

# Systematic review and meta-analysis of reliability of assessment instruments for Frontotemporal Dementia

## Revisión sistemática y metaanálisis de fiabilidad de los instrumentos de evaluación para la Demencia Frontotemporal

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DOI: <https://doi.org/10.58995/redlic.rmic.v3.n2.a114>

### How to cite:

Ramírez Coronel, A. A., Muñoz Arteaga, P. A., Quito Calle, J. V., & Vintimilla Guillén, S. C. (2025). Systematic review and meta-analysis of the reliability of assessment instruments for frontotemporal dementia. *Revista Multidisciplinaria Investigación Contemporánea*, 3(2), 176–208. <https://doi.org/10.58995/redlic.rmic.v3.n2.a114>

### Article Information

Received: 24-01-2025

Accepted: 19-03-2025

Published: 01-07-2025

### Editor's Note

REDLIC remains neutral regarding jurisdictional claims in published messages and institutional affiliations.

### Editorial

Latin American Editorial Network for Contemporary Research (REDLIC)  
[www.editorialredlic.com](http://www.editorialredlic.com)

### Funding Sources

The research was conducted using the authors' own resources.

### Conflicts of Interest

No conflicts of interest are declared.



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## Summary

**Introduction:** Frontotemporal dementia (FTD) is a progressive form of dementia that affects behavior and cognitive function. Assessing knowledge about this disease is crucial for proper diagnosis and treatment. Several assessment instruments have been adapted and validated in different cultural contexts, but their reliability varies. **Objective:** To analyze the scientific literature on assessment instruments used to measure knowledge and progression of FTD, in order to perform a meta-analysis of reliability, focusing on Cronbach's alpha in different cultural adaptations and contexts. **Methodology:** Four scientific databases (Web of Science, Scopus, PsycINFO, and PubMed) on the reliability (Cronbach's alpha) of FTD assessment instruments in various populations. Information was collected on the population, validation method, cultural context, and internal consistency (Cronbach's alpha) of each instrument. **Results:** Results showed that the internal consistency of the instruments varies according to context. For example, the FTDKS obtained an alpha of .846 in the United States, .740 in Spanish-speaking countries, and .800 in Poland. The FTD-FRS showed an exceptional alpha of .975 in Brazil. The meta-analytic model ( $n_{\text{Studies}} = 3$ ) demonstrated an overall reliability of .85 ( $CI \alpha = .80 - .90$ ). **Conclusion:** FTD assessment instruments vary in their reliability depending on the cultural context. Appropriate adaptations are essential to improve its effectiveness in assessing disease knowledge, thus facilitating better diagnosis and patient care.

**Keywords:** Meta-analysis, reliability, Psychometrics, Frontotemporal Dementia.

## Resumen

**Introducción:** La demencia frontotemporal (DFT) es una forma progresiva de demencia que afecta el comportamiento y la función cognitiva. Evaluar el conocimiento sobre esta enfermedad es crucial para un diagnóstico y tratamiento adecuados. Varios instrumentos de evaluación se han adaptado y validado en diferentes contextos culturales, pero su confiabilidad varía. **Objetivo:** Analizar la literatura científica sobre herramientas de evaluación utilizadas para medir el conocimiento y la progresión de la DFT, con el objetivo de realizar un metaanálisis de confiabilidad, centrándose en el alfa de Cronbach en diferentes adaptaciones culturales y contextos. **Metodología:** Se revisaron cuatro bases de datos científicas (Web of Science, Scopus, PsycINFO y PubMed) para recopilar información sobre la confiabilidad (alfa de Cronbach) de las herramientas de evaluación de la DFT en diversas poblaciones. Se recopilaron datos sobre la población, el método de validación, el contexto cultural y la consistencia interna (alfa de Cronbach) de cada instrumento. **Resultados:** Los hallazgos mostraron que la consistencia interna de los instrumentos varía según el contexto. Por ejemplo, la FTDKS obtuvo un alfa de Cronbach de 0,846 en Estados Unidos, 0,740 en países hispanohablantes y 0,800 en Polonia. La FTD-FRS mostró un alfa excepcional de 0,975 en Brasil. El modelo de metaanálisis ( $n_{\text{Estudios}} = 3$ ) demostró una fiabilidad general de 0,85 ( $CI\alpha = 0,80-0,90$ ). **Conclusión:** Las herramientas de evaluación de la DFT presentan variaciones en su fiabilidad según el contexto cultural. Es fundamental realizar adaptaciones adecuadas para mejorar su eficacia en la evaluación del conocimiento sobre la enfermedad, facilitando así un mejor diagnóstico y atención al paciente.

**Palabras clave:** Metaanálisis, fiabilidad, psicometría, demencia frontotemporal

## Introduction

Frontotemporal dementia (FTD) is an umbrella term for a variety of neurodegenerative disorders characterized by predominant atrophy of the frontal and temporal lobes of the brain, manifesting primarily through changes in behavior, personality, and language (1). Unlike other forms of dementia such as Alzheimer's, FTD occurs in younger individuals, usually between 40 and 65 years of age, with symptoms primarily affecting executive function, social behavior, and in some cases, language and communication skills (2,3). Clinical variants of FTD include the behavioral variant (bvFTD), characterized by disinhibition, apathy, impulsivity, and loss of empathy, and language variants, such as progressive non-fluent aphasia (PNFA) and semantic dementia (SD), which affect language production and comprehension, respectively (4). In neuropathological terms, FTD is associated with the abnormal accumulation of proteins such as tau and TDP-43, which contribute to progressive neurodegeneration.

Clinical evaluations for FTD are complex due to the overlap of its symptoms with other psychiatric disorders (5,6). Therefore, it is crucial to develop and validate accurate diagnostic tools to improve the diagnostic accuracy and clinical management of this disease (7,8). Characterization and follow-up of patients with FTD have demonstrated variable disease progression, underscoring the need for longitudinal studies and detailed clinical reviews (9,10).

Public awareness of FTD and other forms of dementia remains limited, affecting perception and management of these conditions (11–13). Evidence-based interventions, such as recommendations to distinguish between FTD and psychiatric disorders, are critical for improving diagnoses and providing support to caregivers (14–17).

The development and validation of knowledge scales and assessment tools, such as the FTD Knowledge Scale, are essential to address these

needs and improve understanding and management of the disease (16, 18).

The overall objective was to analyze the scientific literature on assessment instruments used to measure knowledge and progression of Frontotemporal Dementia, with the aim of conducting a meta-analysis of reliability, specifically Cronbach's alpha, in various cultural adaptations and contexts.

## Methodology

### Study design

The study followed the preferred reporting items for systematic reviews (19,20) and reliability meta-analyses (21).

### Inclusion and exclusion criteria

For the systematic review and meta-analysis of the reliability of assessment instruments for Frontotemporal Dementia, prevalence studies, as well as longitudinal and cross-sectional studies, were included. Participants had to be adults with a confirmed or suspected diagnosis of Frontotemporal Dementia. It was essential that the assessed studies used instruments specifically validated for this condition. Only studies that reported instrument reliability using Cronbach's alpha and McDonald's omega, a key indicator of internal consistency, were considered.

Studies published in English or Spanish that had been peer-reviewed in academic journals were included. Studies that focused on other forms of dementia or neurocognitive disorders unrelated to Frontotemporal Dementia were excluded. Studies that did not provide data on the reliability of the instruments used or that used tools not psychometrically validated were also excluded. Studies that were not peer-reviewed, such

as theses, dissertations, technical reports, or unpublished papers, were also excluded from the analysis.

### Sources of information

Four scientific databases were used as sources of information: Web of Science, Scopus, PsycINFO, and PubMed, with access to the library of the University of Oviedo (Spain) and the Salesian Polytechnic University (Ecuador). Four databases were selected for their international scientific relevance and high-quality coverage of studies in the social and health sciences. The bibliographies of the articles included in the review were reviewed to reduce exclusion bias due to coverage.

### Search strategy

The searches for the systematic review and meta-analysis of the reliability of assessment instruments for Frontotemporal Dementia were conducted on October 2, 2024, following the guidelines outlined in the PRISMA statement (19). In the initial phase, duplicate records with a content overlap greater than 90 % were identified, both algorithmically and by manual verification. Records that did not focus on the assessment of Frontotemporal Dementia were then excluded. Theoretical studies, systematic reviews, or non-systematic narratives were not considered eligible. Two independent researchers reviewed the full texts of the remaining records, comparing their content with previously established inclusion criteria. Disagreements in coding decisions were resolved through deliberation until consensus was reached, classifying studies as included, excluded, or those requiring further discussion.

Coding in this phase was performed using the Rayyan web application (22) and records were categorized into duplicates, deleted, included, excluded, and possible. The reasons for each decision were recorded in detail in the system. Finally, blinding was unblinded to allow

the investigators to cross-check the results and continue with the study analysis (Figure 1).

### Data collection process

A thorough systematic extraction of essential bibliographic data was conducted for the systematic review and meta-analysis of the reliability of assessment instruments for Frontotemporal Dementia. The data collected included author names, publication titles, source journals, and abstracts, providing a comprehensive view of each record. A researcher downloaded these data in RIS format, a standard for bibliographic data exchange, managing each record individually according to the database used.

RIS files were then verified and uploaded to Rayyan (22), a specialized tool for managing and reviewing scientific literature. To ensure accuracy and reduce bias, an independent researcher was recruited as a blind coding partner, allowing for a dual screening process. This meticulous extraction and processing protocol was followed sequentially across the selected databases, ensuring consistency and rigor in data management.

### Data extraction process

For data extraction in the systematic review and meta-analysis of the reliability of assessment instruments for Frontotemporal Dementia, two main categories were defined: 1) the methodological characteristics of the included studies and 2) the psychometric properties of the instruments evaluated. The primary reviewer identified the information based on the predefined variables in a working matrix and compared the findings with the external reviewer. Inconsistencies were resolved by joint verification of the data until an agreement was reached.

Regarding the methodological variables, the following data of interest were collected: 1) author and year of publication; 2) title of the study in the original language of publication; 3) journal and quartile; 4) psychometric instrument used and the number of items in its structure;

5) country, sample size and average age of participants; and 6) reliability measures and, where applicable, the fit indices of the instruments evaluated for Frontotemporal Dementia. The psychometric data of interest were: 1) the reliability of the instrument measured by Cronbach's alpha and McDonald's omega.

### Assessment of the risk of bias of the study

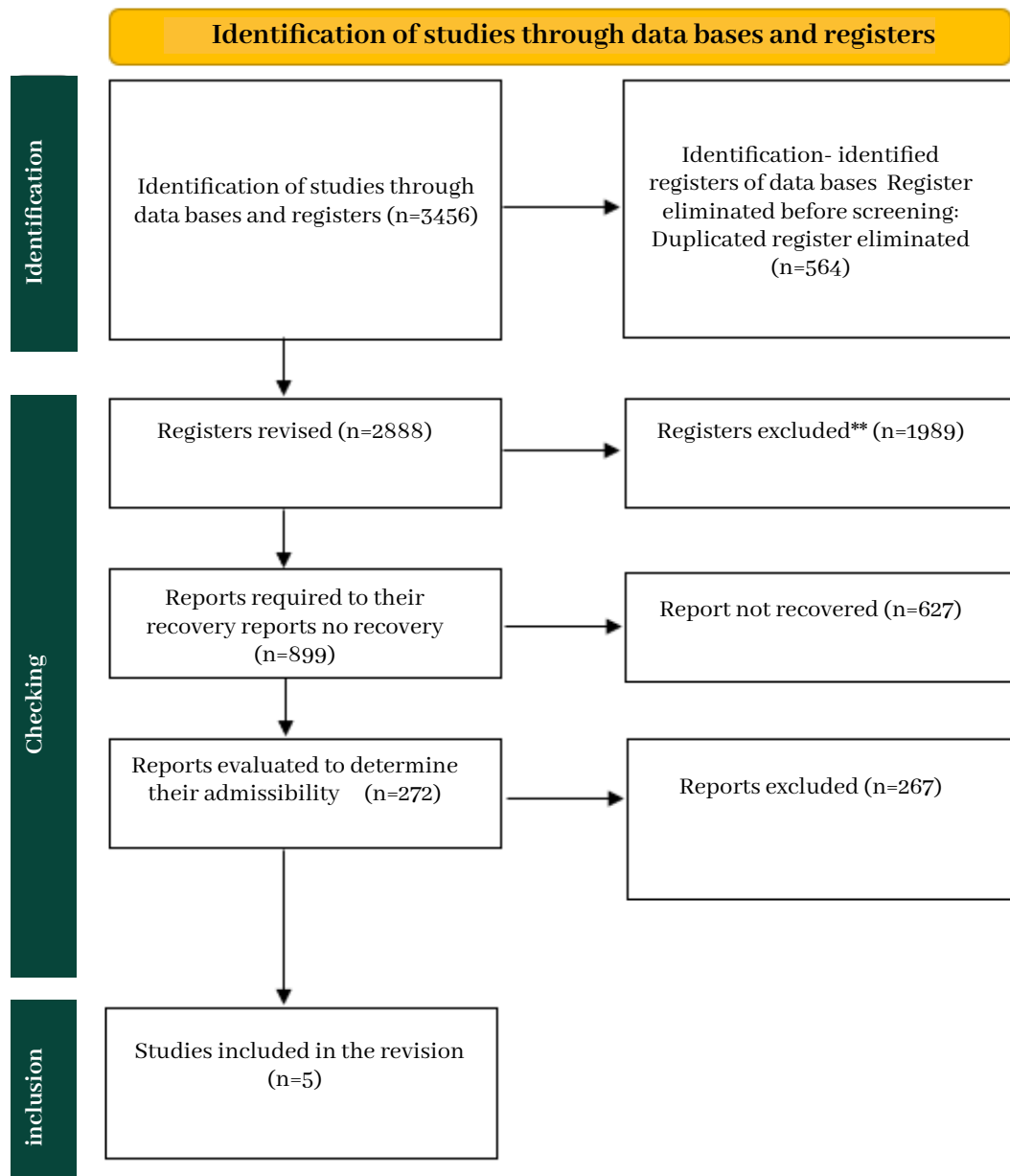
The lead reviewer (AR) and the second reviewer (VQ) analyzed the methodological quality of the included studies, assessing their reliability or internal consistency using Cronbach's alpha for the psychometric instruments used to assess frontotemporal dementia. A Cronbach's alpha value of 0.70 was considered acceptable, in line with established methodological standards. The representativeness of the sample was also assessed in relation to the number of instrument items reported in each study.

The reviewers agreed in 97 % of cases, and discrepancies were resolved through discussion and consensus with a third reviewer (SV). Of the five studies that reported relevant statistical data, the researchers (VQ and AR) decided to document the samples separately, reviewing the full text and comparing the data until reaching a consensus through joint discussion.

Figure 1 illustrates the flow diagram of the systematic review, beginning with the identification of 3456 records through databases, from which 564 duplicate records were removed prior to screening. A total of 2888 records were reviewed, of which 1989 were excluded for not meeting the inclusion criteria. A total of 899 reports were requested for retrieval, but 627 of these could not be retrieved. A total of 272 full reports were assessed for eligibility, resulting in the exclusion of 267 reports. Finally, five studies that reported the reliability (Cronbach's alpha and McDonald's omega) of instruments for assessing frontotemporal dementia and met

the criteria for the systematic review were included, reflecting a rigorous and methodical selection process.

**Figure 1.** Flowchart of the systematic review.



## Statistical analysis

This study employed reliability generalizability and meta-analysis approaches to measure internal consistency and model fit indicators of Frontotemporal Dementia assessment instruments in published studies. Pooled reliability was estimated using Cronbach's  $\alpha$  and McDonald's  $\omega$  (23), transformed using the Hakstian – Whalen method to facilitate random effects modeling (24). Heterogeneity was assessed using Cochran's  $Q$ ,  $I^2$ ,  $H^2$ , and  $\tau^2$  (25).

To ensure the reliability of the results, studies with Cronbach's  $\alpha$  values less than 0.70 or inadequate case-to-item ratios (less than 10:1) were removed using trimming techniques before calculating pooled estimates. Potential publication bias was assessed by visual inspection of funnel plot asymmetry and Egger's regression test (25). By meta-analyzing reliability and validity indicators across diverse applications, this study facilitates generalizations about the effectiveness of existing tools in consistently measuring FTD across diverse samples. All analyses were performed using *Jamovi* and R.

## Results

Table 2 presents the descriptives of the selected studies on assessment instruments for frontotemporal dementia, with a total of five studies analyzed.

Regarding the year of publication, the studies are evenly distributed between 2017, 2018, 2020, 2021, and 2022, with one study (20 %) published in each of these years. This suggests that studies on the reliability of instruments for frontotemporal dementia have been relatively consistent over recent years.

Regarding the scientific journals in which these studies were published, the largest proportion (40%) comes from the journal

Alzheimer's Disease and Associated Disorders , while the other three publications are distributed between Archivos de Neuro- Psiquiatria (20 % ), Dementia and Geriatric Cognitive Disorders (20 % ) and Neurologia (Barcelona, Spain ) (20 % ).

Table 1. Articles selected on the reliability of frontotemporal dementia instruments .

| No. | Authors                     | Year | Magazine                                   | Quartile | SJR 2023 | H-INDEX | Country       | Continent | Sample | n items | Cronbach's alpha |
|-----|-----------------------------|------|--------------------------------------------|----------|----------|---------|---------------|-----------|--------|---------|------------------|
| 1   | Wynn and Carpenter (26)     | 2020 | Alzheimer disease and associated disorders | Q2       | 0.61     | 109     | United States | America   | 174    | 4       | .846             |
| 2   | Magrath-Guimet et al. (27)  | 2022 | Neuro-psychiatry archives                  | Q3       | 0.34     | 58      | Germany       | Europe    | 134    | 18      | .74              |
| 3   | Turró-Garriga et al. (28)   | 2017 | Neurology (Barcelona, Spain )              | Q4       | 0.52     | 50      | Spain         | Europe    | 60     | 30      | .897             |
| 4   | Karasiewicz and Leszko (29) | 2021 | Dementia and geriatric cognitive disorders | Q2       | 0.81     | 123     | Switzerland   | Europe    | 869    | 4       | .80              |
| 5   | Lima-Silva et al. (30)      | 2018 | Alzheimer disease and associated disorders | Q2       | 0.61     | 109     | United States | America   | 97     | 8       | .975             |

Regarding the journal quartile, three of the studies (60%) were published in journals classified in the second quartile (Q2 50% ), indicating a medium-high impact level. One study (20 % ) was published in a third quartile journal (Q3 75% ) and another in a fourth quartile journal (Q4 100% ), indicating lower relevance within the field. Regarding

geographic distribution, the selected studies come from diverse countries. Two studies (40 %) were conducted in the United States, while Germany, Spain, and Switzerland each contributed one study (20 %). Finally, regarding continental distribution, three studies (60%) were conducted in Europe, while the other two studies (40 %) were conducted in America. This suggests a relevant interest in frontotemporal dementia research on both continents.

Table 2. Descriptives of the selected studies on assessment instruments for Frontotemporal Dementia (n = 5).

| Year                                       | n (%)   |
|--------------------------------------------|---------|
| 2017                                       | 1 (20%) |
| 2018                                       | 1 (20%) |
| 2020                                       | 1 (20%) |
| 2021                                       | 1 (20%) |
| 2022                                       | 1 (20%) |
| <b>Magazine</b>                            |         |
| Alzheimer disease and associated disorders | 2 (40%) |
| Neuro- psychiatry archives                 | 1 (20%) |
| Dementia and geriatric cognitive disorders | 1 (20%) |
| Neurology (Barcelona, Spain )              | 1 (20%) |
| <b>Quartile</b>                            |         |
| Q2                                         | 3 (60%) |
| Q3                                         | 1 (20%) |
| Q4                                         | 1 (20%) |
| <b>Country</b>                             |         |
| Germany                                    | 1 (20%) |
| Spain                                      | 1 (20%) |
| Switzerland                                | 1 (20%) |
| United States                              | 2 (40%) |

| Continent |         |
|-----------|---------|
| America   | 2 (40%) |
| Europe    | 3 (60%) |

Table 3 shows the descriptives of the selected publications, analyzing several factors such as the impact of the journals, the sample size, the number of items and the reliability measures of the assessment instruments used for frontotemporal dementia.

Regarding journal impact, all studies report both the *SJR* and the *H-INDEX*. The average *SJR* is 0.578, indicating that the journals in which the studies were published have a moderate to high impact in their field. The average *H-INDEX* is 89.8, reflecting a high level of scholarly recognition of these journals, with a range from 50 to 123. This suggests that the studies come from relevant and well-established sources in the scientific field.

The sample sizes used in the studies vary significantly. The average is 267 participants, although the median is lower at 134, indicating that most studies include moderately sized samples. However, some studies present much larger samples, which raises the average. The number of items in the assessment instruments varies between 4 and 30 items, with an average of 12.8, demonstrating diversity in the length of the instruments used.

All studies report *Cronbach 's alpha* as a measure of reliability, with a mean of 0.852 and a median of 0.846, indicating high internal consistency across the instruments evaluated. The range varies between 0.740 and 0.975, suggesting that some instruments have higher reliability than others. However, only one study reports *McDonald 's omega*, with a value of 0.800, also indicating good internal consistency. The lack of further reporting on *McDonald 's omega* limits a broader comparison between the two reliability measures. Overall, the selected studies reflect a solid methodological basis, with instruments that present acceptable reliability and were published in well-recognized academic journals.

Table 3. Descriptives of the selected publications based on the impact of the journals (SJR and H-INDEX), sample, number of items and reliability (Cronbach's Alpha and McDonald's Omega).

|                    | SJR 2023 | H-INDEX | Sample | n items | Cronbach's<br>alpha | Omega<br>McDonald |
|--------------------|----------|---------|--------|---------|---------------------|-------------------|
| Report             | 5        | 5       | 5      | 5       | 5                   | 1                 |
| Does not<br>report | 0        | 0       | 0      | 0       | 0                   | 4                 |
| M                  | 0.578    | 89.8    | 267    | 12.8    | 0.852               | 0.800             |
| MD                 | 0.610    | 109     | 134    | 8       | 0.846               | 0.800             |
| OF                 | 0.170    | 33.3    | 339    | 11.2    | 0.0901              | ----              |
| Min                | 0.340    | 50      | 60     | 4       | 0.740               | 0.800             |
| Max                | 0.810    | 123     | 869    | 30      | 0.975               | 0.800             |

Note. M = Mean, Md = Median, SD = Standard Deviation, Min = Minimum, and Max = Maximum.

Table 4 presents the results of the random-effects model and heterogeneity statistics for two models examining frontotemporal dementia assessment instruments. Model 1 includes five studies, while Model 2 includes three studies.

Regarding the estimates of the combined effects of the studies, Model 1 has an estimate of 0.855, while Model 2 has a slightly lower estimate of 0.846. Both models have a low standard error (se), 0.0358 for Model 1 and 0.0284 for Model 2, indicating precision in the estimates. The Z values for both models are high (23.9 and 29.8, respectively), demonstrating a strong association in the data. The p values are highly significant for both models ( $p < .001$ ), indicating that the estimates are statistically significant.

The confidence intervals (CIs) for the estimates are also narrow, reinforcing the reliability of the results. In Model 1, the confidence interval ranges from 0.785 to 0.925, and in Model 2, from 0.790 to 0.902, suggesting

that the true parameter values are likely within these ranges, and both models show high consistency.

The heterogeneity statistics show a notable difference between the two models. In Model 1, the Tau value is 0.078, and in Model 2 it is 0.046, indicating less heterogeneity in the second model.  $\text{Tau}^2$ , which measures the variance between studies, is lower in Model 2 (0.0021) than in Model 1 (0.006), suggesting that the studies in Model 2 are more homogeneous.

The  $I^2$  value is extremely high in both models, with 97.44% for Model 1 and 88.94% for Model 2. This indicates that most of the variability observed between studies is not due to chance, but to real differences between studies, although Model 2 shows less heterogeneity compared to Model 1.

The  $H^2$  values, which also reflect heterogeneity, are considerably high in both models, especially in Model 1 (39,038 versus 9,043 in Model 2), again indicating greater heterogeneity in the first model.

Q statistic, which assesses consistency across studies, is significant in both models ( $p < .001$ ), but the Q value is much higher in Model 1 ( $Q = 301.577$ ) than in Model 2 ( $Q = 19.833$ ), reinforcing the idea that studies in Model 1 have more variability across them.

In summary, both models present robust and significant estimates for the reliability of frontotemporal dementia assessment instruments. However, Model 2 shows less heterogeneity, indicating greater consistency across the studies included in this model compared to Model 1.

Table 4. Random effects model and heterogeneity statistics of model 1 (n = 5) and model 2 (n = 3) of the assessment instruments for Frontotemporal Dementia.

|                  | Model 1            | Model 2              |
|------------------|--------------------|----------------------|
| Dear             | 0.855              | 0.846                |
| HE               | 0.0358             | 0.0284               |
| Z                | 23.9               | 29.8                 |
| p                | < .001             | < .001               |
| Lower IQ Bound   | 0.785              | 0.790                |
| Upper IQ Bound   | 0.925              | 0.902                |
| Tau              | 0.078              | 0.046                |
| Tau <sup>2</sup> | 0.006 ( SE= 0.004) | 0.0021 ( SE= 0.0024) |
| I <sup>2</sup>   | 97.44 %            | 88.94 %              |
| H <sup>2</sup>   | 39.038             | 9.043                |
| df               | 4,000              | 2,000                |
| Q                | 301,577            | 19,833               |
| p                | < .001             | < .001               |

Note. Tau<sup>2</sup> Estimator: Restricted Maximum-Likelihood.

Table 5 presents the results of the assessment of publication bias in two models of assessment instruments for frontotemporal dementia.

In Model 1, the Fail-Safe N value is 70,339,000, with a p value < .001, indicating that a large number of additional null studies would be needed to invalidate the results of the meta-analysis . This suggests that the model is robust and not significantly influenced by the lack of published studies. Model 2 also shows a high Fail-Safe N value (9,740,000), with p < .001, reinforcing the reliability of the results in this second model.

Kendall's Tau test in Model 1 has a value of -0.200 and a p-value = 0.817, indicating no significant correlation between effect size and variance, demonstrating no apparent publication bias. In Model 2, the

*Kendall's Tau value* is 1.000, but the *p-value* = 0.333 indicates no significant evidence of bias in that model either.

Regarding Egger 's regression , Model 1 presents a value of -2.418 and a *p-value* = 0.016, suggesting the presence of a statistically significant publication bias. This implies that there may be some asymmetry in the distribution of the studies included in this model, possibly because studies with less favorable results were not published. On the other hand, in Model 2, the *Egger 's Regression* is 1.859 and the *p-value* = 0.063, which is not statistically significant, suggesting that Model 2 does not present considerable publication bias.

*Fail-Safe N* values , indicating that they are robust to publication bias, Model 1 shows evidence of bias according to *Egger 's regression* , while Model 2 does not show significant bias according to the tests applied. This shows that Model 2 is more reliable in terms of avoiding publication bias.

Table 5. Assessment of publication bias.

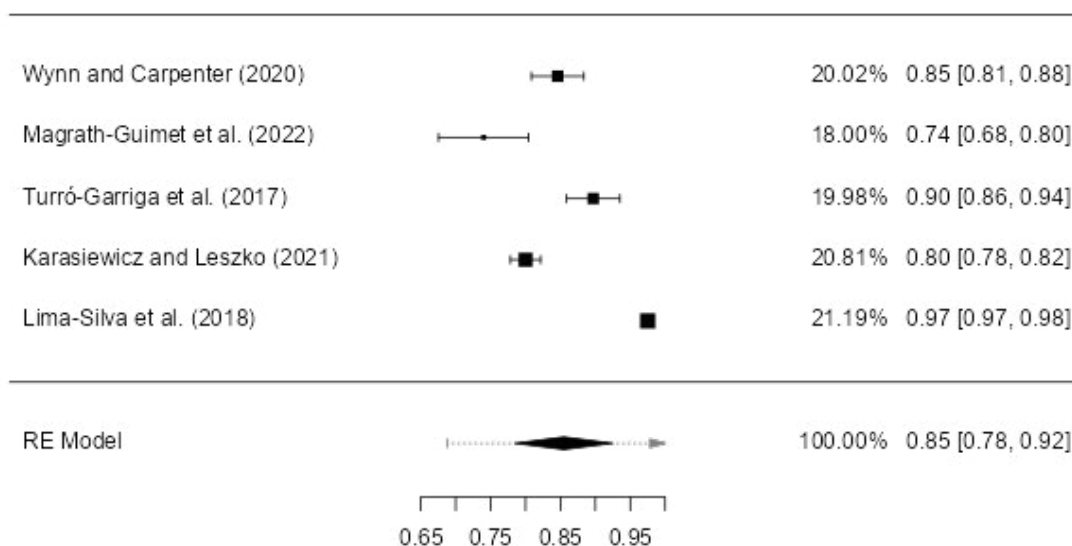
|                       | Model 1     |        | Model 2     |        |
|-----------------------|-------------|--------|-------------|--------|
| Test Name             | Statistical | p      | Statistical | p      |
| Fail-Safe N           | 70,339,000  | < .001 | 9,740,000   | < .001 |
| Kendalls<br>Tau       | -0.200      | 0.817  | 1,000       | 0.333  |
| Egger's<br>Regression | -2.418      | 0.016  | 1,859       | 0.063  |

Note. Fail-safe N Calculation Using the Rosenthal Approach

Figure 1 shows the meta-analysis of the reliability of assessment instruments for Frontotemporal Dementia, with a sample of 5 studies (*n* = 5). Each study is represented by a point indicating the reliability coefficient, with horizontal bars representing the 95% confidence intervals

(CI). Reliability coefficients vary across studies, with some wider intervals suggesting greater uncertainty in the results. The overall coefficient, represented by a diamond at the bottom of the graph, indicates a weighted average of the reliability, showing that the instruments generally have adequate reliability. However, some heterogeneity is observed across studies, suggesting differences in the characteristics of the instruments or the populations assessed.

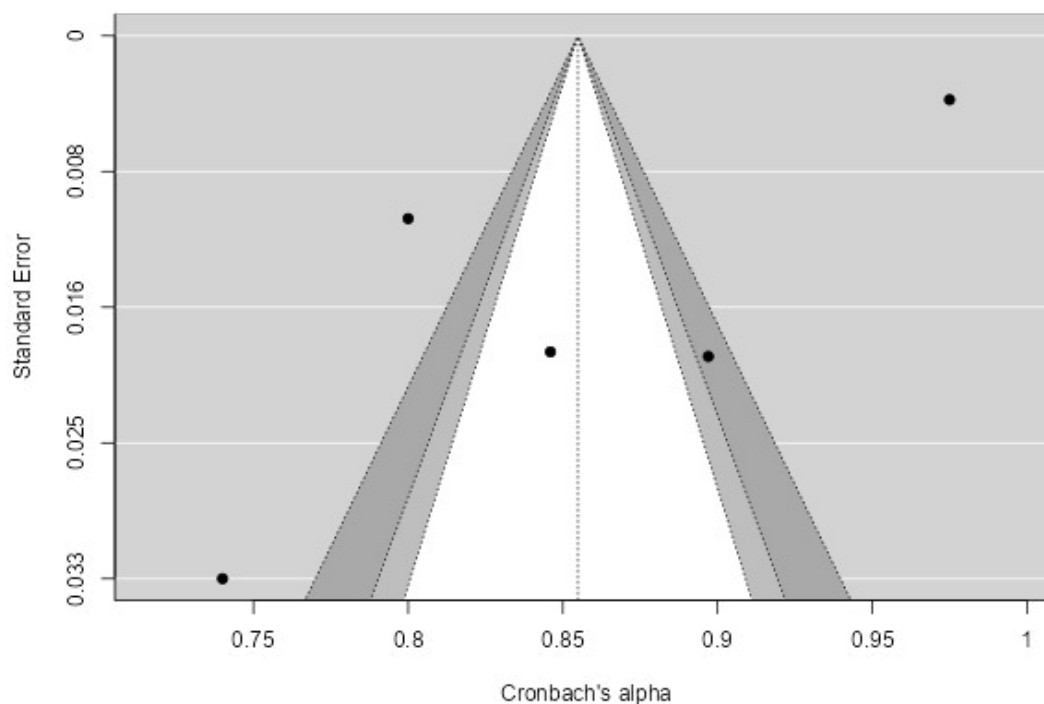
Figure 2. Model 1 of the meta-analysis of reliability of the assessment instruments for Frontotemporal Dementia (n = 5).



It was noted in Figure 2 that the studies are not completely symmetrically distributed around the center line, suggesting the possible presence of publication bias or heterogeneity in the results. Some points are outside the confidence area, indicating studies with more extreme or less precise effects. The asymmetric shape of the graph could reflect the lack of small studies with negative effects or studies with variability in reliability. Although only five studies were included, this visual representation

indicates that further examination of the quality and homogeneity of the studies included in the meta-analysis may be necessary.

Figure 3. Funnel plot of Model 1 ( $n = 5$ ).



The points in Figure 3 indicate the Tau estimates with and without excluding Model 1. In this case, the graph suggests that excluding Model 1 changes the Tau estimate, indicating that this study could be influencing the overall variability across studies. The red points likely represent the Tau values with and without excluding Model 1, showing that the variability across studies could be reduced or increased depending on whether this particular model is included or excluded. This type of analysis is useful for identifying studies that contribute disproportionately to heterogeneity and for assessing the robustness of the overall meta-analysis results.

Figure 3. Tau estimates excluding Model 1 (n = 5).

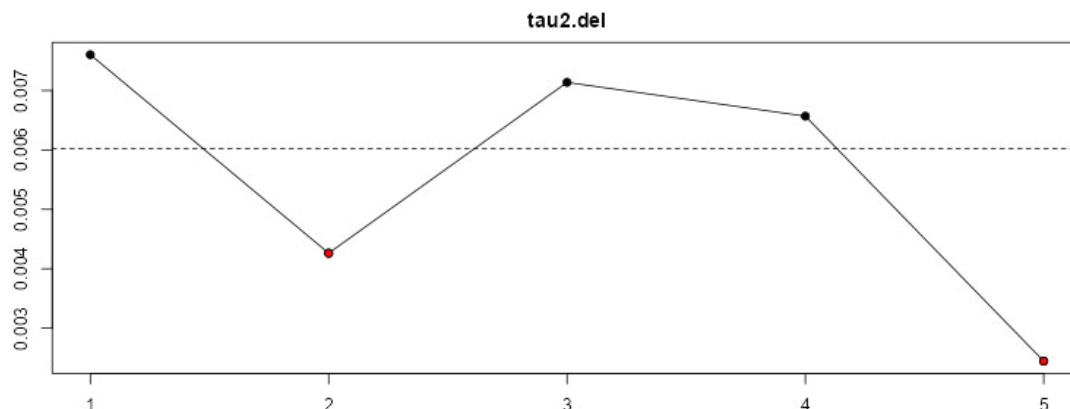


Figure 4 showed a meta-analysis model of reliability for Frontotemporal Dementia assessment instruments, based on three studies. In this analysis, reliability estimates, probably Cronbach's alpha, were displayed for each individual instrument or study, along with an overall summary. The x-axis represented the reliability coefficients, which probably ranged from 0 to 1, with 1 indicating perfect reliability and 0 indicating no reliability. The three studies (n = 3) presented their respective reliability estimates, possibly accompanied by confidence intervals (CIs), which reflected the range within which the true reliability value was expected to lie, with some margin of error. The figure also included a horizontal bar or dot plot showing the reliability estimates for each study. Wider confidence intervals indicated greater uncertainty in the estimates. Finally, the overall meta-analysis model presented a pooled reliability estimate, which summarized the reliabilities of the individual studies.

Figure 4. Model 2 of the meta-analysis of reliability of the assessment instruments for Frontotemporal Dementia (n = 3).

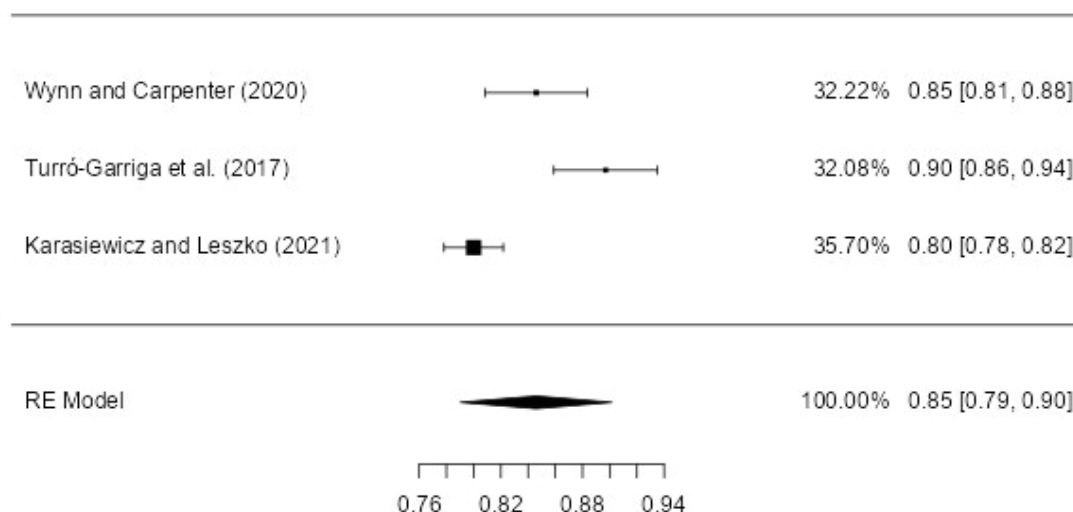


Figure 5 presented a funnel plot corresponding to Model 2, based on 3 studies. This type of plot is commonly used in meta-analyses to detect potential publication bias or to assess symmetry in the data. A symmetrical funnel plot indicates that publication bias is unlikely, while asymmetry may suggest the opposite. In this plot, the points represented the studies included in the meta-analysis. Each point corresponded to a study, and its position depended on the precision of the results (usually represented on the vertical axis) and the effect size or reliability coefficient (on the horizontal axis). The ideal funnel should be symmetrical around a center line (the pooled effect line from the meta-analysis). However, in the figure, one of the studies appeared isolated on the left, which could indicate asymmetry in the plot. This asymmetry could be an indication of publication bias or heterogeneity between the studies, although with only three studies in the analysis, conclusions about the presence of bias should be taken with caution. Additionally, the shaded areas of the graph represented the confidence intervals for the studies. Studies falling within the shaded areas closest to the apex of the funnel indicated greater

precision, while those further from the apex, such as the study on the left, showed lower precision in their results.

Figure 5. Funnel plot of Model 2 ( $n = 3$ ).

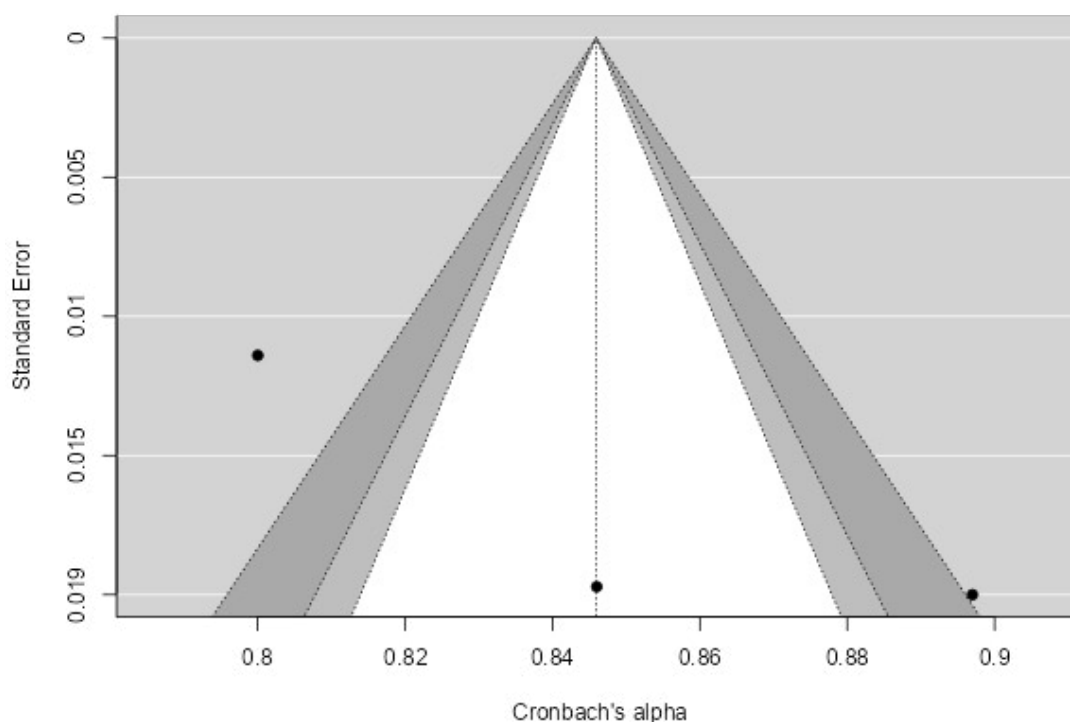
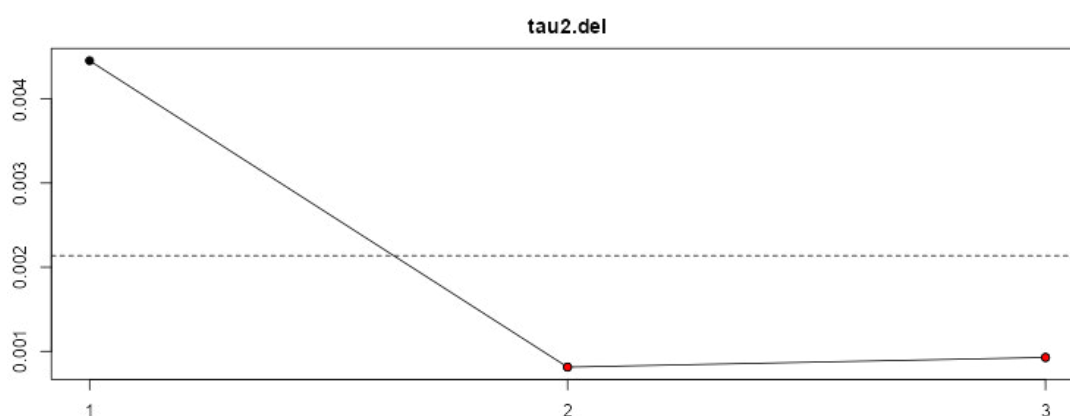


Figure 6 showed the Tau estimates excluding Model 2, based on three studies. Tau is a measure used in meta-analyses to assess heterogeneity among included studies. Specifically,  $\text{Tau}^2$  represents the true variance between studies—that is, the amount of variability in the results that cannot be explained by random error and is attributable to true differences between studies. In this figure, two points were displayed, one on the left and one on the right, representing the Tau estimates when certain outcomes were excluded from Model 2. The red dot in the center of the graph likely indicated the pooled Tau estimate when this exclusion was applied. The fact that the estimates diverged at the extremes could have indicated significant variability between the excluded and included studies, potentially reflecting a high degree of heterogeneity in the data.

This suggested that, when Model 2 was excluded, the variance between studies remained considerable and that the remaining studies were not completely homogeneous in terms of their outcomes or characteristics. Interpretation of these Tau estimates may have indicated the need to further explore differences between studies or to apply more complex models to adjust for this heterogeneity.

Figure 6. Tau estimates excluding Model 2 (n = 3).



## Discussion

The reviewed studies on the adaptation and validation of instruments to measure knowledge about frontotemporal dementia (FTD) highlight rigorous methodological approaches and solid psychometric results. Wynn and Carpenter (26) developed the Frontotemporal Dementia Knowledge Scale (FTDKS) with outstanding internal consistency ( $\alpha = .846$ ) in a sample of 174 people, including health professionals and caregivers. This instrument, designed to measure knowledge about FTD, covers essential aspects of the disease, such as risk factors, symptoms, progression, and treatment, and has become a useful tool in both clinical settings and educational programs in the United States.

In a Spanish-speaking context, Magrath-Guimet et al. (27) adapted and validated the FTDKS in Spanish, obtaining acceptable internal consistency ( $\alpha = .74$ ) with a sample of 134 healthcare professionals. The adaptation followed international guidelines for translation and cross-cultural adaptation, and the results show that this version is applicable in their setting. The usefulness of this instrument lies in its ability to assess knowledge about FTD, which can improve the diagnosis and care of patients with frontotemporal dementia in Spanish-speaking countries, where knowledge about this condition is still limited.

Turró Garriga et al. (28) validated the Frontotemporal Dementia Rating Scale (FTD-FRS) in Spanish, focusing on patients diagnosed with FTD in Spain. This study reported high internal consistency ( $\alpha = .897$ ) and used the Rasch model to validate the unidimensionality of the instrument. The FTD-FRS allows the evaluation of disease progression and the clinical status of patients, being of great value to professionals who care for people with FTD.

In Poland, Karasiewicz and Leszko (29) adapted and validated the FTDKS in their language, achieving adequate internal consistency in both Cronbach's alpha and McDonald's omega ( $\alpha = .80$ ,  $\omega = .80$ ). This study included a large sample of 869 people, which allowed evaluating the effectiveness of the instrument in different subpopulations, such as the general population, health professionals and caregivers. The authors concluded that the FTDKS is effective in measuring knowledge about dementia in various contexts, highlighting its convergent and discriminant validity.

Finally, Lima-Silva et al. (30) validated the FTD-FRS in Brazil with impressive results in terms of internal consistency ( $\alpha = .975$ ) and test-retest reliability (.977). This study focused on patients with FTD and Alzheimer's disease, demonstrating that the FTD-FRS is a valuable tool for assessing the status and progression of dementia. The application of this instrument

in Brazil reinforces its usefulness for documenting changes related to interventions and for the clinical follow-up of patients with FTD.

Taken together, these studies demonstrate that the adaptations and validations of the FTDKS and FTD-FRS instruments are psychometrically sound and applicable across diverse cultural contexts. These instruments allow for the assessment of knowledge and progression of frontotemporal dementia, which is critical for improving the diagnosis, care, and management of this disease in different populations.

Table 6 presents a comparison of studies on the reliability of instruments for measuring knowledge about frontotemporal dementia (FTD) in different cultural contexts. First, the study by Wynn and Carpenter (26) stands out for its focus on health professionals and caregivers in the United States, although it does not specify the validation method used; however, it is considered effective in a context where knowledge about FTD is already more advanced. On the other hand, Magrath-Guimet et al. (27) adapted the instrument to Spanish-speaking countries through translation and cross-cultural adaptation, obtaining lower consistency, which highlights the importance of cultural adaptation to improve the effectiveness of the instrument. In contrast, the work of Turró-Garriga et al. (28) uses the Rasch model to validate their instrument in patients diagnosed with FTD in Spain, reporting high consistency and unidimensionality, making it a robust tool for clinical assessment. In Poland, Karasiewicz and Leszko (29) evaluated the FTDKS in a diverse context including the general population, healthcare professionals and caregivers, although they did not specify the validation method; their study highlights the effectiveness of the instrument and the need to explore its applicability in different subpopulations. Finally, the study by Lima-Silva et al. (30) focuses on patients with FTD and Alzheimer's in Brazil, obtaining outstanding results in internal consistency, suggesting that it is a useful tool for clinical follow-up and documentation of changes. Taken together, these studies highlight the variability in the reliability of the instruments

according to the cultural context and the target population, underlining the need for careful adaptation and validation in different settings.

Table 6. Comparison of studies on instruments for measuring knowledge about frontotemporal dementia.

| Investigation               | Population                                              | Validation Method                         | Cultural Context           | Observations                                                                                                                   |
|-----------------------------|---------------------------------------------------------|-------------------------------------------|----------------------------|--------------------------------------------------------------------------------------------------------------------------------|
| Wynn and Carpenter (26)     | Health professionals and caregivers                     | not specified                             | USA                        | Effective tool, but focused on a context with greater knowledge about FTD.                                                     |
| Magrath-Guimet et al. (27)  | Health professionals                                    | Translation and cross-cultural adaptation | Spanish-speaking countries | Inferior consistency; highlights the need for cultural adaptation.                                                             |
| Turró-Garriga et al. (28)   | Patients diagnosed with FTD                             | Rasch model                               | Spain                      | High consistency and unidimensionality, robust instrument to assess clinical status.                                           |
| Karasiewicz and Leszko (29) | General population, health professionals and caregivers | not specified                             | Poland                     | An effective instrument in various contexts; it highlights the need to evaluate its applicability in different subpopulations. |

|                        |                                   |               |        |                                                                                          |
|------------------------|-----------------------------------|---------------|--------|------------------------------------------------------------------------------------------|
| Lima-Silva et al. (30) | Patients with FTD and Alzheimer's | not specified | Brazil | Exceptional internal consistency; useful for clinical follow-up and documenting changes. |
|------------------------|-----------------------------------|---------------|--------|------------------------------------------------------------------------------------------|

## Conclusions

The findings of studies on the adaptation and validation of instruments to measure knowledge and progression of frontotemporal dementia (FTD) show that both Frontotemporal Dementia Knowledge Both the Frontotemporal Dementia Rating Scale (FTDKS) and the *Frontotemporal Dementia Rating Scale (FTD-FRS)* are valid and reliable tools. These instruments effectively assess both the disease knowledge of healthcare professionals and caregivers, as well as the clinical status and progression of FTD in patients. In each study, cultural and linguistic adaptations followed rigorous procedures, ensuring that the local versions of these instruments retain their original psychometric properties.

The validation of the FTDKS in diverse cultural contexts, including the United States, Spain, Poland, and Spanish-speaking countries, demonstrates its versatility and applicability. The results obtained in various studies suggest that the FTDKS can be effectively used to increase awareness of FTD, a condition that is often misdiagnosed due to a lack of information among healthcare professionals. This reinforces the importance of having tools like the FTDKS to improve diagnostic accuracy and optimize the care of patients with FTD.

Furthermore, the FTD-FRS has proven to be a valuable tool for assessing the status and progression of FTD in patients in clinical settings. Its ability to document changes in disease status and measure

the effectiveness of interventions is essential for ongoing patient care. Adaptations in Brazil and Spain underscore the relevance of this scale in the clinical context, highlighting its psychometric robustness and contribution to FTD management. In summary, both the FTDKS and the FTD-FRS are key instruments for improving the care of patients with FTD and for training healthcare professionals and caregivers. Their validation in diverse cultural settings demonstrates their robustness and global applicability, allowing for a better understanding and management of frontotemporal dementia in different clinical and educational contexts.

### Limitations and future research

Studies on the adaptation and validation of *Frontotemporal Dementia Knowledge The Frontotemporal Dementia Rating Scale* (FTDKS) and the *Frontotemporal Dementia Rating Scale* (FTD-FRS) present several limitations that should be considered. First, many of these studies were conducted with relatively small and specific samples, such as healthcare professionals or caregivers, which limits the generalizability of the results to other populations, such as the general public or patients with different educational levels. The external validity of the instruments could be improved with additional studies that include larger and more diverse samples, both geographically and sociodemographically.

Another common limitation is that most adaptations have focused on specific countries, such as the United States, Spain, Poland, and Brazil, leaving a gap in the validation of these instruments in other regions of the world, especially in developing countries or those with fewer resources for dementia care. This raises the need for additional studies to adapt and validate the scales in other cultural and linguistic contexts, ensuring their applicability in a variety of clinical and educational settings.

Furthermore, although the reviewed studies demonstrated good internal consistency and test-retest reliability, some did not comprehensively assess other important aspects of validity, such as

convergent and discriminant validity, or the scales' sensitivity to detect longitudinal changes in knowledge or disease progression. This limits the instruments' ability to measure the impact of educational interventions or treatments over time.

Regarding future research, it would be valuable to conduct longitudinal studies examining how knowledge about frontotemporal dementia varies in response to educational interventions, as well as to investigate the sensitivity of the FTD-FRS to detect clinical changes across different stages of the disease. It would also be useful to explore the relationship between knowledge measured by the FTDKS and clinical outcomes in patients with FTD, such as caregiver quality of life and more informed clinical decision-making.

Finally, it would be pertinent to incorporate innovative technologies, such as virtual reality or mobile applications, to complement the use of these scales in the training of healthcare professionals and caregivers. This would allow for greater dissemination and accessibility of the tools, enhancing their usefulness in different contexts and fostering research on their effectiveness in digital environments.

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