

Practical clinical tool to monitor dementia symptoms: the HABC-Monitor

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Background: Dementia care providers need a clinical assessment tool similar to the blood pressure cuff (sphygmomanometer) used by clinicians and patients for managing hypertension. A "blood pressure cuff" for dementia would be an inexpensive, simple, user-friendly, easily standardized, sensitive to change, and widely available multidomain instrument for providers and informal caregivers to measure severity of dementia symptoms. The purpose of this study was to assess the reliability and validity of the Healthy Aging Brain Care Monitor (HABC-Monitor) for measuring and monitoring the severity of dementia symptoms through caregiver reports.

Methods: The first prototype of the HABC-Monitor was developed in collaboration with the Indianapolis Discovery Network for Dementia, which includes 200 members representing 20 disciplines from 20 local organizations, and an expert panel of 22 experts in dementia care and research. The HABC-Monitor has three patient symptom domains (cognitive, functional, behavioral/psychological) and a caregiver quality of life domain. Patients (n = 171) and their informal caregivers (n = 171) were consecutively approached and consented during, or by phone shortly following, a patient's routine visit to their memory care provider.

Results: The HABC-Monitor demonstrated good internal consistency (0.73–0.92); construct validity indicated by correlations with the caregiver-reported Neuropsychiatric Inventory (NPI) total score and NPI caregiver distress score; sensitivity to three-month change compared with NPI "reliable change" groups; and known-groups validity, indicated by significant separation of Mini-Mental Status Examination severity groups and clinical diagnostic groups. Although not designed as a screening study, there was evidence for good operating characteristics, according to area under the receiver-operator curve with respect to gold standard clinical diagnoses, relative to Mini-Mental Status Examination or NPI.

Conclusion: The HABC-Monitor demonstrates good reliability and validity as a clinically practical multidimensional tool for monitoring symptoms of dementia through the informal

Keywords: dementia, symptoms, monitor, validation, cognitive impairment, memory care

Introduction

Dementia is a complex brain syndrome with a spectrum of cognitive, functional, behavioral, and psychological symptoms that reduces quality of life for both patients and their informal caregivers.^{1,2} Behavioral and psychological symptoms related to dementia are among the most difficult symptoms of the syndrome to manage.3 Two recent randomized controlled trials^{4,5} demonstrated the effectiveness of using a collaborative care model to reduce both behavioral and psychological symptoms related to dementia in patients and the stress for their informal caregivers. ⁴⁻⁷ However, the success of this

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model required continuous monitoring of both the dementia symptoms and the effectiveness of the individualized care protocols utilized in managing these symptoms. 4-7 Enhancing dementia care by implementing a collaborative dementia care model demands the development of a practical, accurate, sensitive to change, and multidomain clinical tool effective both in identifying the biopsychosocial needs of patients with dementia and in detecting any changes occurring in response to the care plan implemented by clinicians. Ideally, dementia care providers need a clinical tool similar to the blood pressure cuff (sphygmomanometer) used by clinicians, patients, and their family members for the recognition and management of hypertension. A "blood pressure cuff" for dementia would be an inexpensive, simple, user-friendly, easily standardized, and widely available instrument for both providers and informal caregivers to measure and track dementia symptoms.

There are many tools available today to gauge the presence and severity of dementia symptoms through caregiver observation and report. However, most are best suited for research studies and not clinical practice because they are lengthy and/or cover only particular domains. For example, the Clinical Dementia Rating⁸ is one of the gold standards for assessing severity of dementia but is quite extensive and does not include the behavioral and psychological symptoms related to dementia. Conversely, other tools exist for measuring behavioral and psychological symptoms related to dementia, including the Neuropsychiatric Inventory (NPI), which has become a widely used instrument for this purpose.9 However, the time taken to complete the NPI is impractical for most clinic settings and the NPI does not cover functional or cognitive domains. Many additional tools are available to screen specifically for cognitive impairment.² Among instruments that contain more than one domain and intended to have a short administration time, the Dementia Severity Rating Scale¹⁰ assesses the cognitive and functional domains but not the behavioral domain and is lengthier than the HABC-Monitor because the Dementia Severity Rating Scale requires several pages as each of the 12 items has a different set of detailed response options. The 47-item Dementia Severity Scale¹¹ covers the cognitive, functional, and behavioral domains, but does not contain mood (depression or anxiety) symptoms.

Over the last 3 years, we have constructed a prototype of a "blood pressure cuff" for dementia. We have assessed its face and content validity based on the input of real-world users and an international panel of dementia care experts. On the advice of our expert panel, we sought to avoid the potential negative connotation of the word "dementia" by giving

our instrument a name that uses safe, positive, simple, and familiar language, ie, the Healthy Aging Brain Care Monitor (HABC-Monitor or HABC-M). This study was undertaken to determine whether the HABC-Monitor exhibits the psychometric properties of reliability and validity necessary for broad clinical use.

Methods

Instrument development

The first prototype of the HABC-Monitor was developed in collaboration with the Indianapolis Discovery Network for Dementia, which is a local, diverse, and sustainable network dedicated to enhancing the quality of life and care of individuals with dementia. The network includes over 200 members representing 20 disciplines from 20 local organizations, including the four largest health care systems in Indianapolis. Building the HABC-Monitor was accomplished through a series of steps.

With the support of the Indianapolis Discovery Network for Dementia and an unrestricted research grant from Forest Pharmaceuticals, we constructed an interdisciplinary expert panel team of 22 representatives from three disciplines (clinical care, clinical research, and psychometrics) involved in dementia care and research. The clinical team included four primary care physicians, three dementia physicians (a neurologist and two geriatricians), two nurse providers, a pharmacist, and a social worker. The clinical research team included a dementia health services researcher, a dementia epidemiologist, a dementia care coordinator, three neuropsychologists, and two clinical trialists. The psychometric team included three psychometricians. In September 2008, we coordinated and led an offsite two-day retreat to assess the face and content validity as well as feasibility and usability of the instrument. Following the retreat, we contacted all participants by email seeking their subsequent feedback. The expert panel agreed that the target instrument should include items covering four clusters including dementia symptoms (cognitive, functional, and behavioral/psychological) and caregiver quality of life to accomplish the primary goals of measuring severity of symptoms and assessing response to therapy. In a systematic evidence review of the literature, the team identified questions from existing scales to tap the four clusters and created a common item response set that is simple and sensitive to variation over time and treatment. The HABC-Monitor items were selected by consensus amongst the 22 members of our expert panel. The panel elected to use 23 items from legacy instruments consisting of 17 items that best capture the cognitive, behavioral, and

psychological symptoms of dementia (ie, items 1-7 and 18-27, see Appendix) including all eight items from the AD8, 12,13 four items from the PHQ-9,14 ten items from the NPI-O,15 and six instrumental and basic activities of daily living items from the 12-item functional survey used in the Assessing Care of Vulnerable Elders study (ie, items 8–13). 16 Four of the selected items from the AD8, PHQ-9, and NPI-Q overlap. Namely, the second item of AD8 and the seventh item of the NPI-Q are also measured by the first item of the PHQ-9, and all four selected PHQ-9 items are contained in the NPI-Q. The rationale for including these 23 items was that these items were derived from well validated and clinically relevant instruments that capture the cognitive, functional, behavioral, and mood symptoms of patients with dementia and that these items could be translated into items easily reported by informal caregivers. The rationale for the panel to develop eight new items was to capture additional functional symptoms (eg, safety and falling, items 14-17) related to dementia and items that capture the quality of life of the informal caregiver (items 28-31) that is impacted by dementia-related disability. Furthermore, the experts structured the item response options using four ordinal categories to allow measurement of variation over time and to reach consistency in the response set across questions.

Although the panel recognized the importance and value of using clinician observers or performance tests as a possible source of data relevant to dementia care, the panel decided to focus on practical and feasible sources of data relying on the perceptions and observations of the patients' informal caregivers. In addition, the team discussed the various vehicles that could be used to capture data from caregivers and opted to develop a flexible template capable of accommodating paper, telephone, or web-based data entry. The expert team recognized that the relative benefit of each of the four domains of the HABC-Monitor will vary based on the clinical objective. As an example, cognitive and functional domains may facilitate diagnosis, whereas caregiver stress and behavioral and psychological symptoms may contribute to the measurement of response to therapy. All procedures were approved by the institutional review board of the Indiana University-Purdue University campus in Indianapolis.

Clinical setting and population

Our study was conducted at the Healthy Aging Brain Center (HABC), a memory care practice located within Wishard Health Services, a safety net health care system primarily serving an urban, racially and ethnically mixed population of vulnerable adults.⁶ This memory care practice is one of

five memory care practices affiliated with the Indianapolis Discovery Network for Dementia. The HABC staff includes four memory care practitioners, four care coordinators (two social workers and two registered nurses), two medical assistants, and one technician skilled in neuropsychological testing. The care coordinator conducts a previsit structured telephone interview with the informal caregiver to collect the necessary information related to the patient's cognitive, functional, behavioral, and psychological symptoms, as well as caregiver burden. The HABC technician administers the Consortium to Establish a Registry for Alzheimer's Disease neuropsychological battery to every new patient seen in the HABC. The memory care physician performs a structured physical and neurological examination, and orders any necessary laboratory and brain imaging tests. Data collected through these processes are used collectively by the HABC team to make a diagnosis of dementia, mild cognitive impairment, or normal cognitive status.6 Furthermore, the care coordinators provide ongoing telephone support and care management for both patients and caregivers seen in the HABC. During each clinic visit and telephone contact, the care coordinator assesses for cognitive, functional, behavioral, and psychological symptoms in the patient and for caregiver stress. In addition, care coordinators are responsible for contacting the patient's primary care physician to facilitate medical comanagement and for coordinating with local resources, such as the local Alzheimer's Association. The mean age of patients seen in our HABC is 75 years, and 72% are female, 39% are underrepresented minorities, and 80% are Medicare beneficiaries. Using Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision criteria, 32% of the patients seen in the HABC have probable or possible Alzheimer disease, 10% have vascular dementia, 33% have mild cognitive impairment, and 25% are normal or have other cognitive or mood disorders.6

Subject recruitment and testing

During a patient's routine HABC visit, a research assistant approached the patient and the patient's caregiver, or contacted them by phone shortly thereafter, to obtain informed consent for participation in this study. All of the HABC providers agreed to allow their patients and caregivers to be approached. Each subject (caregiver) was asked to complete the HABC-Monitor and the Neuropsychiatric Inventory. Each patient was asked to complete the PHQ-9. The test batteries were repeated 3 months later. The two batteries were administered by a research assistant and completed either face-to-face or via telephone.

Assessment questionnaires HABC-Monitor

The current HABC-Monitor includes 31 items covering four clinically relevant domains of dementia, ie, cognitive, functional, behavioral, and psychological symptoms, and caregiver quality of life. For brevity and practical use in the clinical setting, each item on the four scales was designed to have the same item response options consisting of four categories that use the frequency of the target problem in the past 2 weeks. The appendix outlines all of the items of the HABC-Monitor instrument. A public website hosts our instrument (http://www.wishard.edu/our-services/senior-care/healthy-aging-brain-center/cgm). The HABC-Monitor took approximately 6 minutes to complete.

Neuropsychiatric inventory

The NPI is based on a structured interview administered to an informal caregiver and has been adopted by the Alzheimer's Disease Cooperative Studies Group to obtain information on the presence of psychopathology in behavioral areas including delusions, apathy, hallucinations, disinhibition, agitation, depression, aberrant motor behavior, anxiety, night-time behavior, and euphoria.9 For each of 12 symptoms, if the caregiver reports the presence of psychopathology, a frequency and severity score are multiplied to yield a possible item score range of 0-12, and a possible total score range of 0-144. The NPI can be used to assess changes in the patient's behavior over the past month. The NPI also assesses the level of caregiver distress attributable to each of the 12 patient behaviors, with a possible total caregiver distress score range of 0–60. The administration time is about 20 minutes. The NPI has excellent reliability and validity.9

Other data collection

The research assistants reviewed the memory care practice medical records of each participating patient to record the clinical diagnosis made by the HABC team, ie, dementia, mild cognitive impairment, or normal. The Mini-Mental Status Examination (MMSE)¹⁷ score was collected from the Consortium to Establish a Registry for Alzheimer's Disease battery during the initial visit to the HABC. Patient and caregiver age, gender, race and ethnicity, and the highest level of formal education completed by the caregiver, were also collected.

Scaling procedure

Each HABC-Monitor scale score was computed by summing all items in the scale. A higher score represented a worse

score for all HABC-Monitor scales and total score. When computing scale scores, a person-specific and scale-specific mean of nonmissing items was substituted for missing items if 50% or fewer of the items on the scale were missing.

Statistical analysis

Confirmatory factor analysis was performed using MPLUS software version 5.21 (Muthen and Muthen, Los Angeles, CA).¹⁸ All other analyses were performed with SAS version 9.3 (SAS Institute Inc, Cary, NC).

Data quality and descriptive analyses

Data completeness was assessed by calculating missing data rates for each item. To assess item variability, the item frequency distributions, range, and standard deviations were calculated. Item and scale scores were examined for floor and ceiling effects (ie, clustering of participants at the best and worst possible perceptions, respectively). To determine the range of caregiver perceptions measured by the HABC-Monitor scales, the observed score range and measures of central tendency and variability were computed.

Psychometric analyses

Confirmatory factor analysis was performed with MPLUS to confirm the hypothesized factor structure of the HABC-Monitor item responses. Criteria of good model fit were the following: comparative fit index > 0.95, 19 root mean square error of approximation < 0.06, and weighted root mean square residual < 1.00.20 Modification indices were used to determine whether fit of the confirmatory factor analysis model could be improved by adding any paths or cross-loadings. The items were appropriately modeled as ordinal categorical (not continuous) items. The strength of association between individual items and the hypothesized factors were assessed with item standardized factor loadings. All four factors were hypothesized to be correlated with each other. Internal-consistency reliability was estimated with coefficient alpha.²¹ Reliability of 0.70 or greater was considered satisfactory for group comparison purposes.²² Sensitivity of the HABC-Monitor scores to change was assessed. 23,24 Specifically, because the NPI and HABC-Monitor were both administered to caregivers at baseline and at 3 months, and because the NPI total score is considered a gold standard for the purpose of assessing psychopathology in behavioral areas relevant to dementia,9 "reliable change" groups of NPI total score (decline, stable, improve) were computed by determining for each patient whether the caregivers' NPI

total score declined or improved by more than 1.0 standard error of measurement (SEM) from baseline to follow-up at 3 months. One SEM was defined as the standard deviation of change scores for the NPI total, multiplied by the square root of [1.0 minus reliability], where reliability was specified as 0.79, ie, the published test-retest reliability coefficient of the NPI total score. For each reliable change group, the effect size for the sensitivity to change for the HABC-Monitor total and subscale scores were computed as the standardized response mean: M2 – M1/SDdiff (SDdiff = standard deviation of score changes). The three NPI reliable change groups were statistically compared on the HABC-Monitor change scores using analysis of variance, with pairwise Tukey-Kramer post hoc tests which controlled the familywise Type I error rate at 0.05.

Known-groups validity was assessed by using analysis of variance to compare HABC-Monitor scores between patient groups formed by MMSE scores (0–9, 10–17, 18–23, 24+) and gold standard clinical diagnoses (normal, cognitive impairment, dementia). A significant omnibus F test was followed by pairwise Tukey-Kramer post hoc tests with 0.05 familywise Type I error.

This study was not designed to be a screening study. For example, in a screening study, we would have purposively enrolled a larger number of patients in the "normal" diagnostic category. Nevertheless, we provided a brief description of preliminary data for the operating characteristics of the HABC-Monitor scales, namely, the area under the receiver-operator curve (AUROC) with respect to gold standard clinical diagnostic groups (normal, mild cognitive impairment, dementia).

Results

Demographics

Of 266 patient and caregiver dyads approached, 171 signed the informed consent and Health Insurance Portability and Accountability Act documents and completed baseline assessments. Patient and caregiver characteristics are shown in Table 1. Patients on average were 76 years of age; a majority were female (63%) and a substantial minority were African American (38%). Their informal caregivers were on average 58 years of age, mostly female (76%), and 58% had more than a high school education (see Table 1).

Data quality

Table 2 demonstrates that all items of the HABC-Monitor tool exhibited the full range of response categories across the four item response options. In general, the item responses

Table I Participant characteristics

Patient characteristics	
Age, mean (SD)	75.7 (10.3)
Gender	
Female	63%
Male	37%
Race	
White	61%
African-American	38%
Other	1%
Ethnicity	
Hispanic	1%
Not Hispanic	99%
Caregiver characteristics	
How well caregiver knows patient	
Very well	90%
Well	10%
Relationship of caregiver to patient	
Spouse or partner	34%
Child	52%
Grandchild	4%
Parent	2%
Sibling	6%
Other	2%
Age, mean (SD)	57.7 (14.1)
Gender	
Female	76%
Male	24%
Race	
White	61%
African-American	38%
Other	1%
Ethnicity	
Hispanic	1%
Not Hispanic	99%
Education	
0-11 Years	14%
12 Years	28%
13+ Years	58%

were more heavily distributed among the 0 and 1 scores than the 2 and 3 scores, as indicated by item means that ranged from 0.3 to 1.7. Missing item rates were very low and ranged from 0% (n=171) to 1.8% (n=168), as shown in Table 2. The item-level floor effects ranged from 16% to 82% with a median of 68%. The item-level ceiling effects ranged from 2% to 35% with a median of 12%. The standard deviation was similar for all items, ranging from 0.7 to 1.2. Thus, data quality of the HABC-Monitor was satisfactory.

Confirmatory factor analysis

We tested two alternative or competing models that were specified a priori before analyses and differed only in whether the anhedonia item (item 18, "less interest or pleasure in doing things, hobbies or activities") was hypothesized to Monahan et al Dovepress

Table 2 Item distributions, missing rates, confirmatory factor analysis (CFA), and item-total correlations

HABC-M domains and items	Item d	istribut	ion and	d miss	ing ra	tes	% miss	CFA	ltem-tota
	Item		Resp	onse	count	5			Pearson r
	Mean	SD	0	1	2	3			
Cognitive domain (factor I)								Factor I	
Judgment or decision-making	1.3	1.2	52	54	22	43	0.0	0.87	0.72
2. Repeating the same things over and over such	1.1	1.1	72	41	29	29	0.0	0.78	0.65
as questions or stories									
3. Forgetting the correct month or year	1.5	1.2	54	39	22	56	0.0	0.65	0.59
4. Handling complicated financial affairs such as	0.6	1.0	118	24	12	17	0.0	0.71	0.52
balancing checkbook, income taxes and paying bills									
5. Remembering appointments	1.0	1.2	87	36	15	33	0.0	0.83	0.70
6. Thinking or memory	8.0	1.2	109	17	10	35	0.0	0.81	0.68
Functional domain (factor 2)								Factor 2	
7. Learning to use a tool, appliance, or gadget	1.1	1.2	79	34	18	40	0.0	0.69	0.55
8. Planning, preparing, or serving meals	1.7	1.1	28	53	30	59	0.6	0.78	0.63
9. Taking medications in the right dose at the right time	0.6	1.0	123	18	8	21	0.6	0.67	0.51
10. Walking or physical ambulation	0.7	1.1	115	23	5	27	0.6	0.32	0.24
11. Bathing	8.0	1.1	100	30	15	26	0.0	0.82	0.61
12. Shopping for personal items like groceries	0.4	1.0	138	8	9	16	0.0	0.92	0.74
13. Housework or household chores	0.5	1.0	127	20	2	22	0.0	0.88	0.76
14. Leaving her/him alone	0.5	1.0	128	12	14	17	0.0	0.83	0.59
15. Her/his safety	0.4	0.9	133	16	8	14	0.0	0.93	0.69
16. Her/his quality of life	0.4	0.9	134	18	6	12	0.6	0.67	0.52
17. Falling or tripping	0.7	1.0	102	32	20	16	0.6	0.56	0.41
Behavioral and psychological domain (factor 3)								Factor 3	
18. Less interest or pleasure in doing things, hobbies	0.3	0.7	132	29	6	4	0.0	0.68	0.49
or activities									
19. Feeling down, depressed, or hopeless	1.0	1.1	78	49	18	26	0.0	0.60	0.55
20. Being stubborn, agitated, aggressive or resistive	1.1	1.1	71	48	19	33	0.0	0.67	0.61
to help from others									
21. Feeling anxious, nervous, tense, fearful or panic	8.0	1.1	99	36	14	22	0.0	0.76	0.60
22. Believing others are stealing from them or planning	0.3	8.0	140	15	6	10	0.0	0.67	0.53
to harm them									
23. Hearing voices, seeing things or talking to people	0.3	0.7	138	22	3	8	0.0	0.62	0.39
who are not there									
24. Poor appetite or overeating	8.0	1.2	102	30	9	30	0.0	0.64	0.43
25. Falling asleep, staying asleep, or sleeping too much	1.0	1.1	80	42	18	30	0.6	0.29	0.33
26. Acting impulsively, without thinking through	0.5	0.9	123	25	10	13	0.0	0.84	0.56
the consequences of her/his actions									
27. Wandering, pacing, or doing things repeatedly	0.5	1.0	131	16	6	18	0.0	0.82	0.55
Caregiver quality of life domain (factor 4)								Factor 4	
28. Your quality of life	0.6	0.9	111	34	- 11	12	1.8	0.95	0.50
29. Your financial future	0.5	0.9	127	21	8	13	1.2	0.46	0.48
30. Your mental health	0.3	0.7	135	24	5	5	1.2	0.86	0.59
31. Your physical health	0.5	0.9	121	25	9	14	1.2	0.60	0.53
Fit statistics from confirmatory factor analysis (CFA	A)					RMSEA		CFI	WRMR
Model I (a priori hyothesized model, anhedonia item in fac	tor I not fa	actor 3)				0.062		0.923	1.082
Model 2 (a priori hyothesized model, anhedonia item in fac	tor 3 not fa	actor I)				0.062		0.923	1.078
Model 3 (final revised model, same as model 2 except learning	g gadget ite	m in fac	tor 2 no	t facto	r I)	0.059		0.929	1.055

Notes: All items had a four-category response scale: 0 = None at all (0–1 day), I = Several Days (2–6 days), 2 = More than half the days (7–11 days), 3 = Almost daily (12–14 days). % miss = % of participants missing the item.

Abbreviations: HABC-M, Healthy Aging Brain Care Monitor; RMSEA, root mean square error of approximation; WRMR, weighted root mean square residual.

load on the cognitive factor (factor 1) or the behavioral and psychological factor (factor 3). The other two factors in the confirmatory factor analysis model were the functional factor (factor 2) and the caregiver quality of life factor (factor 4). The fit statistics were very similar for the two competing

models and for the final model; therefore, decisions about the final model were made on the basis of the magnitude and significance of item loadings and conceptual relevance. The loading for the anhedonia item had similar magnitude (0.65 and 0.68), and was significant in both models; however,

when this item was allowed to cross-load on both factor 1 and factor 3, the anhedonia item was not significant on the cognitive factor (factor 1, loading = 0.25, P = 0.068) but was significant on the behavioral and psychological factor (factor 3, loading = 0.43, P = 0.004). Therefore, due to this finding and the fact that anhedonia is more commonly classified as a mood symptom, we decided to place the item in the behavioral and psychological factor. Only one of the modification indices from the two alternative models displayed conceptual relevance. This modification index suggested that the following path could be significant if added to the model: functional factor to item 7, "learning to use a tool, appliance, or gadget". This was investigated by allowing the learning gadget item to cross-load on both the cognitive and functional factors. The learning gadget item was found to be not significant on the cognitive factor (loading = -0.16, P = 0.43) but highly significant on the functional factor (loading = 0.84, P < 0.0001). Therefore, due to this and conceptual relevance, the final model was revised to allow this item to load only on the functional factor and not the cognitive factor and, correspondingly, this item was scored only in the HABC-Monitor functional scale score.

In the final model all four factors were significantly correlated except the cognitive and caregiver quality of life factors (F1, F2, r = 0.80; F1, F3, r = 0.79; F2, F3, r = 0.77; F1, F4, r = 0.11; F2, F4, r = 0.38; and F3, F4, r = 0.38). The fit statistics for the two hypothesized alternative models and the final revised model are shown at the bottom of Table 2. All three models fit the data reasonably well, although the comparative fit index and weighted root mean square residual fit statistics did not quite meet the desired cutoffs. Of note, the only revision we made to the originally hypothesized model 2 was to move the learning gadget item to the functional factor. All items in the final model loaded above 0.40 except two items, ie, item 10(0.32) and item 25(0.29). These two items were retained due to their conceptual relevance. Most items loaded above 0.60. Therefore, the hypothesized four-factor model fit the data reasonably well. The final recommended model contained only one modification to one of the two competing a priori models. The remaining results below apply to the finalized HABC-Monitor scales which were scored by summing the items according to the subscales recommended in our final model.

Reliability and scale score features

The internal consistency of the HABC-Monitor scales was high (0.73–0.92, Table 3). The observed scale scores covered

most of the possible score range, and the mean and standard deviation suggested that the scale scores demonstrated a sufficient dispersion of scores for the purpose of assessing and monitoring the severity of dementia-related symptoms. There were very low (ie, satisfactory) floor and ceiling effects, especially for the scales that the caregiver rated about the patient (0%-18%). The highest floor effect was for the caregiver quality of life scale, in which 49% of the caregivers self-reported the lowest (ie, best) possible scores. The three patient symptom scales were moderately correlated (0.62-0.64) as expected, indicating that the domains are related but substantially distinct. Nevertheless, the total score was also highly internally consistent, suggesting that both the HABC-Monitor total scoring and subscale scoring approaches are valid. The caregiver quality of life scale, as expected, demonstrated low correlations with patient symptom scales, in part because caregivers were asked to rate the quality of life items irrespective of whether it was the patient symptoms or other sources of burden that were associated with their quality of life. Therefore, the HABC-Monitor scales demonstrated adequate internal consistency and scale score features including ample dispersion of scores and moderate correlations between patient symptom scales.

Construct validity

Results in Table 4 showed that at baseline the HABC-Monitor demonstrated construct validity because the highest correlation (0.83) was between the behavioral and psychological subscale of the HABC-Monitor and the NPI total score (0.78), with moderate and significant correlations between the NPI total score and the other two HABC-Monitor patient symptom domain scores (cognitive, 0.62; functional, 0.56). As expected, the HABC-Monitor caregiver quality of life subscale had a significant but relatively lower correlation with the total NPI score (0.35), and a slightly higher correlation with the NPI total score assessment of caregiver distress (0.44). The HABC-Monitor caregiver quality of life and the NPI caregiver distress total score are not expected to be highly correlated because the HABC-Monitor assesses general caregiver quality of life, and does not require the caregiver to identify whether problems with their quality of life are due to patient symptoms or due to other sources. The NPI caregiver distress total score, in contrast, is derived from a more detailed request of the caregiver to assess the impact of 12 patient symptoms on caregiver distress. Like the NPI, the NPI caregiver distress total score demonstrated its highest correlation with the HABC-Monitor behavioral/psychological domain (0.74), and moderate and significant correlations with the HABC-Monitor cognitive

Table 3 HABC-M scale score features: internal-consistency reliability, score distributions, and inter-score correlations

HABC-M scales	Number of items	Reliability	Score fea	tures and	d distrib	utions		% Floor	% Ceiling	Inter-scale Spearman r			
		Coefficient	Number	Observ	ed score	distribut	ion			С	F	В	Т
		alpha	possible levels	Range	Mean	Median	SD						
Patient symptoms													
Cognitive (C)	6	0.86	18	0-18	7.4	7.0	5.4	11	4				
Functional (F)	П	0.87	33	0-30	5.9	3.0	7.0	18	0	0.60			
Behavioral and psychological (B)	10	0.82	30	0–30	7.3	6.0	6.3	13	1	0.64	0.62		
Total (T)	27	0.92	81	0-75	20.6	17.0	16.3	3	0	0.88	0.82	0.88	
Caregiver quality of life (Q)	4	0.73	12	0–11	1.8	1.0	2.5	49	0	0.13	0.33	0.33	0.29

Notes: % Floor is the percentage of caregivers who reported the lowest (best) possible score. % Ceiling is the percentage of caregivers who reported the highest (worst) possible score.

Abbreviation: HABC-M, Healthy Aging Brain Care Monitor.

and functional domain scores. Therefore, the HABC-Monitor demonstrated good construct validity.

Sensitivity to change

The sensitivity to change results are shown in Table 5. The first two rows of data display descriptive statistics that help to describe the "reliable change" groups. Specifically, for the group that declined in NPI total score by more than 1.0 SEM from baseline to 3 months, their mean NPI total score was 11.3 at baseline (time 1) and became worse (20.9) 3 months later at time 2. The NPI stable group retained low (relatively good) mean NPI scores from time 1 to time 2 (4.9 and 5.1, respectively). In contrast, the NPI improved group started at a worse level than the other two groups at baseline (29.8) but improved to a mean score of 18.6 when assessed 3 months later. Because the NPI total score is a gold standard for measuring the behavioral and psychological symptoms related to dementia through the caregiver, sensitivity-to-change validity for the HABC-Monitor would be indicated by significant differences between the NPI reliable change groups on

Table 4 Construct validity of HABC-Monitor

HABC-Monitor scales	NPI	NPI-cg
	(n = 171)	(n = 171)
Patient symptoms (reported by caregiver)		
Cognitive	0.62***	0.51***
Functional	0.56***	0.53***
Behavioral/psychological	0.83***	0.75***
Total score	0.78***	0.69***
Caregiver quality of life (reported by caregiver)	0.35***	0.44***

Notes: Values represent Spearman correlation coefficients. NPI = Neuropsychiatric Inventory (NPI) total score, which is a gold standard of caregiver assessment of the patient's frequency and severity of behavioral/psychological symptoms relevant to dementia. NPI-cg = NPI caregiver distress total score, an indicator of caregiver assessment of caregiver distress due to the patient's symptoms. ***P < 0.001. **Abbreviation:** HABC, Healthy Aging Brain Care.

the mean change scores of the HABC-Monitor scales. The analysis of variance omnibus P value in Table 5 shows that the three NPI groups demonstrate significantly different mean change scores for each and every HABC-Monitor scale score except for the HABC-Monitor caregiver quality of life scale. As expected, of the three HABC-Monitor patient symptom subscales, the behavioral and psychological subscale displayed the strongest differences, including significant Tukey-Kramer post hoc pairwise differences among all three NPI reliable change groups. The HABC-Monitor cognitive subscale significantly separated the improved group from the declined and stable groups but did not separate the declined group from the stable group. The HABC-Monitor functional subscale significantly separated only the improved group from the declined group, and showed marginal ability (P = 0.058)to distinguish the declined group from the stable group. The direction and magnitude of HABC-Monitor change score effect sizes were consistent with theory. For example, the largest effect sizes for the change scores were for HABC-Monitor behavioral/psychological change scores, which demonstrated moderate improvement in the NPI improved group (0.53) and moderate decline in the NPI declined group (-0.43). The HABC-Monitor caregiver quality of life score showed slight to moderate declines, according to effect size, in all three NPI groups. It is not clear why this was, except it should be noted that the mean HABC-Monitor caregiver quality of life score at time 2 was similar for the declined and improved groups (mean = 2.6 for both groups). Furthermore, the quality of life score was indeed lower (ie, better) at baseline for the stable group (1.0) and improved group (1.7) compared with the declined group (2.6). Caregiver quality of life seems to have gotten substantially worse over time (effect size = -0.70) for the NPI stable group, perhaps because the caregivers had a

Table 5 Sensitivity to change

NPI decline (D; n = 48) Mean SD Change Description of NPI change groups NPI time 1 (baseline) NPI time 2 (3 months) Description of the ANDVA	ge : size	NPI stable (S; n = 43) Mean SD Char effec	n = 43)							
Mean SD 11.3 14.7 20.9 17.3		SD	•	NPI im	rove (I;	NPI improve (I; $n = 43$)	Omnibus	Tukey-K	Tukey-Kramer pairwise	wise
11.3	:		Change effect size	Mean	SD	Change effect size	P-value	D vs S	D vs I	S vs I
11.3										
20.9	4.9	7.5		29.8	25.9		<0.001	0.087	<0.001	<0.001
Dood door wasiable in the ANOVA	5.1	7.3		9.81	22.6		<0.001	<0.001	0.521	0.004
responsiveness-to-change models										
HABC-M cognitive change score -0.58 4.77 -0.12	-0.44	3.22	-0.14	1.33	3.12	0.42	0.036	098.0	0.019	0.034
HABC-M functional change score –2.88 6.75 –0.43	-0.35	5.51	-0.06	1.30	6.45	0.20	0.007	0.058	0.002	0.225
HABC-M behavioral/psychological change score —2.31 5.39 —0.43	-0.23	3.44	-0.07	2.19	4.16	0.53	<0.001	0.028	<0.001	0.013
HABC-M total change score -5.77 13.50 -0.43	-1.02	9.54	-0.11	4.81	99.6	0.50	<0.001	0.045	<0.001	0.017
HABC-M caregiver quality of life change score —0.02 2.93 —0.01	-0.70	1.40	-0.50	-0.90	2.50	-0.36	0.218	0.193	0.102	0.730

Abbreviations: HABC-M, Healthy Aging Brain Care Monitor; NPI, Neuropsychiatric Inventory; SD, standard deviation

chance to focus on themselves while the patient was stable; nevertheless, the effect sizes for the three groups should not be overly interpreted because the NPI change groups did not differ significantly on the mean caregiver quality of life change scores as indicated by the *P* values (Table 5). In summary, the HABC-Monitor showed good sensitivity to change indicated by significant omnibus and pairwise differences between the NPI reliable change groups on the HABC-M patient symptom scales.

Known-groups validity

The extent to which the HABC-Monitor scales separate the known groups of cognitive impairment, defined by MMSE cognitive-impairment severity score groups, is evidence of known-groups validity. Separation of consensus clinicianbased diagnoses with HABC-Monitor scores is also evidence of known-groups validity. Table 6 shows that the omnibus test was significant for all of the HABC-Monitor patient symptom scales with respect to separating the MMSE groups. All of the six pairwise differences between MMSE groups were significantly different on at least one of the three HABC-Monitor patient subscale scores. As expected, the HABC-Monitor cognitive scale was the strongest scale for separating the MMSE groups, and it alone separated the normal and mild MMSE groups. Despite a small sample size for the MMSE severe group (n = 10), the severe MMSE group was significantly different from the normal and mild MMSE groups on all HABC-Monitor patient scales and was significantly different from the moderate MMSE group on the HABC-Monitor functional and total scores but not the HABC-Monitor cognitive score, indicating the usefulness of having distinct subscales on the HABC-Monitor.

The clinical diagnostic groups were significantly different on all HABC-Monitor patient symptom scales with respect to the omnibus test. All pairs of the diagnostic groups were significantly different on the mean HABC-Monitor cognitive score. The HABC-Monitor functional, behavioral/psychological, and total scores were able to distinguish the dementia diagnostic group from the normal and mild cognitive impairment diagnostic groups clearly, but could not distinguish the normal diagnostic group from the mild cognitive impairment diagnostic group from the mild cognitive impairment diagnostic group.

Based on the eta-squared values, MMSE group membership was most highly associated with the HABC-Monitor cognitive and functional domains. The clinical diagnostic groups were more highly associated with the HABC-Monitor cognitive domain than the functional or behavioral and psychological domains. In summary, the HABC-Monitor showed good known-groups validity, indicated by significant

Table 6 Known-groups validity

MMSE 24+ MMSE 18-23 MMSE 10-17 MMSE 0-9 normal (1) mild (2) moderate (3) severe (4) (N = 76) (N = 53) (N = 20) (N = 10) main (N = 53) Mean SD Mean SD main S.3 4.7 8.1 4.9 11.5 5.3 14.3 3.9 main S.9 S.0 S.0 S.1 10.9 10.2 15.8 11.5 all 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 ity 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 Clinical diagnostic categories Normal (1) MCI (2) Dementia (3) Mean SD Mean SD Mean SD Mean SD Mean SD md 4.8 6.9 3.3 6.8 7 md 4.8 6.9 6.9 6.9	MMSE 10–17 MMSE 0–5 moderate (3) severe (4) (N = 20) (N = 10) (N =	Eta Omnibus squared P-value 0.25 <0.001 0.21 <0.001 0.11 0.001 0.24 <0.001 0.01 0.556	a	l vs 3	Tukey-Kramer pairwise p-values I vs 2	2 vs 3	7 6	,
normal (1) mild (2) moderate (3) severe (4) (N = 76) (N = 53) (N = 20) (N = 10) Mean SD Mean SD Mean SD t symptoms Figure (3) Figure (3) Figure (4) Figure (4) Figure (1) Figure (4) Figure (1) Figure (2) Figure (3) Figure (4)	Moderate (3) severe (4) (N = 20) (N = 10) Mean SD Mean 9 11.5 5.3 14.3 1 10.9 10.2 15.8 8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 6 1.9 2.3 1.7			0.000	vs 4	2 vs 3	h 21. C	,
Hean SD Mean SD SD <th>D Mean SD Mean .9 11.5 5.3 14.3 .1 10.9 10.2 15.8 .8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7</th> <th></th> <th>0.002 0.544 0.206</th> <th>100.0></th> <th>100.00</th> <th></th> <th>4</th> <th>3 vs 4</th>	D Mean SD Mean .9 11.5 5.3 14.3 .1 10.9 10.2 15.8 .8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7		0.002 0.544 0.206	100.0>	100.00		4	3 vs 4
t symptoms 5.3 4.7 8.1 4.9 11.5 5.3 14.3 3.9 ctional 4.3 5.0 5.0 5.1 10.9 10.2 15.8 11.5 avioral and 5.9 5.6 7.3 5.8 10.1 6.9 13.8 9.0 thological 5.9 5.6 7.3 5.8 10.1 6.9 13.8 9.0 thological score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 al score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 ver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 Clinical diagnostic categories Clinical diagnostic categories Clinical diagnostic categories Normal (1) MCI (2) Dementia (3) (N = 17) (N = 62) (N = 80) Mean SD Mean SD Mean SD T symptoms t symptom	.9 11.5 5.3 14.3 .1 10.9 10.2 15.8 .8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7		0.002 0.544 0.206	100.00	100.00			
tctional 4.3 5.0 5.0 5.1 10.9 10.2 15.8 11.5 avioral and 5.9 5.6 7.3 5.8 10.1 6.9 10.2 15.8 11.5 avioral and 5.9 5.6 7.3 5.8 10.1 6.9 13.8 9.0 11.5 all score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 ver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 Normal (1) MCI (2) Dementia (3) (N = 17) (N = 62) (N = 80)	.1 10.9 10.2 15.8 .8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7		0.002 0.544 0.206	<0.001	<0.001			
tctional 4.3 5.0 5.0 5.1 10.9 10.2 15.8 11.5 avioral and 5.9 5.6 7.3 5.8 10.1 6.9 13.8 9.0 chological al score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 ver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 Clinical diagnostic categories Normal (1) MCI (2) Dementia (3) (N = 17) (N = 62) (N = 80) t symptoms t	.1 10.9 10.2 15.8 .8 10.1 6.9 13.8 .2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7		0.544			0.007	<0.001	0.132
hological score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 score 15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 sver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 sver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 sver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 sver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 sver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 sver quality 3.0 3.4 4.1 4.4 8.1 8.1 8.7 sver quality 3.0 3.4 4.1 4.4 8.1 8.1 8.7 sver quality 3.0 3.4 4.1 4.4 8.1 8.1 8.7 sver quality 3.0 3.4 4.1 4.4 8.1 8.1 8.7 sver quality 3.0 3.4 4.1 4.4 8.1 8.1 8.7 sver quality 3.0 5.6 5.6 5.0 5.0 9.3 6.8 sver quality 3.0 5.0 5.0 5.0 5.0 5.0 5.0 5.0 5.0 5.0 5	.8 10.1 6.9 13.8 2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7		0.206	<0.00	<0.001	0.001	<0.001	0.048
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15.5 13.4 20.3 12.0 32.5 20.0 43.9 22.1 Ver quality 2.0 2.7 1.4 2.6 1.9 2.3 1.7 2.1 Clinical diagnostic categories	2.0 32.5 20.0 43.9 .6 1.9 2.3 1.7							
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Clinical diagnostic categories Normal (1) MCI (2) Dementia (3) (N = 17) (N = 62) (N = 80) Mean SD Mean SD Mean SD 2.9 3.8 5.4 4.4 10.2 5.1 3.0 3.4 4.1 4.4 8.1 8.7 4.8 6.6 5.6 5.0 9.3 6.8	ories		0.157	0.857	0.717	0.436	0.700	0.846
Normal (1) MCI (2) Dementia (3) (N = 17) (N = 62) (N = 80) Mean SD Mean SD 2.9 3.8 5.4 4.4 10.2 5.1 3.0 3.4 4.1 4.4 8.1 8.7 4.8 6.6 5.6 5.0 9.3 6.8			Tukey-K	ramer pair	Tukey-Kramer pairwise p-values	Si		
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d 4.8 6.6 5.6 5.0 9.3 6.8	- 8 	100.0 60.0	0.571	900.0	0.001			
001 346 711 131 011 701	9.3	100.0 60.0	0.634	0.007	0.001			
19 11 11 611 501								
1.5 1.5 1.1 1.6 27.3 18.0	11.6 27.5 18.0	0.17 <0.001	0.287	<0.001	<0.001			
Caregiver quality 1.5 2.3 2.0 2.9 1.5 2.1 0.01	1.5	0.01 0.504	0.445	0.933	0.273			

Abbreviations: MCI, mild cognitive impairment; HABC, Healthy Aging Brain Care; MMSE, Mini-Mental Status Examination.

omnibus and pairwise differences between MMSE and clinician-based diagnostic groups.

Operating characteristics

For predicting dementia (versus mild cognitive impairment or normal), the AUROC (and 95% confidence interval) for the 10-item HABC-Monitor behavioral and psychological scale (0.67; 0.59–0.75) was comparable with the AUROC for the more extensive NPI total score (0.66; 0.58–0.74). The HABC-Monitor total score was slightly better but comparable (0.72; 0.65–0.80). The total score for the 30-item MMSE had an AUROC of 0.88 (0.83–0.93) while the six-item HABC-Monitor cognitive scale demonstrated an AUROC of 0.77 (0.70-0.84)

For predicting normal (versus mild cognitive impairment or dementia), the AUROC for the 10-item HABC-Monitor behavioral and psychological scale was similar (0.67; 0.52–0.82) to that of the NPI total score (0.63; 0.47–0.81), and the HABC-Monitor total score was only slightly better (0.73; 0.59–0.86) than the HABC-Monitor behavioral and psychological scale. The AUROC was 0.91 (0.84–0.97) and 0.79 (0.68–0.90), respectively, for the MMSE total and the HABC-Monitor cognitive score.

Screening studies often report the findings for separating extreme groups (dementia and normal) because the results show, perhaps inappropriately, inflated operating characteristics compared with when the mild cognitive impairment group is included, as would be the case in usual practice. For purposes of comparison with published studies that compare dementia versus normal groups, the HABC-Monitor cognitive score showed an AUROC of 0.88 (0.78–0.98) and the MMSE was 0.97 (0.94–1.00). In summary, this preliminary report of the operating characteristics of the HABC-Monitor suggests good performance compared with the lengthier NPI. Performance was encouraging and adequate compared with the MMSE considering that the MMSE and clinical diagnoses were administered at the same time, which was 1–12 months earlier than the collection of HABC-Monitor data.

Sensitivity analyses

We thank a reviewer for suggesting that we examine possible effects of race and education on results. We re-estimated Cronbach's coefficient alpha and construct validity in three different subgroup dichotomizations, ie, white versus nonwhite patients, white versus nonwhite caregivers, and caregivers with less than 12 years of education versus higher education. (We did not collect patient education level). The results, ie, effect sizes and hypothesis-testing conclusions, did not differ by subgroups. For example, Cronbach's coefficient alpha differed very little by subgroups, and all subgroup

alphas continued to be in the range of 0.73–0.92, as they were in the total sample.

We thank another reviewer for prompting us to address whether the NPI "improved" group was due to intervention effects or due to severely impaired individuals becoming so apathetic that their previous behavioral and psychological symptoms were lessened. As described later in this paper, we believe that the improved group is a reflection of the effect of the collaborative care models for dementia and depression delivered by the selected memory care practice for this study. We performed an additional analysis, the results of which ruled out the interesting apathy hypothesis. The HABC-Monitor apathy item (ie, item 18, the anhedonia item) improved from time 1 to time 2 in the NPI improved group (item mean decreased from 1.8 to 1.4) and worsened in the NPI declined group (item mean increased from 1.0 to 1.5).

Discussion

The HABC-Monitor demonstrates a high degree of reliability and validity (including good sensitivity to change) for assessment and monitoring of the severity of dementiarelated symptoms through the input of informal caregivers. The instrument does this while maintaining the brevity and simple format necessary for use in clinical practice. Thus, the tool appears to exhibit both research validity and has the potential to be used as a simple and practical "blood pressure cuff".

The HABC-Monitor exhibits good data quality, including adequate item and scale score variability and low missing data rates. The hypothesized four-factor solution for the HABC-Monitor items demonstrates reasonably good fit for both of the two a priori alternative models. The final recommended model underwent only one minor revision, namely, the learning tools item was moved to the functional factor in the a priori model that placed the anhedonia item in the behavioral and psychological factor. Perhaps future revisions of the HABC-Monitor by our team or other research/clinical groups will improve the fit of the factor model even further, so that all major fit indices show good fit while maintaining brevity to maximize use of the instrument in routine clinical practice.

The HABC-Monitor demonstrates good sensitivity to change and known-groups validity. For construct validity, the 10-item behavioral and psychological scale of the HABC-Monitor was highly correlated (0.83) with the NPI total score, despite the fact that the NPI is a more extensive questionnaire that accounts for both frequency and severity, whereas the HABC-Monitor tool accounts only for the

frequency of problems. The 31-item HABC-Monitor also met our initial criterion of brevity, taking on average 6 minutes to complete.

Although not designed to be a screening study, the AUROC findings provide preliminary evidence that the HABC-Monitor, especially the cognitive scale, may be useful for the purposes of screening, despite the fact that the HABC-Monitor was developed primarily for the purpose of assessing and monitoring the severity of dementia-related symptoms. This may be largely due to the fact that the cognitive scale contains six of the eight items of the AD8, a dementia screening tool that has been validated in clinical and research samples against gold standard clinical and neuropsychological evaluations^{12,13} and against biomarkers of Alzheimer's disease.²⁶ The operating characteristics of the HABC-Monitor, when compared with the NPI and MMSE, were encouraging, given that the gold standard clinical diagnoses were not obtained as part of this study design. Instead, the gold standard diagnoses were obtained, along with the MMSE, from the HABC intake and Consortium to Establish a Registry for Alzheimer's disease data 1–12 months earlier than the present study's baseline instruments (HABC-Monitor, NPI). For the data that were administered at the same time as the HABC-Monitor (ie, NPI), the HABC-Monitor behavioral/psychological and total scores demonstrated AUROC values that were comparable with AUROC values of the more detailed, but more time-consuming, NPI which is based on structured interview. The NPI is highly reliable and valid, and extremely useful for research studies and perhaps for clinic settings that have protected or funded time for longer instruments. The NPI-Q¹⁵ is a briefer and clinically practical version of the NPI; however, for the purpose of monitoring symptoms with a brief tool that includes not only behavioral and psychological but also cognitive and functional domains, the HABC-Monitor demonstrates validity for research while also being useful for monitoring symptoms in the clinic.

The closest existing multidimensional instrument we found to the HABC-Monitor for capturing dementia-related symptoms through the caregiver in a brief tool is the Dementia Severity Scale. This 47-item scale measures symptoms in the cognitive, functional, and behavioral domains, and has demonstrated good internal consistency, test-retest reliability, and construct validity. The Dementia Severity Scale is slightly longer than the HABC-Monitor (47 versus 31 items). An important content difference between the HABC-Monitor and the Dementia Severity Scale is that the latter does not contain any items that assess mood (depressive

or anxiety) symptoms, which are common in patients with cognitive impairment. The Relevant Outcome Scale for Alzheimer's Disease (ROSA) is a 16-item observer rating scale but requires a trained observer.²⁷ The ROSA uses one to five items to tap symptom domains of patient cognition, communication, function/activities of daily living, behavior, quality of life, and caregiver burden.²⁷ The ROSA demonstrated good internal consistency and inter-rater reliability and validity, including sensitivity to change. However, the ROSA demonstrated only two factors in a factor analysis, one factor related to cognition, communication, function, quality of life, and caregiver burden, and another factor consisting of all behavior items. In addition, the ROSA took an average of 13-15 minutes to complete. Furthermore, important from our perspective, like the Dementia Severity Scale, the ROSA does not include depression or anxiety symptoms in the psychological or behavioral domain.

The HABC-Monitor is brief enough to be printed on one side of a single page in order to maximize clinical utility, yet it includes enough items to demonstrate confirmed multidimensionality in a factor analysis in which each domain exhibits its own factor.

Limitations

The MMSE data and clinical diagnoses were collected up to one year earlier than the baseline administration of the HABC-Monitor. Therefore, our results for known-groups validity and operating characteristics of the HABC-Monitor may have underestimated true magnitudes. Although the study design was severely biased against the HABC-Monitor for these two pieces of validity, the findings were positive for the HABC-Monitor. The known-groups validity was strong. The preliminary results for operating characteristics were encouraging because the HABC-Monitor performance was comparable with the AUROC when administered at the same time as the lengthier gold standard instrument for behavioral and psychological symptoms (NPI). Although the AUROC values were somewhat higher for the MMSE than for the HABC-M cognitive scale, this was expected because the MMSE was administered during the same visit as that during which the clinical diagnoses were made. The absolute values of the AUROC for the HABC-Monitor cognitive scale were reasonably high given the circumstance that the clinical diagnoses were rendered up to one year earlier than administration of the HABC-Monitor. Furthermore, the six-item HABC-M cognitive scale is much briefer than the 30-item MMSE. Therefore, the performance of the HABC-M cognitive scale compared with the MMSE is

encouraging; however, these results are only preliminary and more validation is needed. Future studies should assess the diagnostic accuracy of the HABC-Monitor compared with other instruments, such as the MMSE, as part of a more suitable screening study design in which ample patients are represented for each of three groups (normal, mild cognitive impairment, and dementia), and in which all instruments are assessed at the same time as the gold standard clinical diagnoses.

The development of the HABC-Monitor was in a memory care practice setting where the prevalence of dementia and other cognitive impairment is high. Validating the HABC-Monitor in other settings such as primary care is a reasonable next step. The sensitivity to change of the HABC-Monitor was evaluated over a 3-month period. Future projects will validate the HABC-Monitor in primary care to assess sensitivity to change over longer periods. Thus, although the HABC-Monitor demonstrated good reliability and validity in the present study, more validation studies are needed.

Clinical implications

Patients and informal caregivers enrolled in this study were recruited from our Healthy Aging Brain Center. There were possible effects of the memory care practice on the quality of lives of not only the patients but also the informal caregivers who were enrolled in the study. The biopsychosocial interventions that are delivered by our memory care practice are delivered to both the patients and their informal caregivers. Such an intervention is based on our previous successful demonstration of the collaborative care model for dementia. ^{4,6} This center is a memory care practice that has translated the collaborative care models for dementia⁴ and depression²⁸ into a self-sustained clinical program. ⁶

The collaborative care models for dementia and depression have been successfully able to improve the behavioral, psychological, and mood symptoms of patients suffering from dementia or depression. Based on the present findings and the published literature on the dementia collaborative care model,⁴ as well as our clinical experience in the Healthy Aging Brain Center,⁶ we believe that the HABC-Monitor will benefit patients with Alzheimer's disease, their informal caregivers, and dementia care clinicians of all disciplines by providing clinicians with more frequent, more reliable, and more useful information, making it possible to modify care plans as needed to target problem symptoms more effectively. Better dementia symptom management improves quality of life for both the patient and their informal caregiver.

Disclosure

Author (MB) was the principal investigator of this study. This work was funded by grants from National Institute on Aging (P30AG024967), National Institute of Mental Health (R24MH080827), and Agency for Healthcare Research and Quality (R01 HS019818-01). Dr Galvin's time contribution was supported as part of a grant from National Institute on Aging (R01 AG040211). The HABC-Monitor is a copyrighted instrument by Drs Boustani, Galvin and Callahan and the Indiana University School of Medicine. The HABC-Monitor and scoring rules are available at http://www.wishard.edu/our-services/senior-care/healthy-aging-braincenter/cgm

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Appendix

Items of the HABC-Monitor

Over the past two weeks, how often did your loved one have problems with:

Cognitive items

- I Judgment or decision-making
- 2 Repeating the same things over and over, such as questions or stories
- 3 Forgetting the correct month or year
- 4 Handling complicated financial affairs, such as balancing checkbook, income taxes, and paying bills
- 5 Remembering appointments
- 6 Thinking or memory

Functional items

- 7 Learning how to use a tool, appliance, or gadget
- 8 Planning, preparing, or serving meals
- 9 Taking medications in the right dose at the right time
- 10 Walking or physical ambulation
- II Bathing
- 12 Shopping for personal items like groceries
- 13 Housework or household chores
- 14 Leaving her/him alone
- 15 Her/his safety
- 16 Her/his quality of life
- 17 Falling or tripping

Behavioral and psychological items

- 18 Less interest or pleasure in doing things, hobbies, or activities
- 19 Feeling down, depressed, or hopeless
- 20 Being stubborn, agitated, aggressive, or resistive to help from others
- 21 Feeling anxious, nervous, tense, fearful or panic
- 22 Believing others are stealing from them or planning to harm them
- 23 Hearing voices, seeing things, or talking to people who are not there
- 24 Poor appetite or overeating
- 25 Falling asleep, staying asleep, or sleeping too much
- 26 Acting impulsively, without thinking through the consequences of her/his actions
- 27 Wandering, pacing, or doing things repeatedly

Caregiver quality of life items

Over the past two weeks, how often did you have problems with:

- 28 Your quality of life
- 29 Your financial future
- 30 Your mental health
- 31 Your physical health

Note: A full copy of the HABC-Monitor is available at http://www.wishard.edu/our-services/senior-care/healthy-aging-brain-center/cgm.

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