NACC FTLD Module Training: Behavior Assessments

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Behavior Measures

- Face-to-face tests for patient
 - Social Norms Questionnaire (SNQ22) 3 minutes
 - Dynamic Affect Recognition Test (DART) 5 minutes
- Clinical checklist for neuropsychologist
 - Social Behavior Observer Checklist (SBOCL2) 3 minutes
- Questionnaires on which informants describe the patient's typical behavior
 - Interpersonal Reactivity Index (IRI) 14 questions
 - Revised Self-Monitoring Scale (RSMS) 13 questions
 - Behavioral Inhibition Scale (BIS) 7 questions

Goal was to be quick, low-tech, & non-copyrighted

CONSTRUCT BEING MEASURED

bvFTD patients selectively ignore social norms in real life behavior ("acquired sociopathy"; "social dysdecorum")

- current clinical wisdom suggests they know the rule, but can't/won't follow it when the situation arises
- but evidence suggests they actually develop deficits accessing/correctly representing the rules
- SNQ22 measures patients' ability to identify inappropriate behavior in hypothetical social scenarios

STRUCTURE OF TEST

- 22 yes-no questions
- Asks subjects to determine whether or not a behavior would be appropriate in the presence of an acquaintance (not a close friend or family member) according to "mainstream" culture

% NCs answering correctly **Sample Questions** Cut in line if you are in a hurry? (N) 100% Eat pasta with your fingers? (N) 91% Tell a coworker your age? (Y) 83% Tell someone your opinion of a movie they haven't seen? (Y) 87% Laugh when someone trips and falls? (N) 100% Tell someone the ending of a movie they haven't seen (N) 96% Tell a stranger you like their hairstyle? (Y) 87%

SUBSCALES

1. Overadhere errors

- Can be conceptualized as a control task
- Many patients with different neurodegenerative diseases get some of these wrong due to confusion, inattention, anxiety, general cognitive deficits

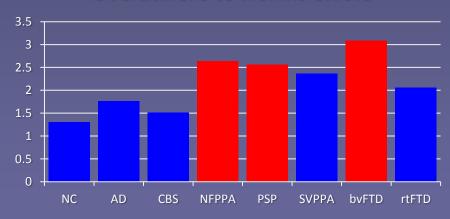
2. Break norms errors

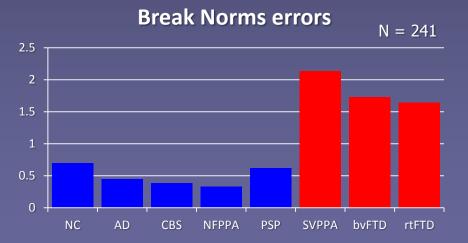
Very unusual to see errors with anyone other than bvFTD patients

Is it OK to eat ribs with your fingers? "No"

Is it OK to cut in line if you are in a hurry? "Yes"

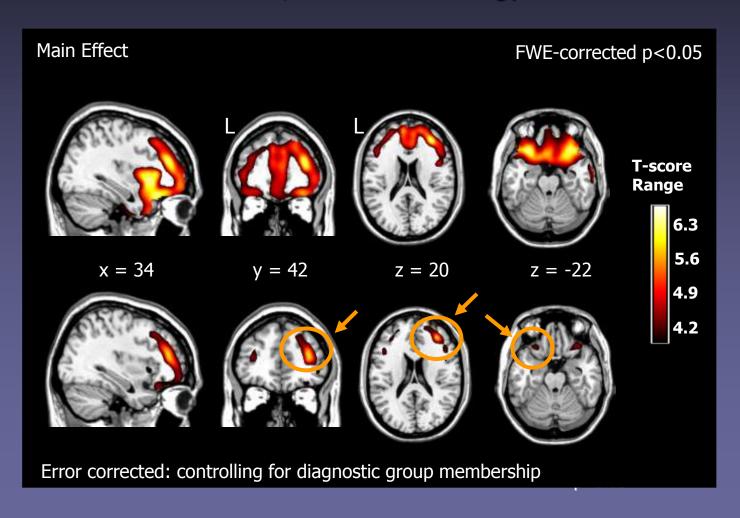
Overadhere to Norms errors



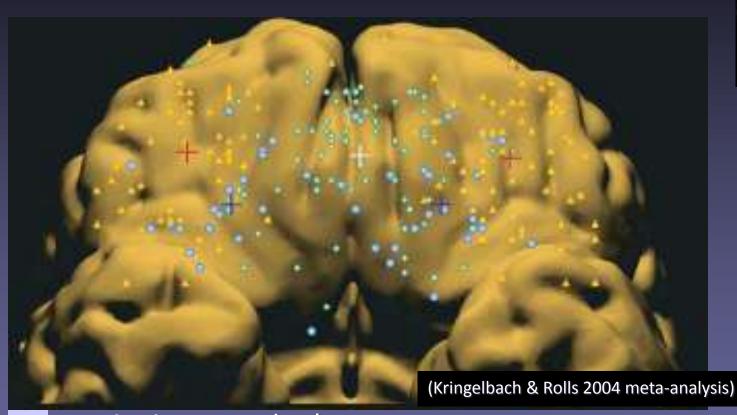


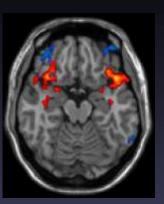
ANATOMIC CORRELATES

L>R ventrolateral OFC, R middle frontal gyrus

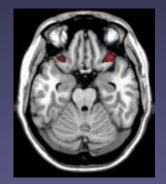


Lateral orbitofrontal cortex function





(Seeley, 2007)



(Our study)

monitoring reward value motivation-independent reinforcer representation punishers leading to change in behavior

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<u>ADMINISTRATION</u>

- To be completed by the subject in the presence of a qualified psychologist or psychometrist during face-to-face testing.
- The examiner should read and explain the instructions to the subject, then ask the subject to complete the questionnaire.

COMMON ADMNISTRATION ISSUES

If the patient asks for clarification of the procedure or questions, the examiner may discuss the questionnaire with him or her:

- Reading questions out loud? OK
- Marking their response for them? OK
- Repeating/closely rephrasing the question? OK
 E.g. "Do you think it's OK to cut in line if you are in a hurry?")
- Helping them think through their answer? NO

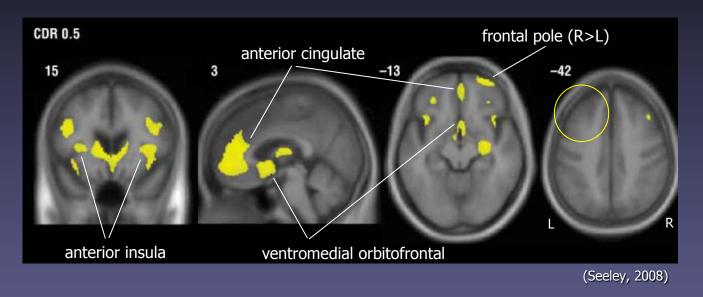
Encourage patients to guess if they are unsure or hesitant, e.g.

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"It's up to you."
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"Answer whatever you think is best."

"It's OK to guess if you're not sure."

CONSTRUCT BEING MEASURED



CDR 1 CDR 2-3

L>R dorsolateral frontal atrophy, corresponding to standard neuropsychological tests of executive functioning, occurs later in the course of bvFTD

CONSTRUCT BEING MEASURED

Many aspects of spontaneous interpersonal, emotional, and task-oriented behavior are represented

These are not all bvFTD-specific, but taps into typical behaviors seen in other neurodegenerative diseases as well:

- Temporal patients, i.e., svPPA with some right-sided involvement:
 adherence to routine, resistance to redirection, monologuing
- Alzheimer's: self-consciousness, anxiety, emotional dependence
- Lewy body disease: fluctuations in attention, loss of set

STRUCTURE OF TEST

14 descriptors:

- Rated on 1-4 scale (not at all, a little bit, moderately, severely)
 - Was overly self-conscious/embarrassed for self
 - Insensitive to others' embarrassment or privacy
 - Was preoccupied with time or kept a strict timetable
 - Lost track of testing parameters, required reorientation

35 checklist items:

- Behavior counts (never, once, 2-3 times, 4+ times)
 - Engaged in belching, flatulence, or nose-picking without apology
 - Physically attempted to leave examination prematurely
 - Made self-critical comments during testing
 - Demanded test protocol be broken for them

STRUCTURE OF TEST

12.	Was overly disclosing or inappropriately familiar:	o Not at all	☐ 1 A little bit	2 Moderately	☐ 3 Severely
	Spontaneously revealed inappropriately personal information concerning self (only)	o Never	☐s Once	☐ z 2-3x	□3 4+
	 Spontaneously revealed inappropriately personal information concerning a relative or friend (can also involve self) 	□o Never	1 Once	□ 2 2-3x	□3 4+
	 Stood or leaned too close to examiner (noticeably entered examiner's personal space) 	□o Never	☐₁ Once	□2 2-3x	□3 4+
	d. Touched examiner	o Never	1 Once	2 2-3x	□3 4+
13.	Showed diminished social / emotional engagement:	o Not at all	☐1 A little bit	2 Moderately	☐ 3 Severely
14.	Showed exaggerated / labile emotional reactivity:	□ n Not at all	☐ 1 A little bit	2 Moderately	3 Severely

ADMINISTRATION

- This form is to be completed by the qualified psychologist or psychometrist who administered the neuropsychological battery to the subject.
- Complete this immediately after the end of the evaluation!
- Check only <u>one</u> box per question.
- Note the amount of time during which this behavioral sample was taken, i.e., how long did cognitive testing take?
 - Does not need to be a standard amount of time
 - However, NACC rules require more than 30 minutes of testing
 - Upper limit is flexible, but may be flagged (can be cleared with explanation from the center) if >4 hours

COMMON ADMNISTRATION ISSUES

EXAMPLE 1:

Item 5 DESCRIPTOR: Was preoccupied with time or kept a strict timetable

 You think this is true of the patient, so you mark "moderately" for this item

Item 5 BEHAVIOR COUNT: Reminded examiner what time evaluation had to be finished

The patient never did this, so you mark "zero"

This is OK! The behavior counts are simply a sample of common behaviors, and do not need to be present for you to endorse a symptom on the related descriptor

COMMON ADMNISTRATION ISSUES

EXAMPLE 2:

Item 12 DESCRIPTOR: Was overly disclosing or inappropriately familiar

 You think this was not true of the patient, so you mark "not at all" for this item

Item 12 BEHAVIOR COUNT: *Touched examiner*

The patient did this, so you mark "once", but it was in an appropriate manner based on the social context

This is OK! If you see a behavior, mark it down, even if you don't believe it occurred in the context of a larger behavioral trait. You don't need to endorse the related descriptor

CONSTRUCT BEING MEASURED

Empathy: This scale measures both cognitive and emotional facets of empathy occurring in everyday social interactions.

- Originally created by Mark Davis in 1980
- We are using two of the four subscales that are part of the full IRI (leaving out Fantasy and Personal Distress subscales)

SUBSCALES

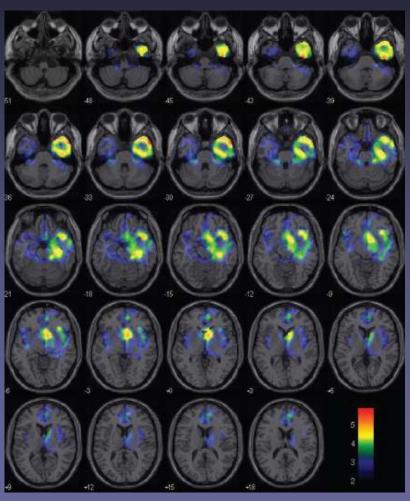
- Perspective Taking (PT): Measures subjects' tendency to spontaneously think of the perspective of others (COGNITIVE EMPATHY)
 - "The patient believes there are two sides to every question and tries to look at them both."
- Empathic Concern (EC): Measures the other-centered emotional response resulting from the perception of another's emotional state (EMOTIONAL EMPATHY)
 - "If the patient sees someone being taken advantage of, they feel protective towards them."

STRUCTURE OF TEST

- Informant completes the questionnaire describing the patient as they are NOW
- 14 items on a 5-point Likert scale (0 = Does NOT describe well . . . 5 = Describes VERY well)

		Does NOT describe well	←		→	Describes VERY well
5.	If the subject sees somebody being taken advantage of, the subject feels kind of protective towards him/her.		2	З	4	5
6.	The subject is likely to try to understand others better by imagining how things look from their perspective.		2	З	4	5
7.	Other people's misfortunes do NOT usually disturb the subject a great deal.		2	3	4	5
8.	If the subject is sure he/she is right about something, he/she doesn't waste much time listening to other people's arguments.			3	4	5
9.	If the subject sees someone being treated unfairly, the subject doesn't feel much pity for him/her.		2	З	4	5

ANATOMIC CORRELATES



Regions where empathy score positively correlates with tissue density

- Predominantly right-sided
- Medial and anterior temporal
- Ventromedial orbitofrontal
- Pregenual cingulate

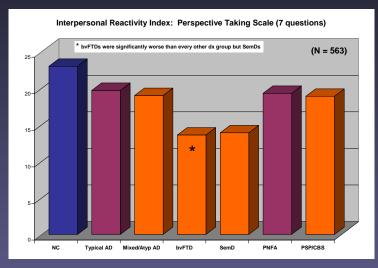
Unthresholded map: 2.0 < T < 6.0

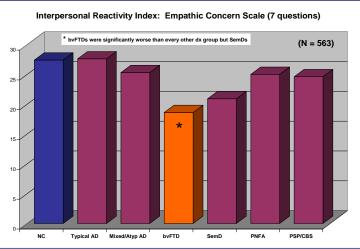
EXPECTED NORMAL PERFORMANCE

 Based on >100 well-characterized, neurologically and psychologically healthy older controls aged 40-90 in San Francisco

		MEAN	Std Dev
MALES	Perspective Taking (max=35)	23.1	6.8
	Empathic Concern (max=35)	26.3	5.9
FEMALES	Perspective Taking	24.5	5.5
	Empathic Concern	28.6	4.5

EXPECTED PATIENT PERFORMANCE





- bvFTD patients score pathologically low on both PT and EC scales
- svPPA patients will score low on both scales to the degree that they have right temporal involvement
- AD patients will score normally on EC, but lower on PT if they have significant executive dysfunction or comorbid pathology (vascular, DLB)

CONSTRUCT BEING MEASURED

"Social Intuition": This scale measures the degree to which an individual is sensitive and responsive to subtle social cues, particularly those that suggest a change in behavior.

- Originally created by Lennox & Wolfe in 1984
- Not to be confused with Snyder's Revised Self-Monitoring Scale, which is actually about self-monitoring, and has poor psychometric validity

SUBSCALES

- Sensitivity to Expressive Behavior of Others (RSMS_EX):
 - "The patient can usually tell when others consider a joke to be in bad taste, even though they may laugh convincingly."
 - "The patient can usually tell when he or she has said something inappropriate by reading it in the listener's eyes."
- Tendency to Monitor Self-Presentation (RSMS_SP):
 - "In social situations, the patient has the ability to alter his or her behavior if he or she feels that something else is called for."
 - "The patient has the ability to control the way he or she comes across to people, depending on the impression he or she wants to give them."

STRUCTURE OF TEST

- Informant completes the questionnaire describing the patient as they are NOW
- 13 items on a 6-point Likert scale (0 = Certainly, always false. . . 5 = Certainly, always true)

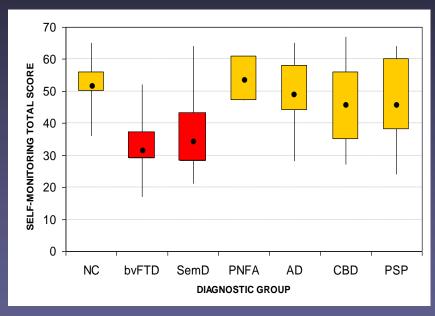
		Certainly, always false (0)	Generally false (1)	Somewhat false, but with exceptions (2)	Somewhat true, but with exceptions (3)	Generally true (4)	Certainly, always true (5)
9.	The subject has trouble changing his/her behavior to suit different people and different situations.	0		2	3	4	5
10.	The subject can adjust his/her behavior to meet the requirements of any situation he/she is in.	o		2	3	4	5
11.	If someone is lying to the subject, he/she usually knows it at once from that person's manner or expression.	o		2	3	4	5
12.	Even when it might be to his/her advantage, the subject has difficulty putting up a good front.	0			3	4	5
13.	Once the subject knows what the situation calls for, it's easy for him/her to regulate his/her actions accordingly.	o		2	З	4	5

EXPECTED NORMAL PERFORMANCE

 Based on >100 well-characterized, neurologically and psychologically healthy older controls aged 40-90 in San Francisco

		MEAN	Std Dev
MALES	EX: Sensitivity to Expression (max=30)	27.3	4.0
	SP: Self-Presentation (max=35)	33.5	6.2
	RSMS TOTAL	60.7	7.7
FEMALES	EX: Sensitivity to Expression	28.4	4.3
	SP: Self-Presentation	33.1	4.5
	RSMS TOTAL	61.4	8.2

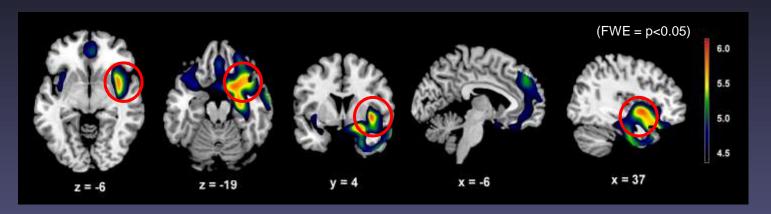
EXPECTED PATIENT PERFORMANCE



N=155

- bvFTD patients score pathologically low on both EX and SP scales
- svPPA patients will score low on both scales to the degree that they have right temporal involvement
- Other patient groups perform normally

ANATOMIC CORRELATES

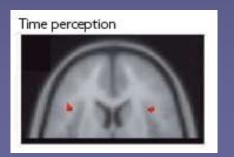


OPINION

How do you feel — now? The anterior insula and human awareness

A. D. (Bud) Craig

"Feeling of knowing"





- Damage to these rightsided medial frontotemporal limbic areas directly predicts behavior
- Insula = limbic sensory (awareness)

CONSTRUCT BEING MEASURED

Self-criticism: Measures the tendency towards behavioral inhibition in response to anticipated punishment, in the form of withdrawal-related behavior traits such as

- Self-criticism
- Sensitivity to punishment cues
- General social anxiety
- Carver & White developed measure in 1994
- Half of the "BIS/BAS", measuring both reward and punishment sensitivity
- Numerous behavioral and physiological studies in healthy subjects and neurologic patients suggest that the BIS is sensitive to right frontal circuits mediating withdrawal behaviors

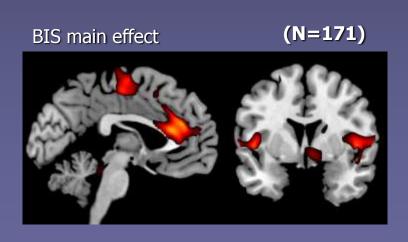
STRUCTURE OF TEST

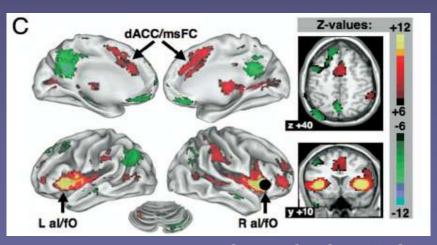
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7 items on a 4-point Likert scale
(1 = strongly disagree. . .4 = strongly agree)
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- "The patient worries about making mistakes"
- "Even if something bad is about to happen to the patient, s/he rarely experiences fear or nervousness."
- "Criticism or scolding hurts the patient quite a bit."

ANATOMIC CORRELATES

- R dorsal "task control" network structures
 - Dorsal anterior cingulate (exerts top-down control)
 - Frontal operculum (maintains task rules)
 - middle frontal gyrus (working memory)
- Help us remain focused on tasks, including the maintenance of social concern





(Dosenbach, 2007)

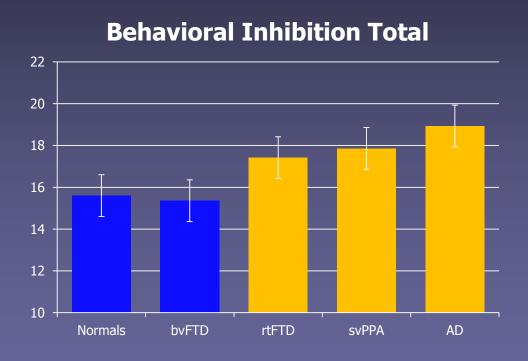
EXPECTED NORMAL PERFORMANCE

- Based on the literature: Mean=20.0 (SD = 3.79)
- Based on >100 well-characterized, neurologically and psychologically healthy older controls aged 40-90 in San Francisco, the numbers are lower (overall: 15.6 +/- 3.3)

max=28	MEAN	Std Dev
MALES	15.3	3.3
FEMALES	15.9	3.4

We don't see gender differences for this

EXPECTED PATIENT PERFORMANCE



- Expected to be LOW to NORMAL in bvFTD
- Only elevated in other disorders (especially AD)
- Also elevated in right temporal FTD

<u>ADMINISTRATION – GENERAL</u>

- These should be completed independently by the informant, who will be describing the subject's typical behavior at the current time.
- This form may be handed to the informant for completion alone at any time during the study visit.

<u> ADMINISTRATION – GENERAL</u>

- If the informant asks for clarification, a qualified psychologist or psychometrist may discuss the questionnaire with them.
- However, if the informant completes this questionnaire collaboratively with the clinician, either face-to-face or via telephone, you must inform NACC of this change in protocol by checking the appropriate box in the gray "FOR CLINIC USE ONLY" area at the top of the questionnaire.
 - This is because people will respond differently in front of or directly to an examiner than they will on a piece of paper, and questionnaires completed this way may have a systematic bias.

COMMON ADMNISTRATION ISSUES

Example 1: The informant turns in the questionnaire but has not answered questions they found too difficult.

Plan A: This is a very common problem. Check the questionnaire over immediately when the informant hands it to you, and then ask them to please revisit any items you find blank. (At this point, you may find it necessary to clarify an item or encourage the informant.)

Plan B: If you don't realize that the form is incomplete until after the informant has left, it is OK to follow-up via phone and get their responses to the items (just inform the NACC)

COMMON ADMNISTRATION ISSUES

Example 2: The informant says "I don't know what the right answer is", or is resistant to answering.

Encourage the informant by:

- Emphasizing that this is a subjective test, and that we only want their opinion about it
- Encourage them to just put whatever seems best
- Tell them it's OK if they are not sure.

COMMON ADMNISTRATION ISSUES

Example 3: The informant does not want to complete the questionnaire alone and asks for your help.

- This is OK, just make sure to check the correct box.
- Similarly to aiding a patient in neuropsychological testing:
 - Reading questions out loud? OK
 - Marking their response for them? OK
 - Repeating/closely rephrasing the question? OK
 - Reiterating anchor points? OK
 - Tell them what you've observed about the patient? NO
 - Tell them what you think they should answer based on how they are describing the behavior to you? OK

If you have additional questions, or are interested in additional face-to-face tests of social behavior/cognition, feel free to email me:

krankin@memory.ucsf.edu