 (4.0%)
Left posterior cerebral artery	2 (4.0%)
Vertebrobasilar system	3 (6.0%)
Hemorrhagic strokes	
Location	**N (%)**
Lobar	**3 (6.0%)**
Right frontal lobe	1 (2.0%)
Right temporo-parietal lobe	1 (2.0%)
Left temporal lobe	1 (2.0%)
Deep	**4 (8.0%)**
Right thalamo-capsular	1 (2.0%)
Right thalamus	2 (4.0%)

Left basal ganglia	1 (2.0%)

The right column represents the number of cases and the corresponding percentage.

B. POST-STROKE SUBJECTIVE COGNITIVE COMPLAINTS

The participants' subjective perception was evaluated using the CLCE-24 scale. The higher the score, the more complaints the patient has. The median score of the CLCE-24 scale was 8.5 (interquartile range = 6–14). Figure 1 illustrates that scores distribution does not follow a normal pattern, showing that most patients obtained a score of 6 (7%), followed by a score of 14 (5%).

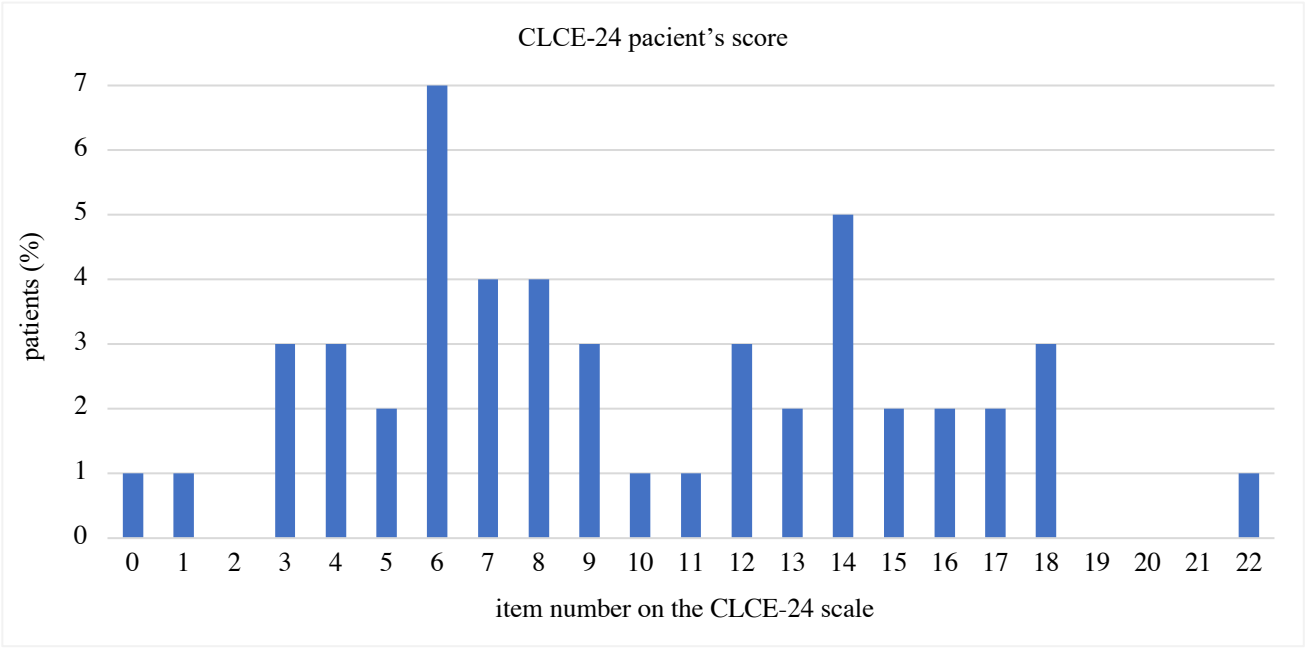

Figure 1 - Percentage of patients in each item of the CLCE-24 scale

Only two patients reported having additional complaints that were not contemplated in the questionnaire (items 23 and 24 of CLCE-24), one reporting headaches and the other experiencing difficulty in sleeping, which are considered noncognitive.

A bivariate analysis between CLCE-24 scale and demographic or clinical features revealed no significant correlations with age (Spearman correlation, r = -0.136, p = 0.345), gender (Mann-Whitney U-test, p = 0.411), literacy (Kruskal-Wallis test, p = 0.290), professional situations (Mann-Whitney U-test, p = 0.438), lesion location (Kruskal-Wallis test, p = 0.312) or type of stroke (Mann-Whitney U-test, p = 0.63).

1. Cognitive and emotional categories

As mentioned, the CLCE-24 scale is composed by two categories, *cognitive* and *emotional*. The *cognitive* category, consisting of 13 questions, had a median score of 5 (interquartile range = 2.7–8). The *emotional* category, consisting of 9 questions, had a median score of 4 (interquartile range = 3–7). Figure 2 illustrates the distribution of scores in the *cognitive* category, with the majority of patients having a total score of 2 and 3 (n = 8), followed by a total score of 9 (n = 7). In the *emotional* category, as shown in Figure 3, most patients had a total score of 4 (n = 10), followed by a total score of 2 and 7 (n = 7).

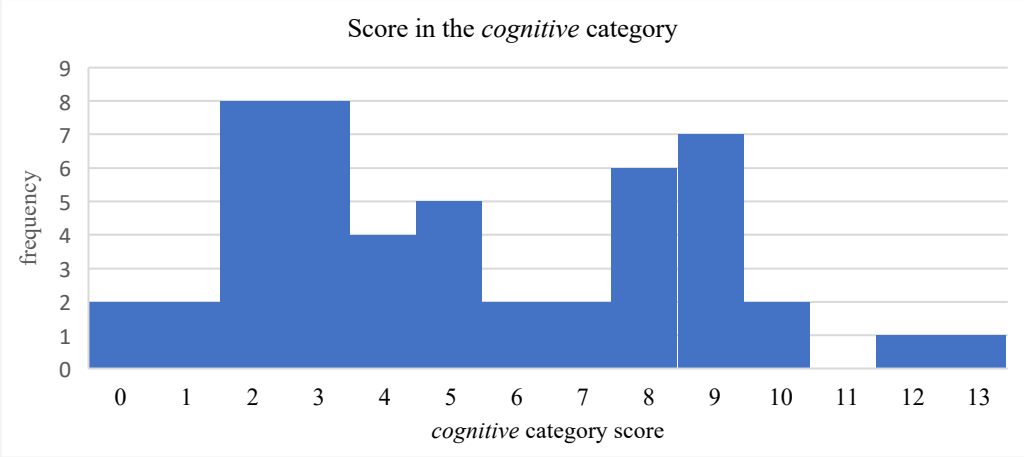

Figure 2 – Number of patients by score in the cognitive category.

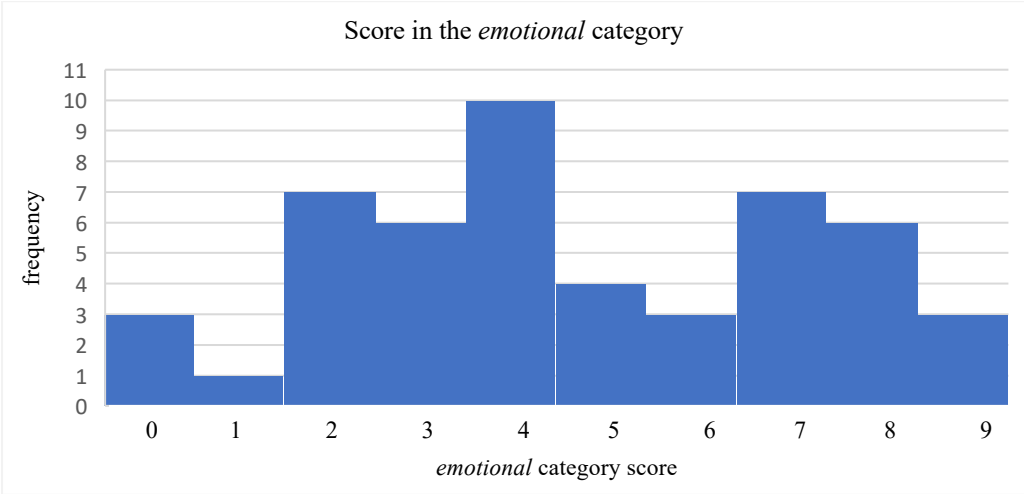

Figure 3 - Number of patients by score in the emotional category.

In the *cognitive* category, the most common complaints were related to questions 1 (*Doing two things at once*), 3 (*Keeping up; has become slower*) and 4 (*Remembering new*

information) (Figure 4). In the *emotional* category, the most common complaints were related to questions 14 (*Depressed*), 15 (*In fear of things to come*) and 21 (*Tired quickly*) (Figure 5). The questions are stated in the CLCE-24 scale, which can be found in the Appendix.

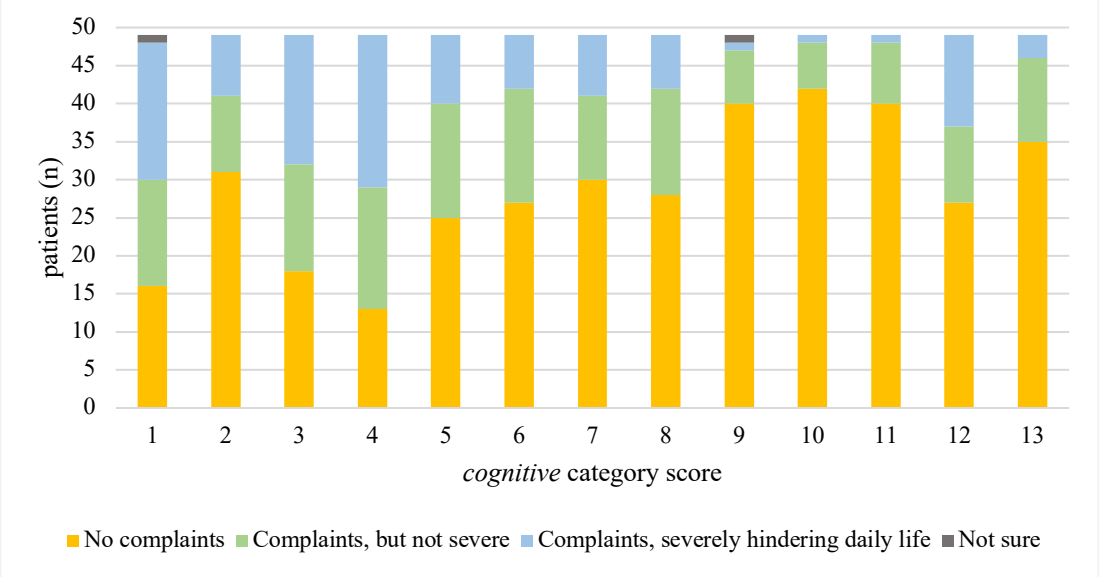

Figure 4 - Number of patients by answer in each question in the cognitive category of the CLCE-24 scale. Legend: y-axis represents the number of patients that were "not sure" if they had complaints on the subject of the question concerned, had "no complains", had "complains severely hindering daily life", "complaints but not sever" and "no complains"

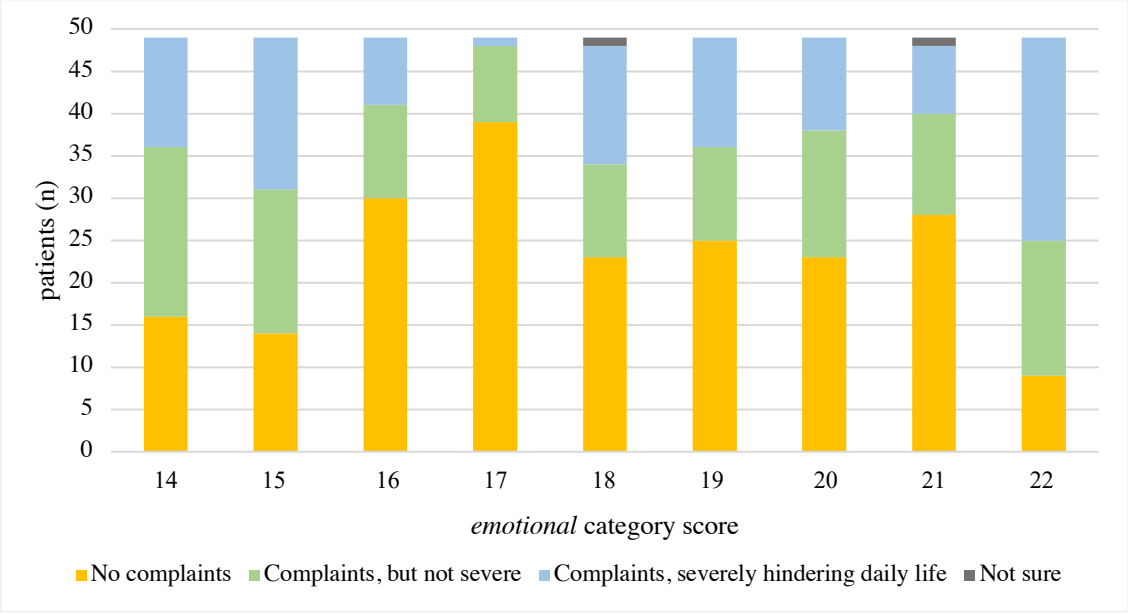

Figure 5 - Number of patients by answer in each question in the emotional category of the CLCE-24 scale. Legend: y-axis represents the number of patients that were "not sure" if they had complaints on the subject of the question concerned, had "no complains", had "complains severely hindering daily life", "complaints but not sever" and "no complains"

A strong and positive correlation was found between the scores of the cognitive and emotional categories of the CLCE-24 scale ($r = 0.631$, $p < 0.01$) (Figure 6). This finding suggests that cognitive and emotional experiences are closely related among stroke patients.

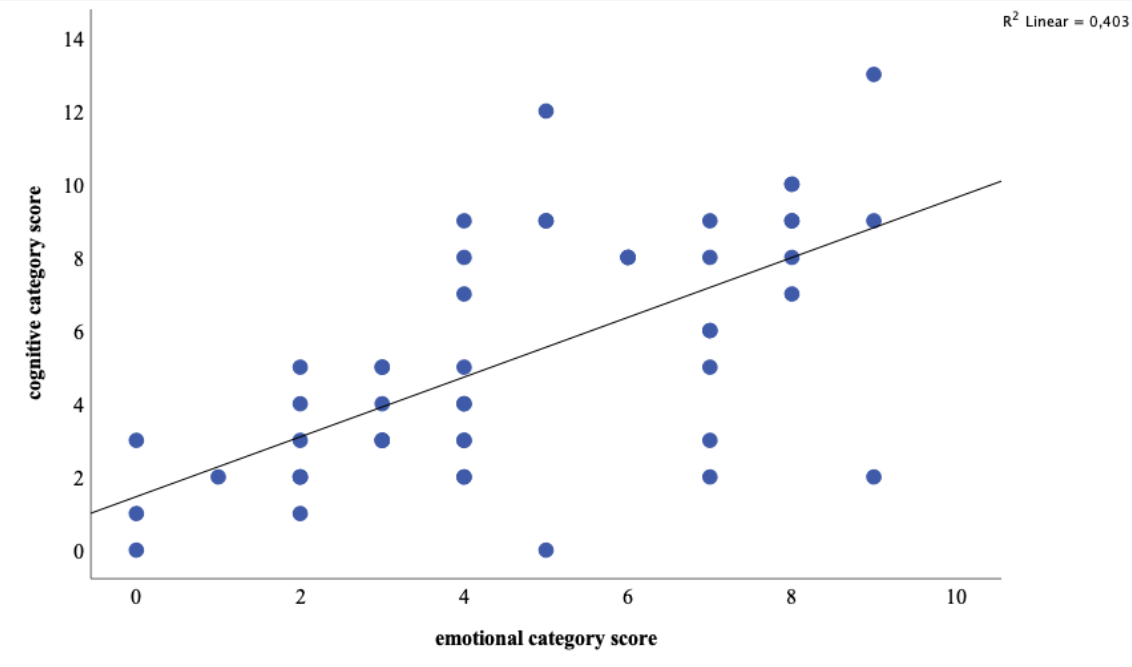

Figure 6 – Simple scatter plot of the correlation between the cognitive category scores and emotional category scores (Discloser: fourteen dots are overlaid because fourteen patients had the same score) (y=1.46+0.82x).

C. RELATIVE'S COMPLAINT REPORTS

Of the 50 patients included in the study, 29 were accompanied to their consultations by a relative, that was their son/daughter, husband, wife, or daughter-in-law. The CLCE-24 scale was also administered to these 29 family members, following the patient assessment.

Family members tended to attribute higher scores (median score = 13, interquartile range 6–16), than patients (median score = 9, interquartile range 6–13). However, the difference did not reach significance (Wilcoxon test, $p = 0.051$), although they had a moderate correlation ($r = 0.599$, $p < 0.01$), as showed in Figure 7, indicating that family members' perceptions are related to patients' subjective experiences.

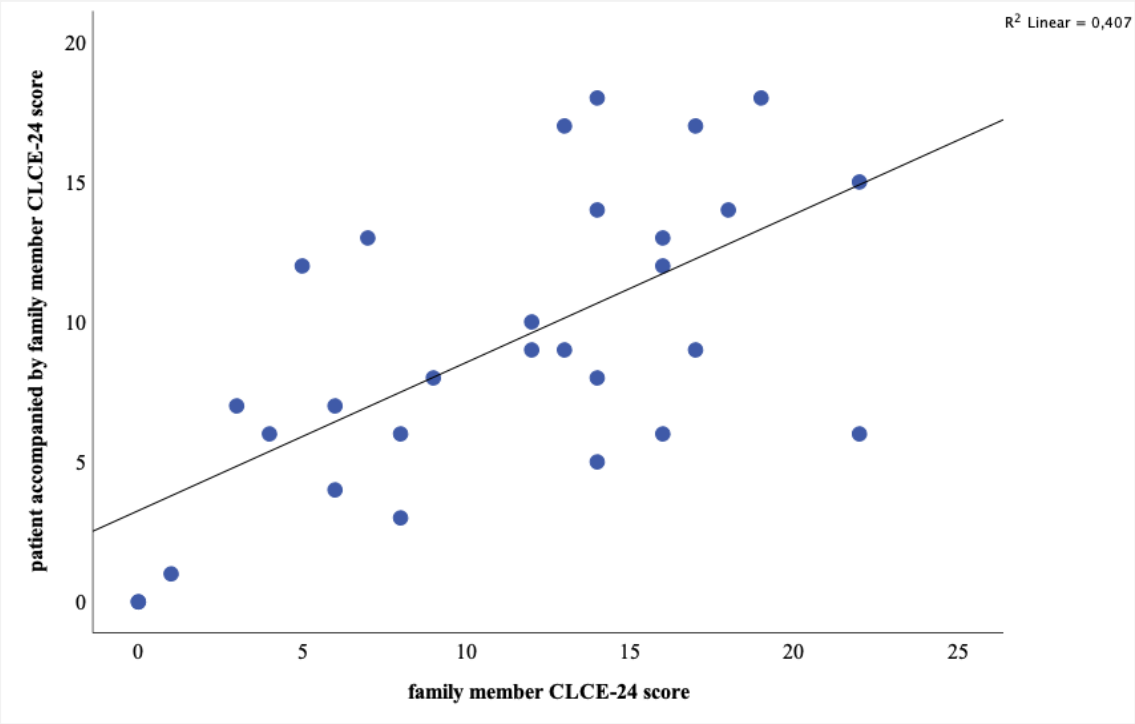

Figure 7 – Simple scatter plot of the correlation between the patient accompanied by a family member score and the family member score, in the CLCE-24 scale. (Discloser: two dots are overlaid because two patients had the same score) (y=3.26+0.53x).

A bivariate Spearman correlation was established to assess if the family members' scores in the CLCE-24 scale were related to demographic or clinical features. There was a significant correlation between the CLCE-24 scale and both Geriatric Depression Scale ($r = 0.446$, $p = 0.015$) and NIHSS score on the day of discharge ($r = 0.405$, $p = 0.036$).

D. SUBJECTIVE COGNITIVE COMPLAINTS AND OBJECTIVE COGNITIVE IMPAIRMENT

The median score obtained in the Addenbrooke's Cognitive Examination scale was 76 (interquartile range = 59.5–82.2) (Figure 8).

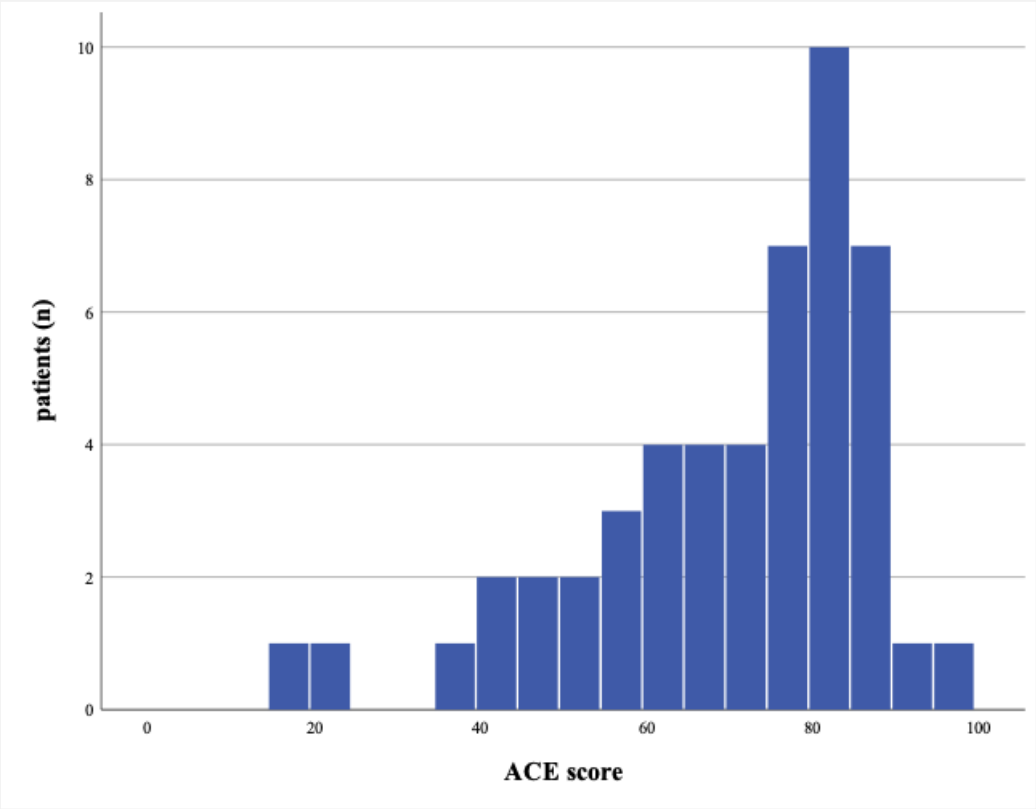

Figure 8 - Histogram of patient scores on the Addenbrooke's Cognitive Examination scale

According to the scale's cut-off scores, 19 patients (38%) were classified as having Dementia, while 12 (24%) had Mild Cognitive Impairment[4] (Figure 9). This classification is based only on the score and did not include loss of autonomy as usually required.

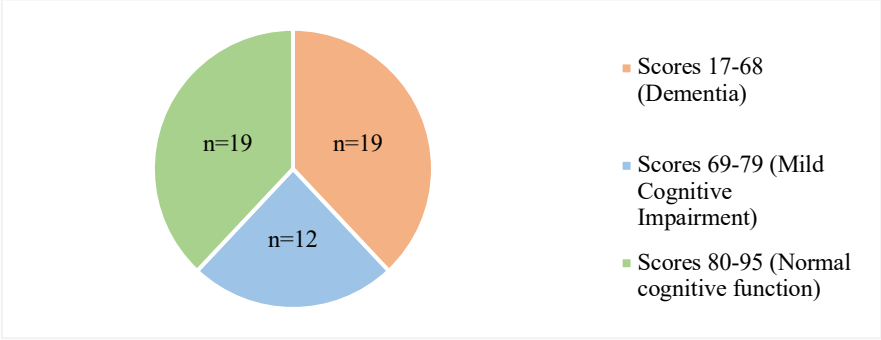

Figure 9 - Number of patients by scores on the Addenbrooke's Cognitive Examination scale, according to the cut-off scores in Simões et al. (2015)

[4] The concept of Dementia and Mild cognitive Impairment is according to Simões et al. (2015), not corresponding to the definitions according to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association, 2013).

The *attention/orientation* category, consisting of 18 questions, had a median score of 14.0 (interquartile range = 12.5–17.0), the *memory* category, consisting of 26 questions, had a median score of 16.0 (interquartile range = 12.5–21.0), the *fluency* category, consisting of 14 questions, had a median score of 7.0 (interquartile range = 3.5–9.0), the *language* category, consisting of 26 questions, had a median score of 21.0 (interquartile range = 16.5–23.0), and the *visuospatial* category, consisting of 16 questions, had a median score of 12.0 (interquartile range = 9.0–15.0), as shown in Figure 10.

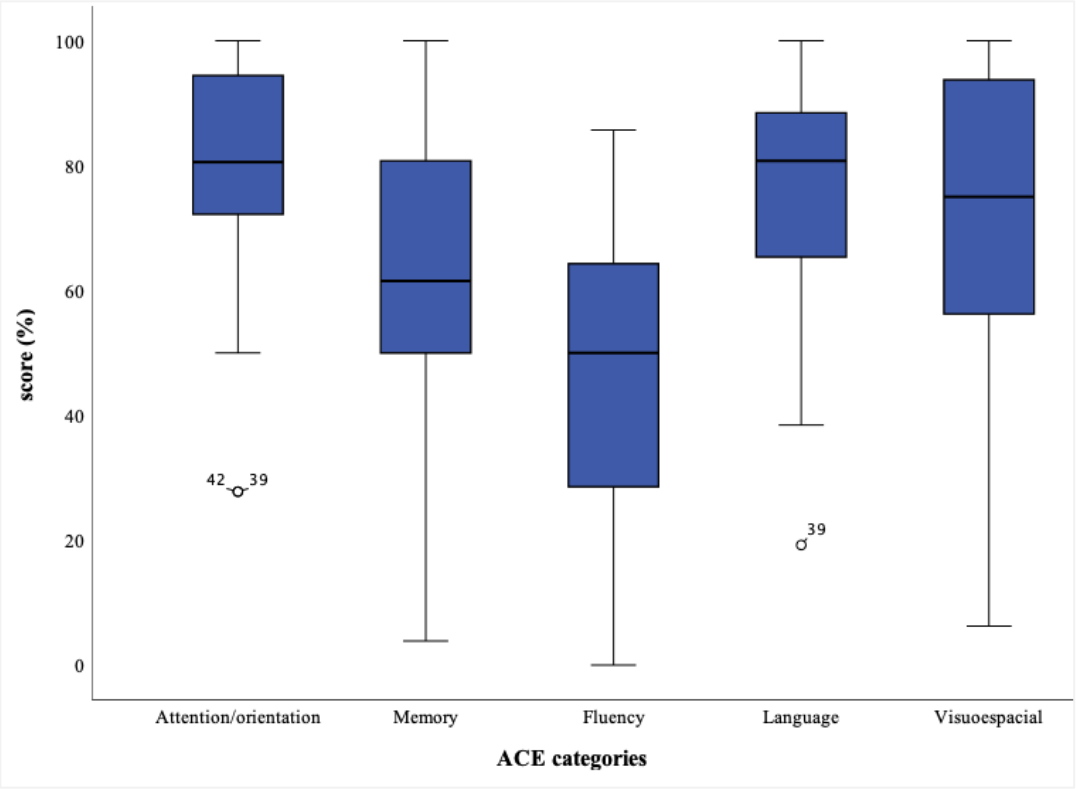

Figure 10 - Boxplot of the percentage scores of patients in each category of the Addenbrooke's Cognitive Examination scale

A bivariate Spearman correlation was performed to assess if the scores obtained in the Addenbrooke's Cognitive Examination scale were related to demographic or clinical features. The analysis revealed a negative moderate correlation with age (r = -0.350, p = 0.013) and a positive moderate correlation with gender (r = 0.383, p = 0.006[5]) and professional situation (r = 0.337, p = 0.013). The correlations with the other demographic features where not significant. There was no correlation with any of the clinical characteristics, such as the Geriatric Depression Scale (r = -0.125, p = 0.392), modified

[5] The correlation is significant at the 0.01 level (2 ends).

Rankin scale (r = -0.202, p = 0.160), NIHSS on the day of stroke (r = -0.173, p = 0.250), or NIHSS on the day of testing (r = -0.168, p = 0.243).

The correlation between the CLCE-24 scale total scores and the Addenbrooke's Cognitive Examination scale scores was not significant (r = -0.199, p = 0.170). However, the Addenbrooke's Cognitive Examination scale scores showed a moderate negative correlation with the CLCE-24 scale *cognitive* category scores (r = -0.322, p = 0.023), and no correlation with the CLCE-24 scale *emotional* category (r = -0.093, p = 0.519).

The correlation between the scores of the Addenbrooke's Cognitive Examination scale and the *cognitive* category was not statistically significantly different from the correlation between the scores of the Addenbrooke's Cognitive Examination scale and the *emotional* category (Cocor software package, F = -1.166, p = 0.243).

There was a negative strong correlation between patient family members' scores on the CLCE-24 scale and the patients' scores on the Addenbrooke's Cognitive Examination scale (r = -0.496, p = 0.006), as presented in Figure 11. There was also a strong negative correlation in the categories *attention/orientation* (r = -0.480, p = 0.008) and *memory* (r = -0.412, p = 0.026), and a moderate correlation in the category *fluency* (r = -0.388, p = 0.038), showing that relative's perception is related to patients' objective scores.

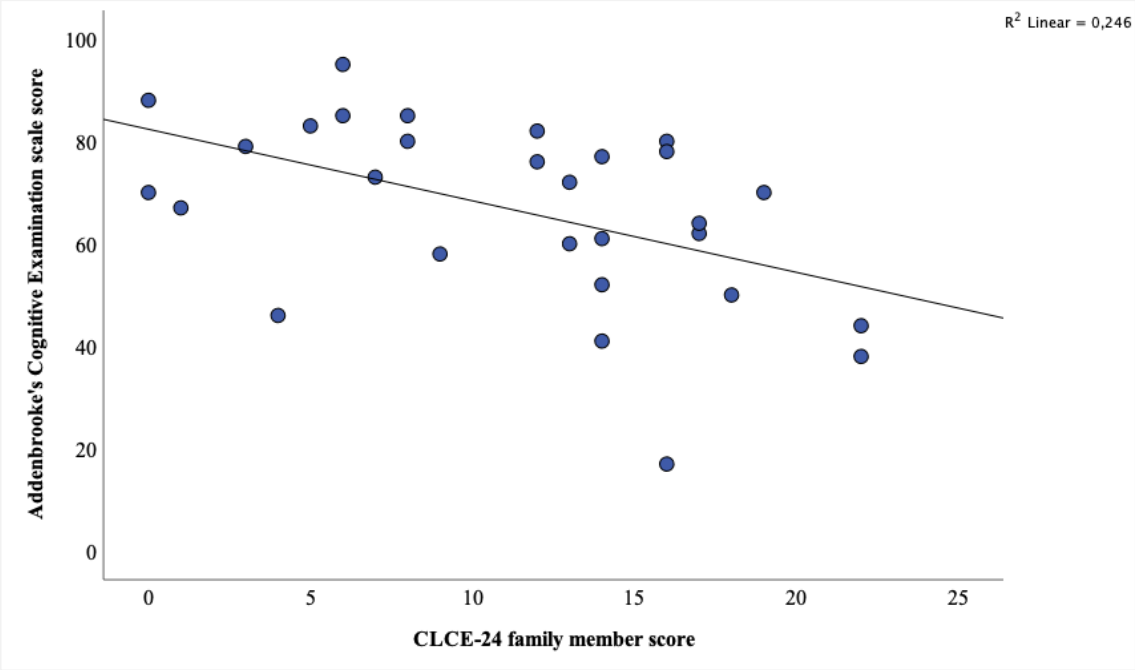

Figure 11 - Simple scatter plot of the correlation between the scores in the CLCE-24 scale applied to family members and in the Addenbrooke's Cognitive Examination scale (y=82.35-1.4x).

E. SUBJECTIVE COGNITIVE COMPLAINTS AND NEUROLOGICAL AND FUNCTIONAL DEFICITS

The scores in the CLCE-24 scale had no significant correlation with the NIHSS score, neither at admission ($r = 0.009$, $p = 0.955$), discharge ($r = 0.251$, $p = 0.096$) or at the time of consultation ($r = 0.203$, $p = 0.157$).

There was a strong correlation between the scores in the Modified Rankin Scale and in the CLCE-24 scale ($r = 0.407$, $p = 0.003$), as presented in Figure 12. There was a moderate correlation between the scores in the Modified Rankin Scale and in the *cognitive* category of the CLCE-24 scale ($r = 0.359$, $p = 0.010$).

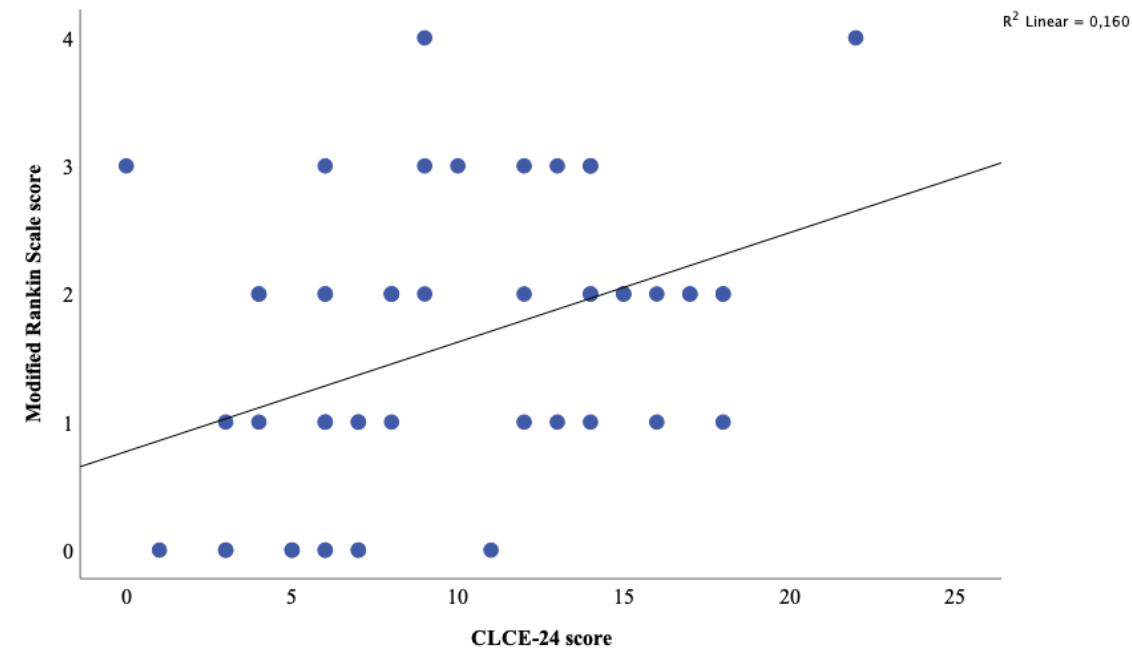

Figure 12 - Simple scatter plot of the correlation between the scores in the Modified Rankin Scale and in the CLCE-24 scale (y=0.77+0.09x).

F. SUBJECTIVE COGNITIVE COMPLAINTS AND DEPRESSION

The Geriatric Depression Scale had a median score of 5.0 (interquartile range = 4.0-9.0). A strong correlation was found between the Geriatric Depression Scale scores and the CLCE-24 scale scores ($r = 0.693$, $p < 0.001$) (Figure 13).

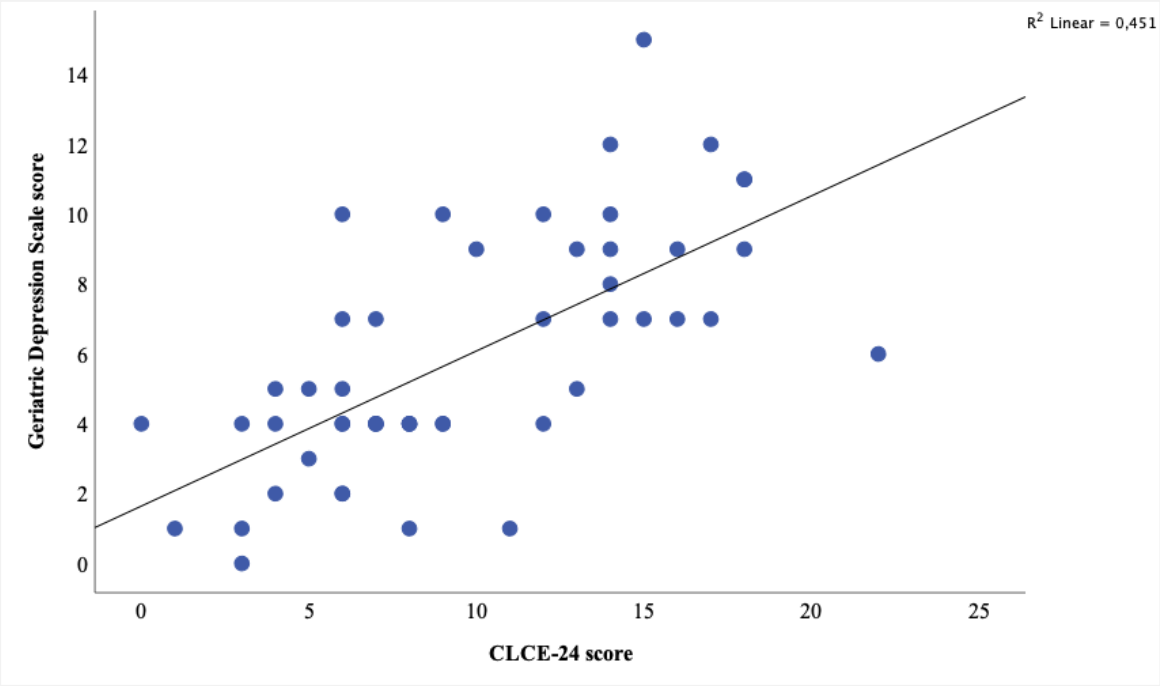

Figure 13 - Simple scatter plot of the correlation between the scores in the Geriatric Depression Scale and in the CLCE-24 scale (y=1.64+0.44x).

There was statistically significant difference between the correlations of the patients' scores on the CLCE-24 scale with patients' scores on the Addenbrooke's Cognitive Examination scale and on the Geriatric Depression Scale (Cocor software package, $F = -3.074$, $p = 0.002$).

Furthermore, a strong correlation was observed between scores on the Geriatric Depression Scale and scores on the *emotional* ($r = 0.680$, $p < 0.001$) (Figure 14) and *cognitive* ($r = 0.674$, $p < 0.001$) (Figure 15) categories of the CLCE-24 scale.

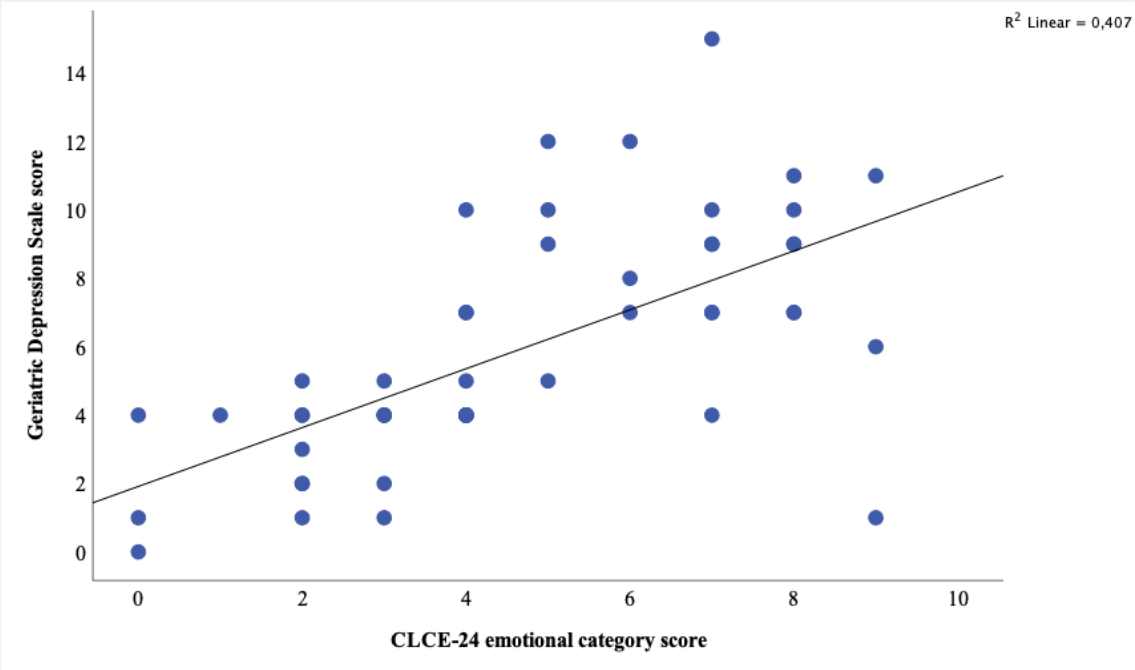

Figure 14 - Simple scatter plot of the correlation between the scores in the Geriatric Depression Scale and in the emotional category of the CLCE-24 scale (y=1.91+0.86x).

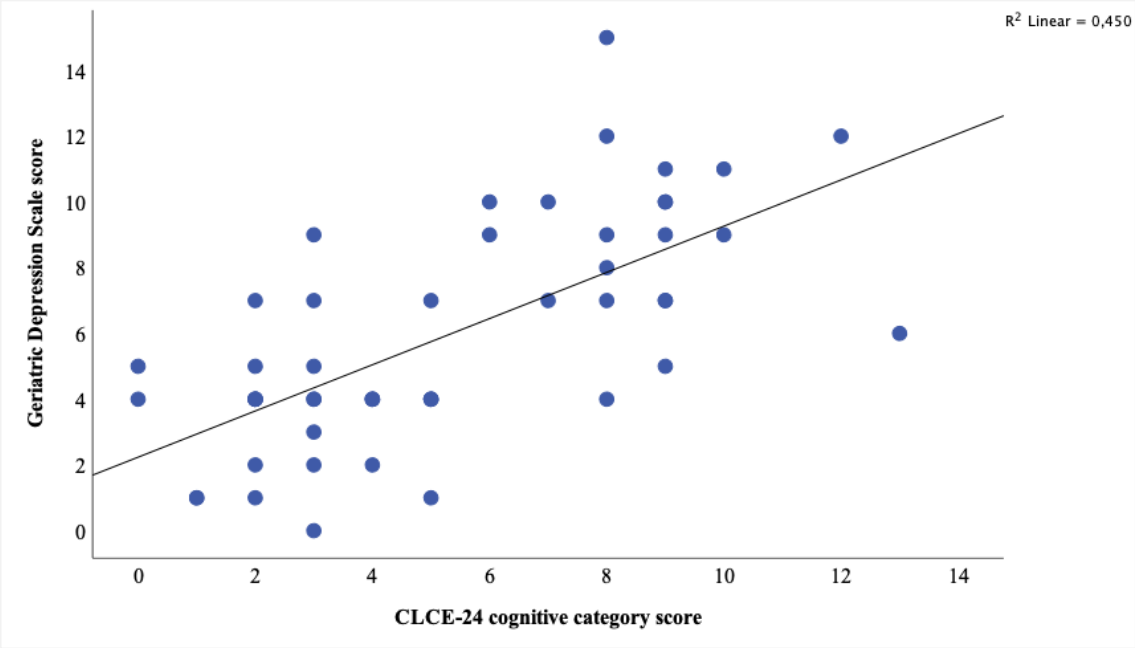

Figure 15 - Simple scatter plot of the correlation between the scores in the Geriatric Depression Scale and in the cognitive category of the CLCE-24 scale (y=2.24+0.7x).

When controlling for depression levels, the correlation between the CLCE-24 scale scores and the Addenbrooke's Cognitive Examination scale scores was still non-significant (r = -0.221, p = 0.126). This suggests that depression levels may not have influence on the relationship between subjective perception and objective cognitive impairment.

D. MULTIVARIATE MODEL

To understand what key factors influenced the post-stroke subjective cognitive complaints reported by patients, a multivariate model was built. In this model, the dependent variable was the extent of these complaints reported by the patients. The multivariate model with the best classification performance incorporated the independent variables "modified Rankin scale scores" (a measure of functional disability) and "Geriatric Depression Scale scores" (a measure of depression) (Table 3), suggesting their potential as significant predictors of post-stroke cognitive complaints. The total scores on the NIHSS test on the day of testing were not independent predictors of cognitive complains. This highlights the association between post-stroke subjective cognitive complaints, functional disability and depression, implying that mitigating depressive symptoms could potentially result in reduced complaint reporting by patients.

Table 3 - Logistic model with the best classification performance

Variable	95% CI	p-value
mRankin	0.12 – 1.13	0.016
GDS	0.23 – 0.60	< 0.01

CI, confidence interval; mRankin, modified Rankin scale; GDS, Geriatric Depression Scale

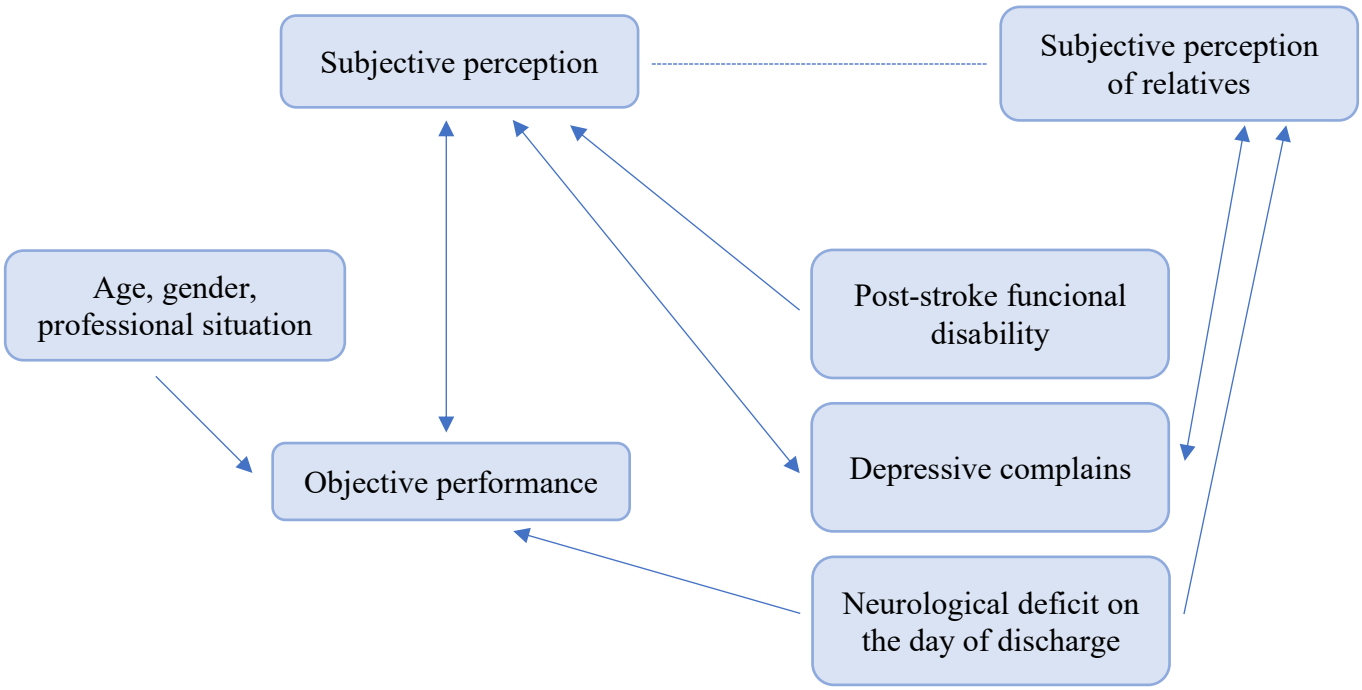

Figure 16 - Diagram of the main results. Arrow means that there is correlation; dashed line means that the results concur

IV. DISCUSSION

The median score on the CLCE-24 scale was 8.5 out of 22 points, which means that cognitive complaints are common after stroke. There were no differences in the distribution of patients' CLCE-24 scale scores according to any of the demographic or clinical features.

After comparing the median scores obtained in both CLCE-24 scale categories, we found that patients had a higher score in the *cognitive* category, which indicates that patients report more complaints in the cognitive than in the emotional part. However, in both categories most patients had no complains, followed by patients that had non-severe complaints. Complaints related to the domains mental speed, concentration and memory found to be the most common (Figure 4 and Figure 5), which is in accordance with that described by the authors Duits, Munnecom, van Heugten & van Oostenbrugge (2008), Wendel et al. (2008), Lamb, Anderson, Saling & Dewey (2013), van Rijsbergen, Mark, de Kort & Sitskoorn (2014) and Nijsse et al. (2021).

Most patients reported to be depressed, afraid of the future and get tired quickly, which is in line with what is mentioned by Ferro, Caeiro & Figueira (2016) and Medeiros, Roy, Kontos & Beach (2020), who say that psychological and neuropsychiatric disorders, such as depression and anxiety, are common in stroke patients, and with what is described by the authors Kutlubaev & Mead (2013), Wu, Mead, Macleod & Chalder (2015) and Cumming, Packer, Kramer & English (2016) who report that fatigue is one of the most common sequelae of stroke, reported by more than 50% of stroke survivors.

Furthermore, cognitive complaints tend to increase when there are more emotional complaints, which is in agreement with the authors Duits, Munnecom, van Heugten & van Oostenbrugge (2008), Nijsse et al. (2017) e Lamb, Anderson, Saling & Dewey (2013).

Relatives obtained a higher score, which shows that relatives report that patients have more complaints than the patients themselves, which is in accordance with what we expected. The current results did not change after including stroke lesion lateralization as covariates in the regression analyses, which is not in line with what we expected and with what is described in the bibliography by van Exel et al. (2005), Wendel et al. (2008) and Barrett (2021).

Also, the observed correlation between the CLCE-24 scale scores of patients and their family members suggests that the relatives concur with the patient perception of their situation, which indicates that family members have a similar perception of the patient's cognitive and emotional problems as the patient. This suggests that family members can provide valuable information about the patient's condition and may be able to help identify cognitive and emotional problems that the patient may not be aware of. However, the family members tend to perceive the patient's condition as more compromised than the patient does. This could be attributed to principles in social psychology that suggest that people who share the same event do not perceive it in the same way, and stroke patients may have a distorted perception of their problems (Hochstenbach, Prigatano, & Mulder, 2005; van Rijsbergen, Mark, de Kort, & Sitskoorn, 2014), and/or because of the patients' reduced awareness (i.e., anosognosia), denial, or emotional distress of patients and/or their partners (van Exel et al., 2005; Wendel et al., 2008; Barrett, 2021). This might also stem from family members potentially overestimating the extent of the patient's cognitive and emotional issues, due to a lack of insight into the patient's perspective or a tendency to have a more pessimistic outlook on the patient's state. This finding highlights the importance of considering both the patient's and family members' perspectives when evaluating cognitive and emotional problems after stroke.

Furthermore, the family members' scores in the CLCE-24 scale were related to the Geriatric Depression Scale, NIHSS on the day of discharge, indicating that family members are able to perceive the psychological and cognitive impairments of their relatives.

Through the analysis of the Addenbrooke's Cognitive Examination scale results, we evidenced that most patients (62%) have Mild Cognitive Impairment[6] and that only 38% of the patients scored above the established norma-based cut-off values for cognitive impairment. Cognitive complains related to language (i.e., patient-reported difficulty in reading, writing, and speaking) seemed to be more prevalent, which is not in accordance with what was evidenced by Hochstenbach, Prigatano, & Mulder 2005, Wendel et al. (2008) e Lamb, Anderson, Saling & Dewey (2013).

[6] The concept of Dementia and Mild cognitive Impairment is according to Simões et al. (2015), not corresponding to the definitions according to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association, 2013).

Additionally, the correlation between the Addenbrooke's Cognitive Examination scale and age, gender and professional situation indicates that older patients tend to have lower cognitive performance, when compared with younger patients, and that male and working patients tend to have higher cognitive performances, when compared with female and retired patients. However, as the scores were not adjusted for age nor gender, these results could indicate that, even if stroke hadn't occurred, people with lower literacy and more age could have lower scores.

We expected cognitive complaints to reflect cognitive impairment in stroke patients. And indeed, there was a tendency for patients with higher scores on the CLCE-24 scale to exhibit poorer objective performance on the Addenbrooke's Cognitive Examination scale. Nonetheless, this association did not reach statistical significance, suggesting that patients could not properly identify their degree of cognitive impairment, which is in conformity with what was evidenced by the authors Martin et al. (2002), Duits, Munnecom, van Heugten & van Oostenbrugge (2008), Winkens, Van Heugten, Fasotti & Wade (2009), Aben et al. (2011), Pendlebury, Mariz, Bull, Mehta & Rothwell (2012) and Lamb, Anderson, Saling & Dewey (2013).

The correlation between the scores in the *cognitive* category of the CLCE-24 scale and in the Addenbrooke's Cognitive Examination scale was significant and moderate, which means that the higher the score of the *cognitive* category of the CLCE-24 scale, the higher the score of the Addenbrooke's Cognitive Examination scale, i.e. the more cognitive complaints patients reported, the more objective cognitive impairment they have. On the other hand, the correlation between the scores in the *emotional* category of the CLCE-24 scale and in the Addenbrooke's Cognitive Examination scale was non-significant. This is neither in line with what we expected nor in line with the authors Davis et al. (1995), Wendel et al. (2008) and Xiong et al. (2011).

The association between objective cognitive performance and the cognitive component of subjective cognitive complaints indicates that those who experience an impact of their subjective cognitive complaints on daily life functioning (compared to those that do not) may be less aware of their objective cognitive limitations and/or may have adequate strategies to compensate for these impairments, which is accordingly in line with Duits, Munnecom, van Heugten & van Oostenbrugge (2008).

There was a strong correlation between the scores in the Modified Rankin Scale and in the CLCE-24 scale, which means that the higher the CLCE-24 scale score, the higher

the Modified Rankin Scale score. Thus, the cognitive state is more correlated with the patient's complaints than the objective performance. Despite the moderate correlation between the scores in the Modified Rankin Scale and in the *cognitive* category CLCE-24 scale, there was a weak correlation between the scores in this scale and in the *emotional* category. This indicates that cognitive problems may be more strongly related to functional disability after stroke and that emotional problems may have a weaker impact on functional outcomes after stroke.

Concerning the scores of the patients' relatives, the correlation between their scores on the CLCE-24 scale and their scores on the Addenbrooke's Cognitive Examination scale, as well as three of its specific categories (*attention/orientation*, *memory* and *fluency*), indicates that the higher the relatives' CLCE-24 scale scores, the higher the patients' score in the Addenbrooke's Cognitive Examination scale, which indicates that relatives have a greater perception of the patients' condition than the patients themselves. Thus, we observed that the number of cognitive complaints reported by relatives increased when patients performed poorly on the objective cognitive test.

The correlation between the scores in the Geriatric Depression Scale and in the CLCE-24 scale was strong, which means that the higher the CLCE-24 scale score, the higher the Geriatric Depression Scale score. Therefore, there is a link between subjective cognitive complaints and depressive symptoms, as described by the authors Duits, Munnecom, van Heugten & van Oostenbrugge (2008), Winkens, Van Heugten, Fasotti & Wade (2009), Aben et al. (2011), Xiong, et al. (2011) and Lamb, Anderson, Saling & Dewey (2013), and the complaints are related more to depression than to cognitive performance.

There was statistically significant difference between the correlations of the patients' scores on the CLCE-24 scale with patients' scores on the Addenbrooke's Cognitive Examination scale and on the Geriatric Depression Scale, meaning that the higher the score on the CLCE-24 scale and on the Addenbrooke's Cognitive Examination scale, higher the score on the Geriatric Depression Scale, that is, the more cognitive complaints and cognitive objective impairment patients report, the more depressive symptoms they have.

The correlation between the scores in the Geriatric Depression Scale and in the *emotional* category of the CLCE-24 test was strong, meaning that the higher the score on

the *emotional* category of the CLCE-24, the higher the score on the Geriatric Depression Scale.

The correlation between the scores in the CLCE-24 test and in the Addenbrooke's Cognitive Examination scale, controlling for the level of depression, was non-significant, meaning that there is no correlation between the CLCE-24 and Addenbrooke's scores for the level of depression, as measured by the Geriatric Depression Scale.

When controlling for depression levels, the correlation between the CLCE-24 scale scores and the Addenbrooke's Cognitive Examination scale scores was weak, suggesting that depression levels may have some influence on the relationship between subjective perception and objective cognitive impairment.

These findings are in line with what we expected and indicate that emotional factors play an important role in subjective cognitive complaints, but not when measures of objective cognitive functioning are taken into account.

The multivariate model with the best classification performance incorporated the modified Rankin scale and Geriatric Depression Scale variables, suggesting their potential as significant predictors of post-stroke cognitive complaints. This highlights the association between these complaints, functional disability and depression, implying that mitigating depressive symptoms could potentially result in reduced complaint reporting by patients. However, the scores were not adjusted for demographic characteristics, so these results could indicate that, even if a stroke had not occurred, people with lower literacy and older age could have lower scores, since the sample has low literacy and high age.

V. LIMITATIONS AND FUTURE DIRECTION

As limitation, this work was performed in a tertiary stroke unit and may not be representative of the entire stroke population. Also, the sample size is relatively small, for the number of variables involved, meaning that the study can be considered exploratory and with a reduced statistical power. Secondly, the CLCE-24 scale was not validated for the Portuguese population. However, the scale was translated, retroverted and adapted by two persons fluent in English and Portuguese. Finally, the study relied heavily on self-report measures as happens when evaluating subjective experience. Patients are only able to make relative decisions about their own cognitive functioning instead of absolute judgments. In some cases, patients are even not aware of their deficits, which is caused by either stroke lesion (i.e. anosognosia) or an emotional defensive mechanism to deny the consequences of stroke. So, both performance and complaints may not perfectly reflect the actual situation, which might explain the lack of association, as self-report measures are susceptible to subjective biases, recall inaccuracies, and social desirability effects, which might impact the reliability and validity of the reported results. Finally, scores obtained in the objective evaluation were not standardized to age and education. This lack of standardization may impact the validity of the results, as cognitive abilities and test performance can vary significantly with age and educational background, and not necessarily due to a stroke, potentially introducing bias.

Future studies should aim to: Include a broader stroke population, encompassing different stroke units or medical centers to increase the representativeness of the findings, as this would allow for a more comprehensive understanding of cognitive complaints across various settings and stroke types; Increase the sample size could enhance statistical power, providing more reliable and generalizable results; Validate measurement tools like the CLCE-24 scale for the specific population under investigation to ensure the accuracy of assessments; Use standardized tests to demographic features; Combine various assessment methods, such as neuroimaging, clinical evaluations, and neuropsychological tests, to provide a more comprehensive understanding of patients' cognitive functioning, as integrating objective measurements with self-report data could mitigate biases and offer a more holistic perspective; Involve collateral informants, such as family members or caregivers, can offer an additional layer of information, as reports from these individuals can provide a more objective viewpoint of patients' cognitive and emotional

states, potentially reducing the impact of biases; Conducting studies over a longer time frame to help capture changes in cognitive complaints and functioning, offering insights into the trajectory of recovery or decline post-stroke; Do experimental designs that incorporate control groups or experimental manipulations to help establish causal relationships and enhance the interpretability of the findings; Explore the influence of emotional factors such as anosognosia, denial, and emotional distress on cognitive complaints, as incorporating emotional assessments and exploring potential mechanisms driving discrepancies between self-report and objective measures can provide a more nuanced understanding.

Addressing these considerations can help overcome the limitations mentioned, ultimately leading to more comprehensive, accurate, and meaningful insights into post-stroke cognitive complaints and their underlying mechanisms.

VI. CONCLUSION

In conclusion, this study aimed to investigate the frequency and nature of cognitive complaints following stroke and their relationship with objective cognitive impairment. The analysis encompassed various cognitive domains and revealed that cognitive complaints are prevalent after stroke, with cognitive concerns being more pronounced than emotional ones. Although the correlation between patients' and family members' CLCE-24 scale scores implies a shared perception of the patient's situation, relatives tended to report more complaints than the patients themselves. This could arise from differences in perception due to the inherent subjectivity of experiences and potential emotional factors such as anosognosia or emotional distress. These findings underscore the need to consider both patient and family perspectives when assessing post-stroke cognitive and emotional problems.

Objective cognitive impairment, neurological deficits, and functional disability were explored, revealing a complex interplay. Relatives report was clearly aligned with objective cognitive performance. However, the correlation between patients' cognitive complaints and objective cognitive impairment was inverse, suggesting that patients reporting more cognitive complaints exhibited milder objective cognitive deficits. Yet, there was a stronger correlation between cognitive complaints and emotional factors. These findings challenge expectations and highlight the role of emotional aspects in shaping the relationship between subjective and objective cognitive states.

Depression emerged as a significant factor, with strong correlations between cognitive complaints and depressive symptoms. When accounting for depression, the association between cognitive complaints and objective cognitive impairment weakened, indicating the influence of emotional variables on this connection.

The multivariate model integrated the modified Rankin scale and Geriatric Depression Scale variables as predictors of post-stroke cognitive complaints. This not only accentuates the importance of incorporating functional disability and emotional well-being into our understanding of these complaints but also suggests that mitigating depressive symptoms could potentially lead to a reduction in reported cognitive complaints among patients.

Overall, this study deepens our understanding of the intricate relationship between cognitive complaints, objective cognitive impairment, emotional factors, and functional disability in stroke patients. It emphasizes the multifaceted nature of these issues and the

necessity of comprehensive assessments that encompass patient and family perspectives, emotional aspects, and objective cognitive performance.

Additionally, in order to address the emotional challenges faced by stroke patients, we propose a holistic approach that integrates neurological monitoring with emotional and social support. We propose: Implementation of cognitive rehabilitation programs designed to equip patients with coping strategies tailored to their cognitive challenges; Emotional and social worker monitoring, alongside neurological monitoring, to address patients' mental health needs and provide emotional support; A socio-behavioural support group, led by professionals, to offer a safe space for patients to share experiences and receive guidance; Involving family members or care takers in consultations, to provide more accurate information about the patient's condition; Establishing a multidisciplinary neuroscience group, comprising neurologists, psychologists, social workers, and other relevant professionals, to oversee the integration of neurological, emotional, and social support services, ensuring a comprehensive approach to patient care. With this approach, we aim to enhance the overall care and well-being of stroke patients by acknowledging and addressing their emotional needs, contributing to their successful rehabilitation and recovery.

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APENDIX

The following pages include the scales used in this Dissertation, in the following order:

1) CLCE-24 scale Cognitive and Language Complaints Evaluation - 24 (CLCE-24)
2) Addenbrooke's Cognitive Examination scale
3) Modified Rankin Scale
4) Geriatric Depression Scale

ID Doente | | | | | | | | | | |

Data de avaliação:___/___/_____

CLCE-24 (*Checklist for cognitive and emotional consequences following stroke*)

Itens	Sim, prejudicando severamente a vida diária[a]	Sim, mas não de forma severa[a]	Não[a]	Não tenho a certeza[a]
Desde o AVC o paciente tem problemas em (problemas cognitivos):				
1. Fazer duas coisas ao mesmo tempo				
2. Cuidar das coisas				
3. Acompanhar; tornou-se mais lento				
4. Relembrar novas informações				
5. Relembrar informações antigas				
6. Tomar iniciativa				
7. Planear e organizar as coisas				
8. Executar atividades da vida diária				
9. Perceber o tempo				
10. Orientar-se para lugares ou pessoas				
11. Compreender a linguagem				
12. Falar ou escrever				
13. Cuidar de uma parte do corpo ou de um espaço				
Desde o AVC o paciente está (problemas emocionais):				
14. Deprimido				

15. Com medo do que está por vir				
16. Menos orientado socialmente				
17. Menos realista sobre as coisas				
18. Emocionalmente menos estável, chora facilmente				
19. Irritado, zangado com mais facilidade				
20. Menos emocional, desinteressado				
21. Com menos controlo do seu próprio comportamento				
22. Cansado mais rapidamente				
Existem outros problemas? 23. 24				

[a] Pontuação: d = doente, c = cuidador, I = entrevistador

Peixoto B, Baeta E & Pimentel P, (2013).
CESPU- IUCS, Centro Hospitalar do Alto Minho, Centro Hospitalar de Trás-os-Montes e Alto Douro

ADDENBROOKE'S COGNITIVE EXAMINATION – ACE-III

Versão experimental Portuguesa (2013)

Nome:	Data da avaliação: ____/___/___
Data de Nascimento:	Avaliador:_____
Hospital ou Morada:	Anos de escolaridade:_____
	Ocupação: _____
	Mão dominante:

ATENÇÃO

➢ PERGUNTE: Qual é o (a)	Dia	Data	Mês	Ano	Estação	**Atenção** [Score 0-5]
➢ PERGUNTE: Em que	Edificio	Piso/ Andar	Cidade	Distrito	País	**Atenção** [Score 0-5]

ATENÇÃO

➢Diga: "Vou lhe dizer três palavras que gostaria que as repetisse depois de mim: Limão, Chave e Bola"
Depois do sujeito repetir, diga "Tente-se lembrar delas porque mais tarde irei voltar a pedi-las" .
➢ Pontue apenas o primeiro ensaio (repita 3 vezes se for necessário).
➢ Registe o número de ensaios:_____

Atenção [Score 0-3]

ATENÇÃO

➢ Pergunte ao sujeito: "Quanto é 7 menos 100? Agora ao número encontrado, volte a subtrair 7".
➢ Se o sujeito cometer um engano, não o interrompa. Deixe-o continuar e verifique as respostas subsequentes (ex: 93,84,77,70,63- score 4).
➢ Pare após cinco subtracções (93,86,79,72,65):____ ____ ____ ____ ____

Atenção [Score 0-5]

Memória

➢ Pergunte: "Quais foram as 3 palavras que lhe pedi para repetir e para se lembrar?" _____ _____ _____

Memória [Score 0-3]

Fluência

➢**Letras**
Diga: "Durante um minuto, diga palavras que se consegue lembrar começadas pela letra P. Não pode dizer nomes de pessoas (ex: Paula), nem de lugares (ex: Porto), nem diminutivos (ex: Pedrinho). Tem alguma dúvida?".

Fluência [Score 0-7]

≥ 18	7
14-17	6
11-13	5
8-10	4
6-7	3
4-5	2
2-3	1
0-1	0
Total	Correcta

➢ **Animais**
Diga: "Agora, começando por qualquer letra, diga todos os nomes de animais que se consegue lembrar. Tem alguma dúvida?"

Fluência [Score 0-7]

≥ 22	7
17-21	6
14-16	5
11-13	4
9-10	3
7-8	2
5-6	1
<5	0
Total	Correcta

Peixoto B, Baeta E & Pimentel P. (2013).
CESPU-IUCS,Centro Hospitalar do Alto Minho, Centro Hospitalar de Trás-os-Montes e Alto Douro

Memória

- Diga: " Vou dizer-lhe um nome e uma morada e gostaria que os repetisse a seguir a mim. Terá oportunidade para aprender, pelo que o faremos 3 vezes. Mais tarde perguntar-lhe-ei o nome e a morada."

Pontue apenas o terceiro ensaio.

Memória [Score 0-7] ☐

	1º Ensaio	2º Ensaio	3º Ensaio
João Silva **Rua dos Ferreiros,73** **Amares** **Braga**	_____ _____ _____ _____ —	_____ _____ _____ _____ __ _____	_____ _____ _____ _____ __ _____

Memória

- Nome do atual Primeiro Ministro..... .....
- Nome do atual Presidente da República ……
- Nome do Presidente dos EUA.……
- Nome da fadista mais famosa de todos os tempos……..

Memória [Score 0-4] ☐

Linguagem

- Coloque um lápis e uma folha de papel em frente ao sujeito. Como ensaio, peça ao sujeito para "**Pegar no lápis e depois no papel**". Se for incorreto, pontue 0 e não continue.
- Se o sujeito desempenha corretamente o ensaio, continue com as seguintes três ordens.
  - Peça ao sujeito para "**Colocar o papel em cima do lápis**"
  - Peça ao sujeito para "**Pegar no lápis mas não no papel**"
  - Peça ao sujeito para "**Dê-me o lápis depois de tocar o papel**"

Linguagem [Score 0-3] ☐

Linguagem

- Peça ao sujeito para escrever duas (ou mais) frases completas acerca das suas últimas férias/ fim de semana/ Natal. Escreva frases completas e não use abreviaturas. Dê 1 ponto se foram produzidas duas (ou mais) frases completas acerca do tópico; dê 1 ponto se a gramática e as palavras estão corretas.

Linguagem [Score 0-2] ☐

Linguagem

Peça ao sujeito para repetir: **"Lagarta"**; **"Excentricidade"**; **"Ininteligivél"**; **"Estatistico"** Pontue 2 se todas as palavras estão corretas; pontue 1 se 3 estão corretas; pontue 0 se 2 ou menos estão corretas

Linguagem [Score 0-2] ☐

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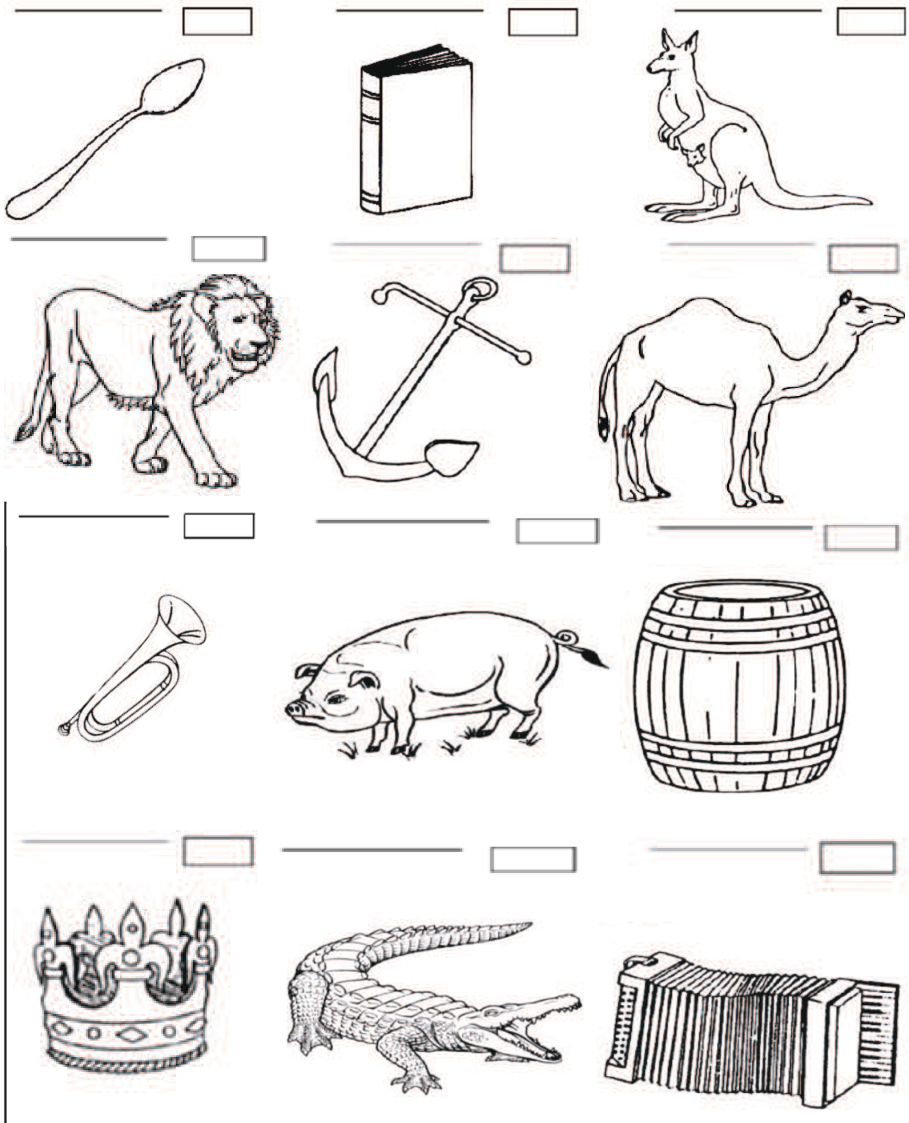
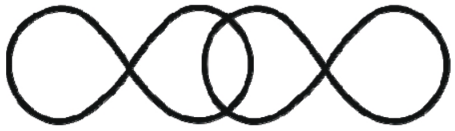
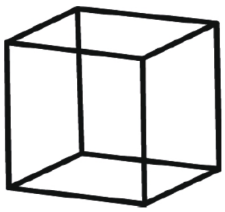
Linguagem	
➢ Peça ao sujeito para repetir: "**Nem tudo o que brilha é ouro** "	**Linguagem** [Score 0-1] ☐
➢ Peça ao sujeito para repetir: "**Homem prevenido vale por dois** "	**Linguagem** [Score 0-1] ☐
Linguagem	
	**Linguagem** [Score 0-12] ☐
Linguagem	
➢ Usando as figuras apresentadas, peça ao sujeito: • Apontar para figura associada á monarquia…….. • Apontar para figura que serve para guardar vinho…….. • Apontar para figura que é o rei da selva…… • Apontar para figura ligada ao mar……	**Linguagem** [Score 0-4] ☐

Linguagem

➢ Peça ao sujeito para ler as seguintes palavras: (Pontue 1 apenas se todas estiverem corretas) **Ler** **Pia** **Frio** **Presa** **Altura**	**Linguagem** [Score 0-1]

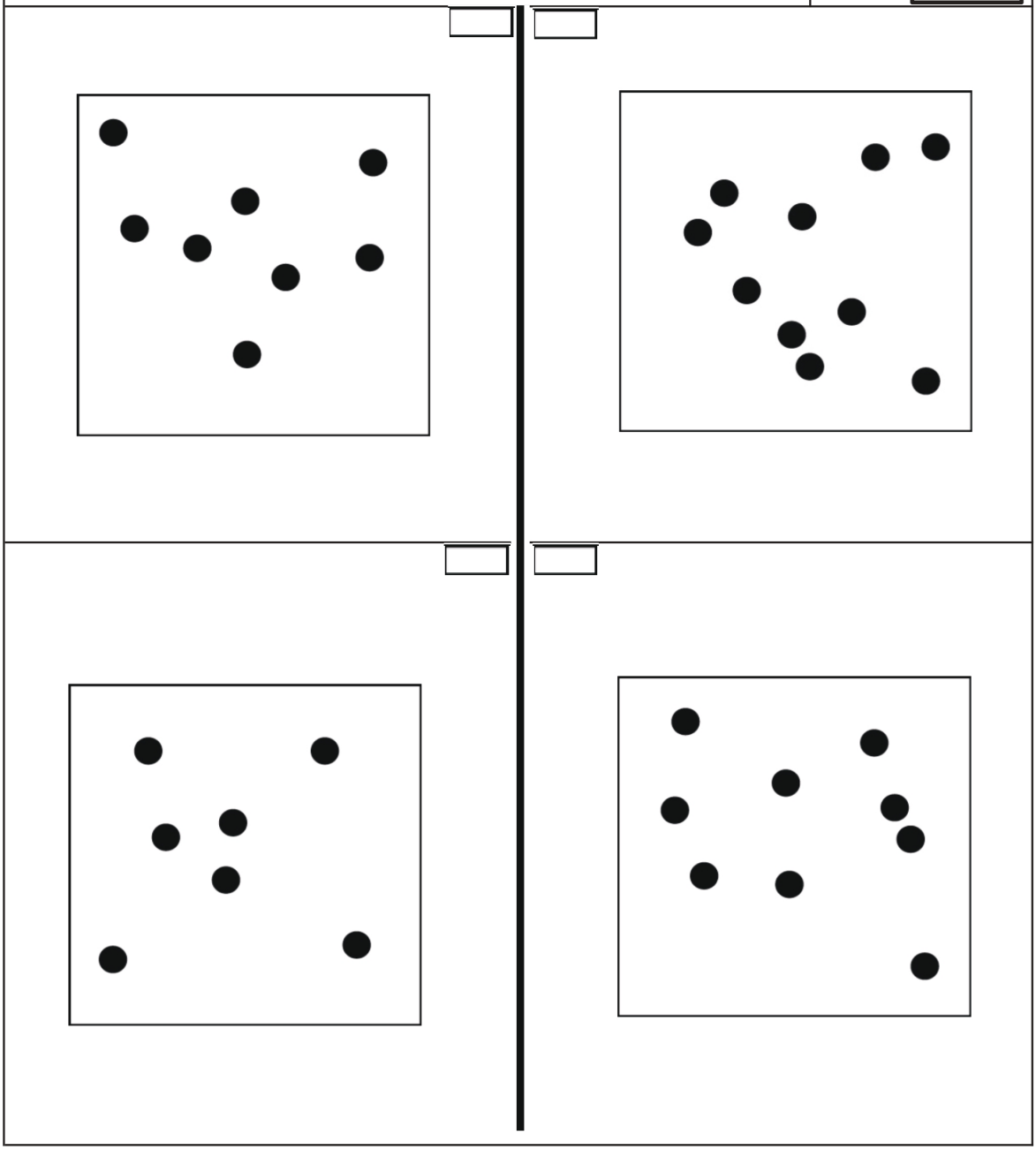
Habilidades visuoespaciais

➢ Diagrama infinito: Peça ao sujeito para copiar o diagrama	**Visuoespacial** [Score 0-1]
	
➢ Cubo ligado: Peça ao sujeito para copiar o desenho (para pontuar veja as instruções	**Visuoespacial** [Score 0-2]
	
➢ Relógio: Peça ao sujeito para desenhar um relógio com números e os ponteiros a marcar as onze e dez. (Para pontuar veja as instruções: circulo=1, números=2, ponteiros= 2)	**Visuoespacial** [Score 0-5]

Habilidades visuoespaciais

- Peça ao sujeito para contar os pontos sem apontar

Visuoespacial
[Score 0-4]



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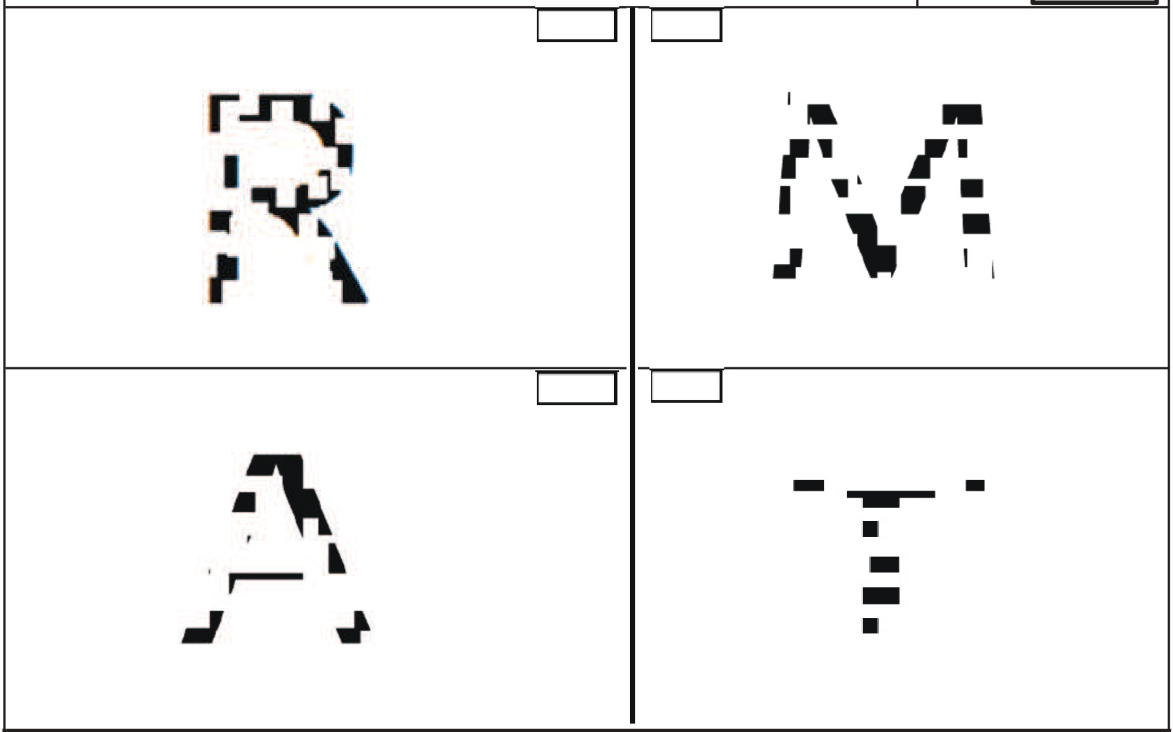
Habilidades visuoespaciais

- Peça ao sujeito para identificar as letras

Visuoespacial
[Score 0-4]



Memória

- Pergunte: "Agora diga-me o que se recorda do nome e da morada que repetimos no início"

João Silva Rua dos Ferreiros,73 Amares

Memória
[Score 0-7]

Memória

Este teste só deve ser realizado se o sujeito não evoca um ou mais itens. Se todos os itens forem evocados, não se aplica a prova e atribuem-se 5 pontos. Se apenas alguma parte for evocada, cancele esses itens na coluna sombreada á direita; teste os itens não evocados dizendo ao sujeito "Vou lhe dar algumas pistas; o nome era X, Y ou Z?" e assim sucessivamente. A cada reconhecimento atribua 1 ponto, que será somado aos pontos obtidos na evocação.

Memória
[Score 0-5]

José Silva		João Silva		João Pereira		Evocado	
37		73		76		Evocado	
Avenida dos Ferreiros		Rua dos Cesteiros		Rua dos Ferreiros		Evocado	
Cacém		Amares		Gandra		Evocado	
Braga		Paredes		Sintra		Evocado	

Pontuações

Total ACE III	/100
Atenção	/18
Memória	/26
Fluência	/14
Linguagem	/26
Visuoespacial	/16

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Escala de avaliação funcional pós-AVC – Escala de Rankin modificada[1]

Grau	Descrição	
0	**Sem sintomas**	
1	**Nenhuma deficiência significativa, a despeito sintomas**	Capaz de conduzir todos os deveres e atividades habituais
2	**Leve deficiência**	Incapaz conduzir todas as atividades de antes, mas é capaz de cuidar dos próprios interesses sem assistência
3	**Deficiência moderada**	Requer alguma ajuda mas é capaz de caminhar sem assistência (pode usar bengala ou andador)
4	**Deficiência moderadamente grave**	Incapaz de caminhar sem assistência e incapaz de atender às próprias necessidades fisiológicas sem assistência
5	**Deficiência grave**	Confinado à cama, incontinente, requerendo cuidados e atenção constante de enfermagem
6	**Óbito**	

1. Wilson JTL, Harendran A, Grant M, Baird T, Schulz UGR, Muir KW, Bone I. Improving the assessment of outcomes in stroke: Use off a structured interview to assign grades on the modified rankin scale. *Stroke*. 2002;33:2243-2246.

Escala de Depressão Geriátrica (GDS)

D.1) Você está basicamente satisfeito com sua vida? (0) SIM (1) NÃO
D.2) Você deixou muitos de seus interesses e atividades? (1) SIM (0) NÃO
D.3. Você sente que sua vida está vazia? (1) SIM (0) NÃO
D.4) Você se aborrece com freqüência? (1) SIM (0) NÃO
D.5) Você se sente de bom humor a maior parte do tempo? (0) SIM (1) NÃO
D.6) Você tem medo que algum mal vá lhe acontecer? (1) SIM (0) NÃO
D.7) Você se sente feliz a maior parte do tempo? (0) SIM (1) NÃO
D.8) Você sente que sua situação não tem saída? (1) SIM (0) NÃO
D.9) Você prefere ficar em casa a sair e fazer coisas novas? (1) SIM (0) NÃO
D.10) Você se sente com mais problemas de memória do que a maioria? (1) SIM (0) NÃO
D.11) Você acha maravilhoso estar vivo? (0) SIM (1) NÃO
D.12) Você se sente um inútil nas atuais circunstâncias? (1) SIM (0) NÃO
D.13) Você se sente cheio de energia? (0) SIM (1) NÃO
D.14) Você acha que sua situação é sem esperanças? (1) SIM (0) NÃO
D.15) Você sente que a maioria das pessoas está melhor que você? (1) SIM (0) NÃO

Pontuação: _____

UNIVERSIDADE DE LISBOA
Faculdade de Medicina

Study of subjective cognitive complaints and their relation to cognitive impairment in stroke survivors

Margarida Garcia Monereo Areias

Orientador: Professora Doutora Maria Isabel Segurado Pavão Martins Catarino Petiz
Co-orientador: Professor Doutor Pedro Nascimento Alves

Dissertação especialmente elaborada para obtenção do grau de Mestre em Neurociências

2024