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Observational themes of social behavioral disturbances in frontotemporal dementia

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ABSTRACT

Background: Caregivers report early disturbances in social behavior among patients with behavioral variant frontotemporal dementia (bvFTD); however, there are few direct observational studies of these social behavioral disturbances. This study aimed to identify social behavioral themes in bvFTD by direct observation in naturalistic interactions. The identification of these themes can help caregivers and clinicians manage the social behavioral disturbances of this disease.

Methods: Researchers observed 13 bvFTD patients in their homes and community-based settings and recorded field notes on their interpersonal interactions. A qualitative analysis of their social behavior was then conducted using ATLAS.ti application and a constant comparison method.

Results: Qualitative analysis revealed the following themes: (1) diminished relational interest and initiation, indicating failure to seek social interactions; (2) lack of social synchrony/intersubjectivity, indicating an inability to establish and maintain interpersonal relationships; and (3) poor awareness and adherence to social boundaries and norms. These themes corresponded with changes from caregiver reports and behavioral scales.

Conclusion: This analysis indicates that real-world observation validates the diagnostic criteria for bvFTD and increases understanding of social behavioral disturbances in this disorder. The results of this and future observational studies can highlight key areas for clinical assessment, caregiver education, and targeted interventions that enhance the management of social behavioral disturbances in bvFTD.

Key words: Behavioral variant frontotemporal dementia, social behavior in dementia, observational study, intersubjectivity in dementia, early onset dementia

Introduction

Behavioral variant frontotemporal dementia (bvFTD) is a neurodegenerative disease that results in social behavioral disturbances. BvFTD strikes the neural regions involved in social behavior including emotional expression (Joshi *et al.*, 2014), social bonding (Mendez *et al.*, 2013a), empathy (Rankin *et al.*, 2005), theory of mind (Pardini *et al.*, 2013), and awareness of self and others (Mendez and Lim, 2004). Individuals with bvFTD commonly violate social or moral norms and fail to appreciate the impact of their actions on others (Mendez and Shapira, 2011). For the family members and caregivers of bvFTD patients, disturbances in social behavior are associated with significant caregiver burden and depression (Passant *et al.*, 2005; Diehl-Schmid *et al.*, 2013).

The social disturbances in bvFTD pose unique challenges in recognition and diagnosis. Most information on these disturbances come from caregiver reports, rather than direct examination or observation. The patients themselves lack insight into their behavioral changes and fail to report them. Therefore, the diagnosis of bvFTD usually depends on the availability and accuracy of reports of patients' social behavior. Moreover, in the clinic, providers often fail to recognize that changes in social behavior indicate symptoms of dementia, which may lead to delayed or incorrect diagnoses and ineffective intervention (Rankin *et al.*, 2008).

The recognition of social behavioral disturbances in bvFTD is most evident in descriptive, qualitative

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investigation involving direct observation of their social interactions (Mendez *et al.*, 2013b). For example, one observational study of bvFTD found more pervasive environmental dependency behaviors among bvFTD patients compared to those with Alzheimer's disease (AD) (Ghosh *et al.*, 2013). Another observation study found that apathy, disinhibition, failure to maintain eye contact and initiate interactions, and a lack of concern with meeting clinicians' expectations were prevalent in bvFTD (Rankin *et al.*, 2008). In one of the few observational studies in naturalistic settings in bvFTD, investigators found significantly decreased "you" comments and tact and manners among those with bvFTD as compared to those with AD (Mendez *et al.*, 2013a).

The aim of the current study is to expand on this literature by utilizing behavioral observation and qualitative methodology to identify the social categories or themes disturbed in bvFTD in natural settings. The presence of social behavioral disturbances are most evident and valid when observed in patients' most natural and familiar settings, such as their homes (Black and Rabins, 2007; Han *et al.*, 2013). Thus, among patients with bvFTD, the current study predicts real-world disturbances in basic social themes, which can be targeted for improvements in the diagnosis and management of these patients.

Methods

Participants

Participants were recruited from the UCLA Behavioral Neurology Clinic upon approval from the Institutional Review Board. The participants were community-based bvFTD patients who completed clinical neurobehavioral, neuropsychological and neuroimaging evaluations. Patients with severe comorbid medical, neurologic, or psychiatric disorders were excluded. The bvFTD participants ($n = 13$) were diagnosed based upon revised International consensus diagnostic criteria for bvFTD (Rascovsky *et al.*, 2011) and supported by frontotemporal hypometabolism on fluorodeoxy-glucose positron emission tomography imaging. The clinical features of bvFTD was further characterized by the Clinical Dementia Rating Scale (CDR) (O'Bryant *et al.*, 2010), the Functional Activities Questionnaire (FAQ) (Pfeffer *et al.*, 1982), the Center for Epidemiologic Studies Depression Scale (CES-D) (Carleton *et al.*, 2013), the Neuropsychiatric Inventory (NPI) (Cummings *et al.*, 1994), and the Frontal Systems Behavior Scale (FrSBe) (Grace and Malloy, 2001).

Procedures

Observational method

Onsite. Observation of participants occurred in social interactions associated with three separate research visits, but outside of formal testing scenarios. Researchers took walks ($n = 6$), ate meals and snacks ($n = 8$), and spent time in waiting rooms with patients and their caregivers ($n = 11$). A single researcher also visited each participant one to three times for three to four hours each visit, including: personal homes ($n = 12$), residential neighborhoods ($n = 6$), local parks ($n = 4$), car rides ($n = 3$), coffee shops ($n = 3$), department stores ($n = 2$), bus stops ($n = 2$), and restaurants ($n = 2$). Researchers documented observations directly afterward in field notes and audio-recorded memos, and strove to utilize descriptive and objective language in recording interactions to reduce bias. Reflexive statements involving observational views about patients' behaviors were documented in order to recognize and exclude any researcher interpretation of the data during data collection.

Coding and theme development

The total textual corpus of field notes included 40 documents comprising 74 single-spaced pages with a 45,278-word count. Observational field notes were transcribed in ATLAS.ti (a qualitative data analysis software package). A team of independent raters, not involved in data collection reviewed the textual corpus for emergent patterns using open, line-by-line coding to develop a codebook of behavioral themes (Glaser, 1992). The independent rater team utilized an iterative process of written memos and audit trail of emergent concepts to identify unrecognized concepts not previously captured in the coding process. Concepts were regarded as essential if they described social phenomena and recurred throughout the field notes and across participants. A constant comparison method (Glaser, 1992) was utilized to identify and tag subsequent themes. Axial coding combined an inductive and deductive process to sort and sift data, as well as describe and condense concepts into broader themes (Eaves, 2001; Charmaz, 2006; Corbin and Strauss, 2007). The code-building process concluded upon consensus that the list of codes captured the most inclusive and comprehensive framework regarding the specified study aims. Once the corpus reached saturation through constant comparison, the entire transcript text was exported from ATLAS.ti at the theme and subtheme level.

Table 1. Participants demographics (Total $n = 13$)

	MEAN (S.D.)	RANGE
Age (years)	61.39 (9.62)	(45–76)
Estimated age of onset	58.31 (9.53)	(43–74)
Time since onset (years)	3.08 (1.04)	(2–5)
Education (years)	15.31 (2.39)	(12–20)
Mini-mental state examination	24.62 (3.53)	(16–30)
Clinical dementia rating global score	1.08 (0.45)	(0.5–2.0)
Clinical dementia rating sum of boxes	6.54 (2.08)	(3–11)
Functional Activities Questionnaire	16.85 (6.72)	(1–25)
Center Epid. Studies Depression Scale	16.09 (14.63)	(1–39)
Neuropsychiatric Inventory	Freq.XSeverity	Caregiver Distress
Appetite/ Eating changes	7.83 (3.38)	1.42 (1.62)
Apathy/ Indifference	7.17 (3.54)	2.33 (1.56)
Aberrant motor behavior	7.08 (3.45)	2.08 (1.56)
Disinhibition	6.17 (4.51)	2.92 (1.73)
Agitation/ Aggression	4.29 (2.05)	3.14 (1.57)
Frontal Systems Behavior Scale	Before	After
Apathy	20.00 (4.24)	46.92 (9.10)
Disinhibition	23.17 (5.79)	39.75 (15.33)
Executive dysfunction	27.83 (8.20)	67.25 (14.21)
Total score	71.00 (16.64)	153.92 (30.68)

Results

Clinical features of the sample (see Table 1)

The bvFTD group was composed of 5 women and 8 men and were 85% White. The dementia severity of the group was mild to moderate on the CDR with impairment in independent completion of instrumental activities of daily living on the FAQ. The CES-D was not indicative of significant depression, but the NPI disclosed five common neuropsychiatric symptoms: appetite/eating changes ($n = 12$), apathy/indifference ($n = 12$), aberrant motor behaviors ($n = 12$), disinhibition ($n = 12$), and agitation/aggression ($n = 7$). On the FrSBe, participant caregivers reported pre- to post- disease increases in apathy, $t(11) = 10.60$, $p < 0.001$, disinhibition, $t(11) = 3.54$, $p < 0.001$, and executive dysfunction $t(11) = -9.11$, $p < 0.001$ (Total Score pre- to post- change was $t(11) = 8.69$, $p < 0.001$)

Three main social themes with their common subthemes were generated from iterative category development (See Table 2). These three main themes were (1) Diminished relational interest and initiation in seeking social interactions; (2) Lack of social synchrony/intersubjectivity (establish, maintain relationships); and (3) Poor awareness and adherence to social boundaries and norms. Descriptions of the three themes are provided below along with italicized examples listed below were deemed most representative for their subthemes.

Diminished relational interest and initiation in seeking social interactions

This category pertained to initiation of social contact, apparent interest in engaging in interaction, and attachment/ proximity seeking behaviors. This theme differs from the subsequent theme, *lack of social synchrony/ Intersubjectivity,* as this category was specific to the primary or initial demonstration of social drive, described as an impetus to begin an interaction. The construct conceptually corresponds with attachment seeking behavior, and establishing social bonds (Magai and Cohen, 1998).

Failed social engagement

On multiple occasions, participants demonstrated lack of social connection, leaving others feeling unheard, ignored, and relationally frustrated, for example: *Mr. A was involved in a card game but doesn't seem to care what is going on during the game... He isn't paying attention to the game; he seems careless... He never reacts to being corrected [i.e. multiple attempts by others to engage his interest in the social situation].*

Ignores/disinterested in questions

This subtheme included instances in which participants were frequently disinterested or ignored the researchers' or family members' questions. *The [female] participant is very concentrated on this puzzle and she does not take her gaze off of it [even when others are having conversations]. She did not look around or*

Table 2. ATLAS.ti major themes and subthemes

Themes/Subthemes
(1) Diminished relational interest and initiation in seeking social interactions
Fails to socially engage
Ignores/ disinterested in questions
Does not initiate conversation
Absence of appropriate relational affect
Lack of initial concern for others
(2) Lack of Social Synchrony/Intersubjectivity (establish, maintain relationships)
Abnormal social responses
Short answers, brief or impoverished verbal content
Absence of questions about self and others
Lack of empathic responding
Impulsive answers
Triggers frustration in relationship/observer
(3) Poor Awareness and Adherence to Social Boundaries and Norms
Unawareness of correct social boundaries or distances (Verbal or Nonverbal)
Inappropriate humor/laughter
Over self-disclosure
Inappropriate bathroom behavior
Absence of politeness (e.g. use of please and thank you)
Violations of table manners

make eye contact with family members when they called to her.

Does not initiate conversation

The participants often failed to initiate conversations or interject themselves into ongoing conversations, showing a lack of relational interest. *He had a somewhat blank, direct look when I first walked in [to meet him]. No smile recognition, [no change in his face, in response to my presence]. In response to [my greeting] "I'm [name]", he said "ok" with no smile or change in expression.*

Lack of social synchrony/intersubjectivity (establish, maintain relationships)

The theme focuses on behaviors involved in establishing and maintaining the reciprocal sending and receiving of signals in social interaction. Examples of this theme include the length and depth of interactions, the degree of engagement, the presence of empathic responses, and the appropriateness or thoughtfulness of responses.

Abnormal social responses

This subtheme included un-prefaced or tangential interruptions or interjections to conversation or a failure to respond in a manner that facilitated or sustained an interaction. [*Participants often made interjections that seemed to have salience to the participant or, alternatively, left dead space or long uncomfortable pauses in the conversation].*

Short answers, brief or impoverished verbal content

Participants demonstrated an inability to maintain social synchrony in giving short, blunt replies. *Interlocutor: Why don't you show me one of the grandkids [photo albums]? Participant: [to spouse, perplexed] Why would she want to see our photo albums? Interlocutor: [Nonverbally motioned with interest in seeing photo album of family.] Participant: [flipped through photo album quickly, said some people's names but rarely gave context; gave no stories or commentary about what was happening in the photos, despite researcher's verbal and nonverbal expression of interest].*

Absence of questions about self and others

This subtheme includes inappropriate, intrusive, tangential, or perseverative inquiries about subjects. *The participant asked repetitive questions to the researcher such as, "Are you Chinese? Do you have a boyfriend? [did not wait for or monitor researcher's response between questions] Are you Asian? . . . Thrilla in Manila [tangential reference to historic boxing match in Philippines] . . . "You can see I like Asian women [pointing to his own wife]."*

Lack of empathic responding

Several participants exhibited incongruence between conversational content and their affective responses, such as a failure to offer empathic gestures or words of consolation in response to family members' distress. *While a family film was playing, B's wife began to cry. He looked at his wife*

and did not exhibit a response to his spouse's crying or initiate any signs of affection [no attempt to comfort her] . . . [But] there was a time when B wasn't like this, before the onset of the disorder [per his wife].

Poor awareness and adherence to social boundaries and norms

This theme included violations of mainstream social norms such as physical boundaries, manners, and appropriate use of humor in social situations.

Unawareness of correct social boundaries or distances (verbal or nonverbal)

This subtheme included instances when participants would abruptly and without explanation walk away from an ongoing interaction (especially in open spaces), intrude and violate another's physical space, or make inappropriate comments. *This patient would also shout out in the elevator "this is ridiculous" a couple of times . . . stood in middle of elevator that was crowded (spatially intrusive) and blurted out "this is ridiculous and said "f*ck" as they were leaving an office. While on the elevator the patient presses all the buttons with other individuals in the elevator.*

Inappropriate humor or laughter

This subtheme includes telling inappropriate jokes, sharing humor only of relevance to the participant (devoid of context), and unprompted laughter not connected to any identifiable trigger. *The participant began laughing out loud for no apparent reason while in an aisle at the store. The patient continued to laugh and did not change his behavior; despite him seeing that [others] appeared annoyed with him. He apparently did not realize the effect he was having on them or that they were responding to his laughing.*

Over self-disclosure

Participants over-disclosed personal information pertaining to both themselves and family members that would otherwise be private, such as family secrets or private financial and medical information (e.g., sexual orientation). *He would make socially inappropriate remarks like announcing in public shopping settings [department store] "My grandson's girlfriend turned gay" or "I didn't go [to an event] because I had diarrhea . . . He also shared to strangers that he, "loved ice cream, and has Pick's disease, but does not have diabetes."*

Discussion

The current study provided concrete examples of abnormal social behaviors in bvFTD that occurred in a variety of real-life environments. Qualitative analysis yielded three primary thematic behavioral clusters which included (1) Diminished interest and initiation in seeking social interactions; (2) Lack of social synchrony (bonding or sustaining attachments) (Atzil *et al.*, 2013), and inter-subjectivity (generating and sharing meaningful experiences) (Allen and Williams, 2011); and 3) Poor awareness and adherence to social boundaries and norms. These themes catalogue specific behaviors illustrating the disconnection between patients with bvFTD and others in their environment and are consistent with their neuropsychiatric symptoms and the apathy and disinhibition seen on the NPI and FrSBe scales (Mendez *et al.*, 2008). These findings can facilitate caregiver advice and education on the management of these patients and help clinicians target their diagnostic questions.

BvFTD patients demonstrated an inability to preserve the "social glue" required to sustain connectedness. They wandered away from interactions, had intrusive behaviors, gave indifferent responses (e.g., "I don't care"), and lacked relational curiosity. The group had trouble sustaining the ebb and flow of sending and receiving interactive communication signals inherent in reciprocal socioemotional interactions. When they were able to establish a degree of basic interaction, the cognitive and affective depth of the interaction was lacking and impoverished. BvFTD patients were also typically unable to detect and/or respond to cues of emotional discomfort or frustration in observers, such as a failure to redirect prolonged gazes after the receiver exhibited discomfort. These results align with studies suggesting that bvFTD patients exhibit difficulty responding to the emotional expressions of others (Rosen *et al.*, 2006).

Assessing socioemotional deficits as part of a diagnostic workup is essential, as these features reliably distinguish bvFTD from other common dementias such as AD (Mendez *et al.*, 1998). However, few appropriate clinical assessment tools exist. The observational examples from this study can be utilized to develop effective clinical methods of assessing social deficits in these patients. The current findings can serve as a paradigm for generating observational tables, coding systems, and quantitative methods for evaluating patients with bvFTD, as well as other neurological disorders characterized by disturbances in social behavior.

In addition to helping in the diagnosis of bvFTD, clinicians can use these social behavioral themes

to educate caregivers and providers on potentially disturbed behaviors. BvFTD patients have unique caregiver needs compared to other dementias (LoGiudice and Hassett, 2005; Nunnemann *et al.*, 2012). For example, caregivers can anticipate social intrusions in more enclosed or smaller spaces, whereas they must anticipate wandering and difficulty maintaining physical interpersonal proximity in more open spaces. Given the patient's lack of concern for their own and others' privacy, caregivers may choose to refrain from disclosing new private or sensitive information to individuals with bvFTD. Furthermore, caregivers can interpret a patient's social disinterest as a symptom of the disease, rather than a willful choice to disengage. The social behavior themes described in this study can aid both caregivers and providers in meeting the unique caregiving needs of bvFTD patients (Bakker *et al.*, 2013).

There were limitations to this qualitative study. They included the potential for observer bias, small sample size, and natural restrictions of qualitative methods. Individual observer bias was probably inevitable when choosing and recording social behaviors during this observational study. Because of the labor involved in observational study of each participant, this study had a small sample of 13 participants, and this sample may not be representative of a larger bvFTD cohort. Additionally, the qualitative nature of this study limited the ability to establish frequency or prevalence of behaviors across the entire sample.

In conclusion, this study describes observable disturbances in major social behavioral themes in bvFTD and validates the diagnostic criteria for this disorder (Rascovsky *et al.*, 2011). These findings offer a source for future studies regarding behavioral phenomena in bvFTD. In particular, the use of observational research in natural settings may advance the assessment of interpersonal behaviors in this, and related disorders. Thus, future studies using this approach may yield further information regarding social functioning in bvFTD that can help in the recognition and management of this disorder (Mendez and Manes, 2011).

Conflict of interest

None.

Description of authors' roles

F. R. Nedjat-Haiem (FRN-H) (primary rater) and C. Velasco (CV) (research assistant) analyzed data and identified behavioral themes. J. Barsuglia (JB) drafted the paper. M. J. Mather (MJM) contributed to data collection and paper revision. Jimenez (EJ), J. Shapira (JS), and M. Mendez (MM) contributed to critical review and paper revision.

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