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WASHINGTON UNIVERSITY IN ST LOUIS

Department of Psychological and Brain Sciences

Frontotemporal Dementia Knowledge Scale: Development and Preliminary Psychometric Properties

by

Matthew John Wynn

A thesis presented to
The Graduate School
of Washington University in
partial fulfillment of the
requirements for the
degree of Master of Arts

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Dedicated to SC, KT, AI, KD, and DG.

ABSTRACT OF THE THESIS

Frontotemporal Dementia Knowledge Scale: Development and Preliminary Psychometric Properties

by

Matthew John Wynn

Master of Arts in Psychological and Brain Sciences

Washington University in St. Louis, 2018

Brian D. Carpenter, Chair

Frontotemporal dementia (FTD) accounts for about 10 percent of dementia cases and is a common cause of early-onset dementia. Although knowledge about the symptoms and course of FTD has expanded in the past decade, there exists no well-validated instrument to measure FTD knowledge. As a step toward that goal, this study sought to create a scale to measure knowledge of FTD based on contemporary understanding of the disease. Standard scale development methods were used to create items, and their psychometric properties were evaluated in a sample of 174 healthcare providers and caregivers of people with FTD. The resulting scale (Frontotemporal Dementia Knowledge Scale; FTDKS) contains 18 items and takes approximately five minutes to complete. The FTDKS displays good psychometric properties in terms of reliability (internal consistency and split-half reliability) and validity (content, predictive, concurrent, convergent, and divergent) in the current sample. The FTDKS can be used with healthcare providers and caregivers of people with FTD to assess their knowledge in clinical care and program evaluation. Further research is needed to examine the

psychometric properties in more diverse samples and to evaluate its utility in educational initiatives.

Frontotemporal dementia (FTD) refers to a group of disorders caused by progressive and selective degeneration of the frontal and temporal lobes of the brain (Pressman & Miller, 2014). As a group, the FTD family of syndromes accounts for approximately 10 percent of dementia cases, affecting 4.6 million people worldwide, with a prevalence of 15-22 per 100,000 (Bang, Spina, & Miller, 2015; Onyike & Diehl-Schmid, 2013). FTD is the third most prevalent cause of dementia and about as common as Alzheimer's disease (AD) in terms of early-onset dementias (Bang et al., 2015; Lashley et al., 2015; Vieira et al., 2013). Approximately 60 percent of people with FTD are between the ages of 45 and 60 (Pressman & Miller, 2014). Knowledge about the symptoms and course of FTD has expanded in the past decade, both in terms of what we know and who knows it (Lashley et al., 2015; Nunnemann et al., 2012; Warren, Rohrer, & Rossor, 2013), yet it remains unclear to what extent healthcare providers and caregivers of people with FTD are knowledgeable about the disease. Adequate knowledge about FTD is important for providers, as they are the main point of contact for early detection, diagnosis, and ongoing support (Shinagawa et al., 2016). Knowledge is also important among caregivers because they support patients with FTD in a myriad of ways (Küçükgüçlü et al., 2017; Lima-Silva et al., 2015). Although educational resources exist to enhance knowledge about FTD (O'Connor, 2013; Ghoshal, 2018), to our knowledge there exist no empirical studies that examine what different groups know about the disease, and there are no instruments to measure FTD knowledge. The purpose of the current study was to create a scale to measure knowledge of FTD based on contemporary understanding of the prevalence, causes, symptoms, progression, and treatment of FTD. This new scale could be utilized in clinical care and to guide the development and evaluation of education initiatives.

A crucial first step in FTD care management is timely and accurate diagnosis, and knowledge among providers plays an important role in allowing that to happen. In the United States, less than half of older adults living with dementia or their caregivers say that a physician has diagnosed them with dementia (Bradford et al., 2009; Connolly et al., 2011) and even fewer have a diagnosis of a dementing condition listed in their medical record (Chodosh et al., 2007; Riley McCarten et al., 2012). This situation may occur because some providers do not recognize the symptoms of dementia and lack other critical knowledge that could facilitate diagnosis. In the case of FTD, in order to make an accurate diagnosis, providers need to have an understanding of the heterogeneity of FTD presentation and progression. One person may exhibit early behavioral changes and progress rapidly, while another may struggle more with language disruption and decline gradually over a number of years. Identifying FTD as the cause underlying these different patterns of symptoms can be difficult for specialist and non-specialist providers alike, as evidenced in several studies. For example, one recent study conducted in an outpatient memory clinic tracked the clinical progression of 97 people with later confirmed FTD and found that nearly a quarter (22%) were not diagnosed with FTD while still alive (Landqvist Waldö et al., 2015). Furthermore, reviewing medical records (including relevant clinical records from other hospitals and general practitioners) in order to pinpoint symptom onset, only 14% of people with confirmed FTD received FTD as their first diagnosis, with the majority first diagnosed with a psychiatric disease, such as depression. The median time from symptom onset to first FTD diagnosis was four years, with some diagnoses taking as long as 15 years. The investigators hypothesized that providers may not be aware of the specific features of FTD and therefore are more prone to misdiagnosis.

Another study of people with FTD in an outpatient memory clinic found evidence of both missed diagnosis and misdiagnosis (Shinagawa et al., 2016). Of the 247 patients whose clinician referred them with a sole provisional diagnosis of behavioral variant FTD (bvFTD), 60% did not have bvFTD according to specialists. Conversely, of the 313 patients diagnosed with FTD by experts, 14% did not have any mention of FTD on their initial referral. False-positive and false-negative diagnosis of FTD by non-specialist providers can have significant consequences, such as medication mismanagement for people with FTD and delay to resources for caregivers (Pressman & Miller, 2014; Warren et al., 2013). Therefore, educating physician providers about how to identify FTD accurately is an important public health effort.

In addition, nonphysician providers such as psychologists, social workers, and nurses are receiving increasing attention for their role in the dementia diagnostic process (Maslow & Fortinski, 2018). These providers interact with older adults who have not had a formal evaluation but are showing signs of cognitive impairment, and they may be closely connected with caregivers and consequently in a position to assist with detection, diagnosis, and education about cognitive impairment. Recent dementia care guidelines advocate for training of nonphysician direct care providers so they can recognize the signs of dementia and understand when and how to communicate these changes to experts, people with dementia, and their families (Wiener et al., 2016). Likewise, the U.S. Administration for Community Living (ACL), in its dementia-capable states and communities initiative, funded training for nonphysician staff and for professional care providers to help them identify persons with cognitive impairment and refer them for diagnosis and services (National Alzheimer's and Dementia Resource Center, 2014). Knowledge of FTD, similar to the other dementias, among nonphysician professionals is important in order to help patients and their families receive an accurate and timely diagnosis, as well as referrals to FTD-specific resources.

Knowledge about FTD is also important for the caregivers who support people with the disease. FTD caregivers experience high rates of stress and burden (Lima-Silva et al., 2015), higher than people caring for individuals with other types of dementia (Liu et al., 2017; Mioshi et al., 2009). Several features of the disease, such as personality changes, disinhibition, and language disruption, can make caregiving particularly challenging. Caregiving stress models (e.g., Pearlin et al., 1990) identify a lack of knowledge as contributing to stress and educational initiatives as moderating stress (Judge, Menne, & Whitlatch, 2010). Moreover, when asked about their needs, FTD caregivers highlight information about FTD symptoms, effective communication, and behavior management strategies as important (Diehl-Schmid et al., 2013). Despite the need for education, one review cited lack of knowledge and information regarding the disease as a major problem facing caregivers (Nunnemann et al., 2012). An FTD knowledge scale could be used to evaluate the benefit of educational interventions as learning tools. Moreover, it could be used to measure the relationship between disease-specific knowledge and caregiver stress, as well as to characterize the effect of educational interventions on caregiver quality of life and other outcomes.

National and state organizations have undertaken efforts to increase detection of cognitive impairment and facilitate earlier and more accurate diagnosis, often by increasing providers’ knowledge of dementia (Comas-Herrera, et al., 2016; U.S. Department of Veterans Affairs, 2016). Similar initiatives specific to FTD will require tools to gauge knowledge of FTD among physicians, nonphysicians, and caregivers and to guide education efforts among these groups. To our knowledge, however, no studies have attempted to measure knowledge of FTD in any systematic way, nor is there a well-validated tool with which to measure FTD knowledge. The purpose of this project was to create and validate a Frontotemporal Disease Knowledge Scale (FTDKS) to measure knowledge of FTD based on contemporary understanding of the disease.

Method

Development of FTDKS Items

We developed an initial set of 38 scale items by reviewing the literature for information about frontotemporal dementia corresponding to several content domains. These content domains (risk factors, assessment and diagnosis, symptoms, course, life impact, treatment and management, caregiving) were adapted from similar scales measuring knowledge of Alzheimer's disease (Annear et al., 2015; Carpenter et al., 2009) and were used as a framework for our literature search, ensuring content relevance and coverage. Informed by test development guidelines (DeVellis, 2016; Kline 2005; Streiner & Norman, 2016), the research team reviewed each item, removed those with overlapping content, and rewrote items for clarity. Despite our effort to create items easy to understand, disease-specific terms, which may be difficult to understand for some people, were present due to their importance to knowledge about FTD. The resulting Flesch-Kinkaid Grade Level reading score (Kincaid et al., 1975) of 11.8 corresponds to a twelfth-grade reading level. At the conclusion of this process, 27 potential items remained.

The 27 items were reviewed by eight experts currently working in FTD clinical research (six physicians, one nurse practitioner, and one psychologist) who commented on accuracy, wording, and overall content coverage. Based on their feedback, three items were removed from the scale, seven were rewritten for clarity, and three new items were added in order to increase content coverage. Next, two groups, one consisting of community-dwelling older adults and the other graduate students in clinical psychology (n = 5 in each group), reviewed the items to identify unclear phrasing. After each individual participant had answered all items, group members were asked to explain what they thought each item was asking and why they responded as they did. This “think-aloud” technique identified errors based on misunderstanding of the question and questions that were easily answered despite a lack of knowledge regarding FTD. At this phase, three items were removed from the scale and six were rewritten for clarity. The final scale contained 24 items.

We adopted a 4-point Likert-type scale format, with an auxiliary “Don’t Know” option adapted from the Dementia Knowledge Assessment Scale (DKAS; Annear et al., 2015). Compared to a True/False response format, the 4-point scale plus Don’t Know detect a wider range of uncertainty about each item, which more precisely reflects knowledge (Annear et al., 2016).

Participants and Procedure

To evaluate the final items we recruited medical professionals and caregivers of people with FTD to complete the scale, the types of people with whom the final version of the FTDKS might be used. Characteristics of the subsamples appear in Table 1. Providers were contacted through publicly available email addresses and snowball sampling. Primary care clinics, Alzheimer’s Disease Research Centers, and professional organization listservs were targeted to recruit providers from varying disciplines with varying degrees of knowledge about FTD. Providers were sent emails containing a brief description of the study and a link to participate via an online survey.

With the collaboration of the Association for Frontotemporal Degeneration (AFTD), caregivers were recruited from FTD support groups throughout the United States. Using publicly available email addresses, 95 support group leaders were contacted, with permission of the AFTD, and given email templates and flyers containing a brief description of the study and a link to participate in the online survey. Support group leaders then distributed these materials to members of their caregiver support group. Additional caregiver recruitment was conducted through postings on the AFTD's Facebook page and the FTD Support Forum website. Given these methods of recruitment, it was not possible to know exactly how many emails were forwarded to providers and caregivers we did not contact directly, and thus it was not possible to calculate a final response rate. The online survey was hosted by Qualtrics, a secure, HIPAA-compliant platform for collecting survey data (Qualtrics, Provo, UT).

Measures

Demographics and background. Demographic items inquired about gender identity, age, race, ethnicity, education, and occupation. Respondents also completed a series of questions to assess experience with FTD. These questions were tailored for providers versus caregivers and addressed practice setting, experience with FTD, current or previous FTD caregiving experience, where they had received information and education related to FTD, and self-rated knowledge of FTD (0 = "I've never heard of FTD" to 10 = "I am extremely knowledgeable about FTD").

Objective knowledge about FTD and dementia. The Dementia Knowledge Assessment Scale (DKAS; Annear et al., 2015) was included as a measure of general dementia knowledge. The DKAS is a 25-item scale that uses a 4-point Likert-type scale (False, Probably

False, Probably True, True) with an auxiliary Don't Know option. Item content covers causes and characteristics, communication and engagement care needs, and risk factors and health promotion. Scores can range from 0 to 50, with higher scores indicating more accurate knowledge about dementia. According to the original validation study, the DKAS has good internal consistency (Spearman-Brown correlation coefficient of 0.78; alpha of 0.86), and validity as a measure of dementia knowledge in a sample of health workers and students. The second knowledge scale, the FTDKS, was developed as described above.

General intelligence. The Shipley Institute of Living Scale (Shipley, 1940) includes 40 progressively difficult vocabulary words. Respondents choose which of four listed words "means the same or nearly the same" as a target word. The number of correct items is the final score, with possible scores ranging from 0 to 40. The Shipley has good test-retest reliability (median r = .78), internal consistency reliability (alpha = .80 in the current sample), validity as a measure of general intelligence (median r = .71 with more formal measures of IQ such as the WAIS), and the scale has been normed in a wide range of populations (Zachary, 1991).

Analytic Plan

The aim of the current study was to assemble a set of items that had sufficient face validity and content coverage about FTD and a scale that had good reliability and validity. We used descriptive statistics to investigate the utility of the 4-point response scale with the "Don't Know" option. Independent sample t-tests between provider and nonprovider group were used to examine possible differences in the use of scale response options. To aid with item selection we calculated the discrimination index and item difficulty index for each item. Internal consistency reliability was evaluated with Cronbach's alpha (average interitem correlation), split-half reliability, and item-total correlations. Independent sample t-tests between provider and nonprovider groups and correlations between FTDKS total score and independent variables were used to examine the predictive validity, convergent validity, concurrent validity, and divergent validity of the FTDKS.

Results

Sample Characteristics

A small number of respondents (*n* = 4) were not medical professionals or did not know anyone with FTD and were therefore removed from analysis, leaving a final sample of 174. Respondents were grouped into two subsamples, providers and nonproviders, and their characteristics appear in Table 1. Providers were, on average, younger, $t(171)= -7.17$, $p < .001$, and more educated, $\chi^2(5) = 82.86$, $p < .001$, but there were no differences between groups in terms of gender, $\chi^2(2) = 2.99$, $p = .224$, race, $\chi^2(5) = 7.403$, $p = .116$, or self-rated knowledge of FTD, $t(172) = -.721$, $p = .472$. The subsample of providers (*n* = 72) was comprised of experienced (53% with eight or more years of experience) and educated (71% with doctoral degrees) professionals from various disciplines, who had at least “some” experience treating, diagnosing, or managing the care of people with FTD. The subsample of nonproviders (*n* = 102) was made up of spouses, children, relatives, and friends, and professional caregivers of people with FTD, the large majority of whom identified as the primary caregiver (73%).

Use of the Response Scale

A 4-point response scale was chosen over a more conventional dichotomous True/False scale in order to increase precision. We calculated several descriptive statistics to examine whether respondents utilized the full range of response options. For example, one respondent did not vary in their use of the different response options (e.g., 100% of their responses were either “True” or “False” and 0% of their responses were “Probably True,” “Probably False,” or “Don’t

Know”), while other respondents made use of all response options. Respondents answered items with either “True” or “False” a majority of the time (*M* = 69.7%, *SD* = 20.5%, range = 0% - 100%), followed next by “Probably True” and “Probably False”(*M* = 23.2%, *SD* = 16.9%, range = 0% - 83%), and used “Don’t Know” only occasionally (*M* = 7.11%, *SD* = 9.44%, range = 0% - 46%). The use of different response options was also variable across items (see Table 2). Providers and caregivers did not significantly differ in their use of the certain and probable options, and providers were slightly less likely to use “Don’t Know” than caregivers, $t(172) = -3.88$, $p < .001$. Overall, it appears that most respondents made use of the full range of the scale.

Item Difficulty and Discrimination Indices

Performance of individual items was examined to identify potential items for removal. Item difficulty and discrimination indices, described below and appearing in Table 2, are both helpful in identifying candidates for removal. First, percent correct (difficulty index; *p*) was calculated. Six items had difficulty indices above .95, indicating that at least 95% of respondents answered the item correctly. These items are unlikely to be useful in discriminating respondent knowledge due to their relative ease. Next, discrimination indices were calculated for each item. The sample was divided into two groups based on their total FTDKS score, using cutoffs recommended by Kline (2005): 27% of the sample who scored lowest ($n = 47$) and 27% of the sample who scored highest ($n = 48$). Scores on the FTDKS ranged from 11 – 32 (*M* = 25.6, *SD* = 5.82) for low scorers and 41 – 48 (*M* = 43.3, *SD* = 2.01) for high scorers. Individual item difficulty indices (*p*) were calculated for both low and high scorers. The difference of these indices (e.g., p_{high}-p_{low}) is the discrimination index. A low percentage for the discrimination index (<10%; Kline, 2005) indicates that the item does not perform differently among the highest and lowest scoring respondents, suggesting that the item is not helpful in identifying respondents with less versus more knowledge. Five items had a discrimination index below 10%, and these were five of the six items that had a difficulty index above 95%. The sixth item ("People with the behavioral variant of frontotemporal dementia often act on impulse instead of thinking things through.") had a discrimination index of 11%. These six items included two about a FTD subtype (e.g., behavioral variant). Four different "subtype" items survived item analyses, so the poorly performing items were removed without losing core content. The other four items were more broad questions about course and progression and potentially represent core facts about FTD, but given their low difficulty and discriminability, these items were removed from the final scale, leaving 18 items.

Properties of the 18-Item FTDKS

On the 18-item FTDKS, the maximum score is 36. In this sample, scores on the FTDKS ranged from 5 to 36 (M = 24.2, SD = 6.70).

Reliability. Internal consistency reliability (Cronbach's alpha) was .806, indicating good internal consistency. Examining individual items, Cronbach's alpha if an item were deleted ranged from .789 - .806, and the item-total correlations ranged from .230 - .513 (M = .392, SD = .075). Therefore, dropping items would not increase alpha substantially. Split-half reliability was calculated by randomly dividing the scale in half and correlating the items on the first and second halves, resulting in a Spearman-Brown coefficient of .792.

Validity. Correlations among knowledge indices and respondent characteristics are shown in Table 3. In terms of *predictive validity*, FTDKS Total Score should be significantly associated with variables related to knowledge of FTD. FTDKS Total Score was significantly, though modestly, correlated with self-rated FTD knowledge, $r = .488$, $p < .001$. This significant association was present within both provider, $r = .57$, $p < .001$, and nonprovider subsamples, $r =$

.47, $p < .001$. In terms of *convergent validity,* performance on the FTDKS should be significantly associated with performance on other scales that measure related constructs. The correlation between scores on the FTDKS and scores on the DKAS was .615, $p < .001$. The correlation between scores on the FTDKS and general intelligence as measured by the Shipley Vocabulary Test was .247, $p <.05$, as would be expected given that the two scales measure distinct constructs. In terms of *concurrent validity*, scores on the FTDKS should be significantly associated with people's experience with FTD**.** Among providers, the FTDKS Total Score was significantly associated with experience treating people with FTD, $r = .349$, $p < .01$. Among nonproviders, FTDKS Total Score was significantly related to level of care provided to people with FTD, $r = .231$, $p < .05$. In an unexpected finding, an independent-samples t-tests revealed no significant difference on FTDKS performance between providers and nonproviders, $t(172) = 1.41$, $p = .160$ (see Table 1 for means). In terms of *divergent validity* scores on the FTDKS should not be significantly associated with variables that do not necessarily relate to knowledge of FTD. Among providers, FTDKS Total Score was not significantly associated with general experience (years) as a provider, $r = .167$, $p =.178$. Among nonproviders, FTDKS Total Score was not significantly related to number of people with FTD known, $r = .190$, $p = 0.05$.

Discussion

This study establishes the reliability and validity of a new scale to measure knowledge about frontotemporal dementia, the Frontotemporal Dementia Knowledge Scale (FTDKS). The 18-item scale is designed to be used with healthcare providers and caregivers of people with FTD. It covers general knowledge about FTD, including prevalence, symptoms, course, treatments, and caregiving. It can be administered in approximately five minutes and uses a response scale that enable respondents to indicate degrees of certainty about their knowledge. In this validation study the scale had good psychometric attributes when evaluated in two samples, healthcare professionals with varying degrees of experience with FTD and individuals with FTD caregiving experience. The scale, along with a scoring key and documentation of answers, is available at http://pages.wustl.edu/geropsychology/ftdks.

Although FTD is less common than Alzheimer's disease, it is one of the most common forms of early-onset dementia, and people with FTD and their caregivers incur significant financial and emotional burden as a result of the disease (Warren et al., 2013). Timely diagnosis and appropriate care play a critical role in offsetting these costs, and knowledge of FTD among providers and caregivers increases the likelihood that patients will receive an early and accurate diagnosis and subsequent support. The FTDKS could be useful in documenting knowledge among providers and caregivers and could be utilized in steps to develop and evaluate educational initiatives for these groups.

Several limitations of the study should be noted. First, the scale was evaluated in only two subsamples, a group of FTD professionals and a group of individuals with FTD caregiving experience. We do not have evidence of how the scale would perform in other groups, such as people diagnosed with FTD or the general public. Additional research could verify the psychometric properties of the scale in other groups. Second, in a somewhat unexpected finding, we did not find a significant difference in FTDKS scores between our subsamples, indicating that, on average, providers and nonproviders were equally knowledgeable about FTD. It may be that because we recruited caregivers from AFTD support groups, they are especially involved and educated about the disease, with a level of knowledge equivalent to that of the providers. Future research with a broader sample, including caregivers of patients soon after diagnosis of FTD, highly specialized providers, and lay audiences will provide a clearer picture of how different groups perform on this measure. Third, because the scale includes some technical language related to specific FTD facts, it is written at a fairly high grade level. As such, the scale may be less accessible among individuals with more limited literacy.

Fourth, in creating a scale to measure general knowledge of FTD that can be completed quickly, concerns about content coverage arose. In our initial pool of 24 items, six were answered correctly by almost all respondents. These items include two items about an FTD subtype (e.g., behavioral variant) and four items about general course and progression of the disease (see lower section of Table 2). We believe that the wording of the two FTD subtype questions may have been leading, which resulted in the high correct response rate despite the relatively deep knowledge required to identify the behavioral variant. In contrast, the other four general items potentially represent core facts about FTD that, while too easy for the current sample, may nonetheless represent basic common knowledge that could be used to gauge knowledge in a group that may be less familiar with the disease, such as community dwelling older adults or recently diagnosed patients and their caregivers.

Moreover, FTD refers to a group of clinical syndromes caused by frontotemporal lobar degeneration (FTLD), so a general scale about FTD will necessarily leave some specifics out. For example, items about some FTD subtypes, genetic risk factors, and the biological progression of the disease were not included because they were often too specific to have a universally accepted answer across the FTD spectrum. Different types of FTD progress at different rates, under different mechanisms, and with different symptoms and outcomes. Instead, the FTDKS includes items designed to reflect general knowledge of FTD, and the scale is not meant as an exhaustive measure of FTD. Likewise, as the scientific community continues to discover new facts and revise old ones regarding the disease, the FTDKS will require revision.

At the moment, however, the FTDKS is a reliable and valid scale of FTD knowledge across a range of domains relevant to healthcare provider and caregivers.

References

Annear, M. J., Toye, C. M., Eccleston, C. E., Mcinerney, F. J., Elliott, K. J., Tranter, B. K., Hartley, T., & Robinson, A. L. (2015). Dementia knowledge assessment scale: Development and preliminary psychometric properties. *Journal of the American Geriatrics Society, 63,* 2375–2381. https://doi.org/10.1111/jgs.13707

Annear, M. J., Eccleston, C. E., McInerney, F. J., Elliott, K. E. J., Toye, C. M., Tranter, B. K., & Robinson, A. L. (2016). A new standard in dementia knowledge measurement: Comparative validation of the dementia knowledge assessment scale and the Alzheimer's disease knowledge scale. *Journal of the American Geriatrics Society*, *64*(6), 1329–1334. https://doi.org/10.1111/jgs.14142

Bang, J., Spina, S., & Miller, B. L. (2015). Frontotemporal dementia. *The Lancet*, *386*(10004), 1672–1682. https://doi.org/10.1016/S0140-6736(15)00461-4

Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Disease and Associated Disorders*, *23*(4), 306–314. http://doi.org/10.1097/WAD.0b013e3181a6bebc

Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's disease knowledge scale: Development and psychometric properties. *Gerontologist*, *49*(2), 236–247. https://doi.org/10.1093/geront/gnp023

Chodosh, J., Mittman, B. S., Connor, K. I., Vassar, S. D., Lee, M. L., DeMonte, R. W., Ganiats, T. G., Heikoff, L. E., Rubenstein, L. Z., Della Penna, R. D. & Vickrey, B. G. (2007), Caring for patients with dementia: How good is the quality of care? Results from three health systems. *Journal of the American Geriatrics Society*, *55*, 1260-1268. doi:10.1111/j.1532-5415.2007.01249.x

Comas Herrera, A., Prince, M., Knapp, M., Karagiannidou, M., & Guerchet, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people with dementia. Coverage, quality and costs now and in the future*. doi:10.13140/RG.2.2.22580.04483.

Connolly, A., Gaehl, E., Martin, H., Morris, J., & Purandare, N. (2011). Underdiagnosis of dementia in primary care: Variations in the observed prevalence and comparisons to the expected prevalence. *Aging & Mental Health*, *15*(8), 978–984. https://doi.org/10.1080/13607863.2011.596805

DeVellis, R. F. (2016). *Scale development: Theory and applications* (Vol. 26). Chapel Hill, NC: Sage Publications.

Diehl-Schmid, J., Schmidt, E.-M., Nunnemann, S., Riedl, L., Kurz, A., Förstl, H., Wagenpfeil, S., & Cramer, B. (2013). Caregiver burden and needs in Frontotemporal dementia. *Journal of Geriatric Psychiatry and Neurology*, *26*(4), 221–229. https://doi.org/10.1177/0891988713498467

Ghoshal, N. (2018). *Webinar: What You Should Know about Behavioral Variant FTD (bvFTD).* Available from https://www.theaftd.org/webinar-what-you-should-know-about-behavioral-variant-ftd-bvftd/

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia. *The Gerontologist*, *50*(3), 294–302. http://doi.org/10.1093/geront/gnp162

Kincaid, J. P., Fishburne, J., Robert P., R., Richard L., C., & Brad S. (1975). Derivation of new readability formulas (automated readability index, fog count and Flesch reading ease formula) for Navy enlisted personnel. *Institute for Stimulation and Training.* Paper 56. https://doi.org/10.21236/ADA006655

Kline, T. J. B. (2005). *Psychological testing: A practical approach to design and evaluation*. Thousand Oaks, CA: Sage.

Küçükgüçlü, Ö., Söylemez, B. A., Yener, G., Barutcu, C. D., & Akyol, M. A. (2017). Examining factors affecting caregiver burden: A comparison of Frontotemporal dementia and Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, *32*(4), 200–206. https://doi.org/10.1177/1533317517703479

Landqvist Waldö, M., Gustafson, L., Passant, U., & Englund, E. (2015). Psychotic symptoms in frontotemporal dementia: A diagnostic dilemma? *International Psychogeriatrics / Ipa*, *27*(4), 531–539. http://doi.org/10.1017/S1041610214002580

Lashley, T., Rohrer, J. D., Mead, S., & Revesz, T. (2015). Review: An update on clinical, genetic and pathological aspects of frontotemporal lobar degenerations. *Neuropathology and Applied Neurobiology*, *41*(7), 858–881. https://doi.org/10.1111/nan.12250

Lima-Silva T, B, Bahia V, S, Carvalho V, A, Guimarães H, C, Caramelli P, Balthazar M, L, Damasceno B, Bottino C, M, Brucki S, M, Nitrini R, Yassuda M, S. (2015). Neuropsychiatric symptoms, caregiver burden and distress in behavioral-variant frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, *40*(5–6), 268–275. https://doi.org/10.1159/000437351

Liu, S., Jin, Y., Shi, Z., Huo, Y. R., Guan, Y., Liu, M., … Ji, Y. (2017). The effects of behavioral and psychological symptoms on caregiver burden in frontotemporal dementia, Lewy body dementia, and Alzheimer's disease: Clinical experience in China. *Aging & Mental Health*, *21*(6), 651–657. https://doi.org/10.1080/13607863.2016.1146871

Maslow, K., & Fortinsky, R. H. (2018). Nonphysician care providers can help to increase detection of cognitive impairment and encourage diagnostic evaluation for dementia in community and residential care settings. *The Gerontologist*, *58*(suppl_1), S20–S31. https://doi.org/10.1093/geront/gnx171

Mioshi, E., Bristow, M., Cook, R., & Hodges, J. R. (2009). Factors underlying caregiver stress in Frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, *27*(1), 76–81. https://doi.org/10.1159/000193626

National Alzheimer's and Dementia Resource Center. (2014). ADSSP dementia capable systems integration grants profiles for 2014. Retrieved September 25, 2018, from https://nadrc.acl.gov/node/104

Nunnemann, S., Kurz, A., Leucht, S., & Diehl-Schmid, J. (2012). Caregivers of patients with frontotemporal lobar degeneration: A review of burden, problems, needs, and interventions. *International Psychogeriatrics*, *24*(9), 1368-1386. doi:10.1017/S104161021200035X

O'Connor, C. M., Clemson, L., da Silva, T. B. L., Piguet, O., Hodges, J. R., & Mioshi, E. (2013). Enhancement of carer skills and patient function in the non-pharmacological management of frontotemporal dementia (FTD): A call for randomized controlled studies. *Dementia & Neuropsychologia*, *7*(2), 143–150. http://doi.org/10.1590/S1980-57642013DN70200002

Onyike, C. U., & Diehl-Scmid, J., (2013). The epidemiology of frontotemporal dementia. *International Review of Psychiatry*, *25*(2), 130–137. https://doi.org/10.3109/09540261.2013.776523

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. https://doi.org/10.1093/geront/30.5.583

Pressman, P. S., & Miller, B. L. (2014). Diagnosis and management of behavioral variant Frontotemporal dementia. *Biological Psychiatry*, *75*(7), 574–581. https://doi.org/10.1016/j.biopsych.2013.11.006

Riley McCarten, J., Anderson, P., Kuskowski, M. A., McPherson, S. E., Borson, S. and Dysken, M. W. (2012). Finding dementia in primary care: The results of a clinical demonstration project. *Journal of American Geriatrics Society*, 60: 210-217. doi:10.1111/j.1532-5415.2011.03841.x

Shinagawa, S., Catindig, J. A., Block, N. R., Miller, B. L., & Rankin, K. P. (2016). When a little knowledge can be dangerous: False-positive diagnosis of behavioral variant Frontotemporal dementia among community clinicians. *Dementia and Geriatric Cognitive Disorders*, *41*(1-2), 99–108. http://doi.org/10.1159/000438454

Streiner, D., Norman, G., & Cairney, J. (2014-11). (Ed.), Health Measurement Scales: A practical guide to their development and use. Oxford, UK: Oxford University Press,. Retrieved 17 Oct. 2018, from http://oxfordmedicine.com/view/10.1093/med/9780199685219.001.0001/med-9780199685219.

U.S. Department of Veterans Affairs. (2016). VHA dementia steering committee recommendations for dementia care in the VHA health care system 2016. Retrieved September 25, 2018, from https://www.va.gov/GERIATRICS/docs/VHA_DSC_RECOMMENDATIONS_SEPT_2016_9-12–16.pdf

Walter C. Shipley. (1940). A self-administering scale for measuring intellectual impairment and deterioration. *The Journal of Psychology*, 9:2, 371-377, doi:10.1080/00223980.1940.9917704

Warren, J. D., Rohrer, J. D., & Rossor, M. N. (2013). Frontotemporal dementia. *The BMJ*, *347*, f4827. http://doi.org/10.1136/bmj.f4827

Wiener, J.M., Gould, E., Shuman, S.B., Kaur, R., Ignaczak, M. & Maslow, K. (2016) Examining models of dementia care: Final report appendices. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Retrieved September 25, 2018, from https://aspe.hhs.gov/system/files/pdf/257216/ExamDCMod.pdf.

Vieira, R. T., Caixeta, L., Machado, S., Silva, A. C., Nardi, A. E., Arias-Carrión, O., & Carta, M. G. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical Practice and Epidemiology in Mental Health : CP & EMH*, *9*, 88–95. http://doi.org/10.2174/1745017901309010088

Zachary, R. A. (1991). *Shipley Institute of Living Scale Revised Manual*. Los Angeles : Western Psychological Services.

Table 1

Characteristics of Respondents

	Total (*n* = 174)		Providers (*n* = 72)		Non-Providers (*n* = 102)	
Characteristic	*M/n*	*SD/%*	*M/n*	*SD/%*	*M/n*	*SD/%*
Age (years)	51.5	15.7	42.5	12.7	57.8	12.5
Female	133	76.4	58	80.6	75	73.5
White	157	90.2	60	83.3	97	95.1
Education						
High School	5	2.9	0	0.0	5	4.9
Some college	17	9.8	0	0.0	17	16.7
Associate degree	7	4.0	3	4.2	4	3.9
Bachelor's degree	45	25.9	4	5.6	41	40.2
Master's degree	40	23.0	14	19.4	26	25.5
Doctoral degree	60	34.5	51	70.8	9	8.8
Professional experience with FTD						
None			4	5.6		
A little			17	23.6		
Some			18	25.0		
A lot			18	25.0		
Extensive			10	13.9		
Years of experience as a provider						
0-1			7	9.7		
2-4			15	20.8		
5-7			7	9.7		
8-10			7	9.7		
More than 10			31	43.1		
Professional discipline/specialty						
Geriatrician			13	18.1		
Primary care physician			2	2.8		
Psychologist			31	43.1		

Neurologist			5	6.9		
Registered nurse/Nurse practitioner			9	12.5		
Other			12	16.7		
Number of people with FTD known					5.20	1.78
Level of care provided						
Never been involved in care					10	9.8
Helped arrange for care					2	2.0
Assisted in caregiving					16	15.7
Primary caregiver					74	72.5
FTDKS Total Score	24.1	6.70	25.0	5.47	23.5	7.40
Self-rated FTD knowledge	7.07	1.79	6.96	1.78	7.16	1.80
DKAS Total Score	35.9	6.94	40.3	6.36	35.3	6.84
Shipley Institute of Living Scale	34.9	3.08	35.1	2.85	34.9	3.13

Note. FTD = frontotemporal dementia; FTDKS = Frontotemporal Dementia Knowledge Scale; DKAS = Dementia Knowledge Assessment Scale.

Table 2

Item Characteristics of the Frontotemporal Dementia Knowledge Scale

Item	Statement	True or False	Probably True or False	Don't Know	Difficulty Index (*p*)	Discrimination Index	Item-Total Correlation	Alpha if item dropped
1	Frontotemporal dementia is a type of Alzheimer disease. (F)	89.33%	10.11%	0.56%	93.82%	19%	.499	.793
2	For the majority of people with frontotemporal dementia, symptoms appear before they are 65 years old. (T)	71.35%	23.04%	5.62%	83.71%	32%	.513	.789
3	Among all people with dementia, 5-10% of them have frontotemporal dementia. (F)	40.45%	46.07%	13.48%	78.09%	36%	.389	.796
4	People in their thirties can develop symptoms of frontotemporal dementia. (T)	71.34%	25.28%	3.37%	88.20%	30%	.423	.795

5	Memory loss is a major symptom of frontotemporal dementia. (F)	72.48%	26.97%	0.56%	72.47%	45%	.435	.793
6	Frontotemporal dementia can be passed down from parent to child. (T)	63.48%	26.97%	9.55%	68.54%	55%	.481	.790
7	Among people under 60 years old, frontotemporal dementia is about as common as Alzheimer disease. (T)	43.26%	37.08%	19.66%	41.57%	48%	.299	.802
8	The results of a brain scan by itself can tell you whether a person has frontotemporal dementia. (F)	69.67%	28.66%	1.69%	88.20%	23%	.404	.796
9	People with frontotemporal dementia do best when given choices among many options. (F)	75.28%	19.66%	5.06%	87.08%	26%	.331	.800

10	There are treatments to slow down frontotemporal dementia. (F)	78.09%	21.35%	0.56%	92.70%	15%	.432	.795
11	After symptoms of frontotemporal dementia appear, the average life expectancy is 7 to 13 years. (T)	55.06%	38.20%	6.74%	82.02%	17%	.298	.802
12	Based on their age, people who are 70 years old are more likely to develop frontotemporal dementia than people who are 50 years old. (F)	57.31%	31.47%	11.24%	75.28%	45%	.476	.791
13	On average, caregivers of people with frontotemporal dementia report more stress than caregivers of people with other dementias. (T)	48.88%	35.96%	15.17%	74.72%	45%	.318	.801

14	Medications designed to improve memory and thinking in people with Alzheimer disease are also appropriate for people with frontotemporal dementia. (F)	68.54%	22.48%	8.99%	86.52%	28%	.395	.796
15	The language variant of frontotemporal dementia is more common than the behavioral variant. (F)	38.20%	29.22%	32.58%	55.06%	47%	.336	.800
16	People with the behavioral variant of frontotemporal dementia have difficulty remembering events from the past. (F)	55.62%	34.27%	10.11%	68.54%	56%	.391	.796
17	People with the behavioral variant of frontotemporal dementia lack interest in things they used to find enjoyable. (T)	61.24%	30.34%	8.43%	84.83%	28%	.412	.795

18	People with the language variant of frontotemporal dementia are able to read and write without difficulty. (F)	62.36%	29.78%	7.87%	80.90%	17%	.230	.806
	Items removed from the final scale							
	Frontotemporal dementia is a disorder that causes a decline in a person’s behavior or language. (T)	97.19%	2.25%	0.56%	99.44%	2%		
	There are different forms of frontotemporal dementia that lead to different major symptoms. (T)	92.69%	7.30%	0.00%	96.63%	9%		
	After an initial period of decline, people with frontotemporal dementia do not experience further change in their symptoms. (T)	93.26%	6.18%	0.56%	99.44%	2%		

When people with frontotemporal dementia act inappropriately, you can get them to stop by explaining why they should not do it. (F)	85.95%	12.92%	1.12%	96.07%	9%
People with the behavioral variant of frontotemporal dementia often act on impulse instead of thinking things through. (T)	89.32%	8.42%	2.25%	95.51%	11%
People with the language variant of frontotemporal dementia have difficulty in spoken conversations. (T)	87.08%	10.11%	2.81%	97.19%	6%

Table 3

Correlations Among Major Study Variables

	1	2	3	4	5	6	7	8
1. FTDKS	–							
2. DKAS	.615**	–						
3. Self-Rated FTD Knowledge	.488**	.450**	–					
4. Shipley Institute of Living Scale	.247*	.256*	.075	–				
5. Professional experience with FTD[a]	.349**	.334	.634**	-.036	–			
6. Years of experience as a provider[a]	.161	.530	.384**	-.292	.327**	–		
7. Level of care provided[b]	.231*	.085	.187	.086	-	-	–	
8. Number of people with FTD known[b]	.179	.213	.371**	.165	-	-	-.167	–

Note. FTDKS = Frontotemporal Dementia Knowledge Scale; DKAS = Dementia Knowledge Assessment Scale; FTD = frontotemporal dementia.

[a] Provider only

[b] Non-provider only

* $p < 0.05$. ** $p < 0.01$.