

A Psychosocial Intervention for Managing Disinhibition in People With the Behavioral Variant of Frontotemporal Dementia: A Matter of Focusing



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ABSTRACT

Management of disinhibited behavior in people with the behavioral variant of frontotemporal dementia is challenging. To support health care professionals in long-term care, we developed "Focusing," a psychosocial intervention based on theory of automatic behavior, stimulus processing, and resident-staff interactions. The intervention was evaluated for feasibility and limited efficacy with a replicated single-case A-B observation study in 6 cases, and using questionnaires and interviews with health care professionals. The intervention was feasible in all cases and a decrease in disinhibited behavior was observed following the introduction of the intervention in 4 cases. Professionals deemed the intervention highly relevant, as they perceive disinhibition as a complex problem. These results form a foundation for larger-scale evaluation of effectiveness and show promise of the intervention for further implementation in clinical practice.

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Keywords: Disinhibited behavior, frontotemporal dementia, young-onset dementia, behavioral variant, psychosocial intervention

Problem and Significance

Frontotemporal dementia (FTD) is the third most common cause of young-onset dementia (YOD), with a worldwide estimated prevalence of 2.3 per 100,000 in those aged 30–64 years.¹ Clinically, FTD can be regarded as a spectrum of symptoms encompassing 2 main syndromes: the primary progressive aphasias and the behavioral variant (bvFTD), the latter being 4 times as common.² Three of 4 people with bvFTD show disinhibited behavior, which is the inability to inhibit inappropriate behavior, resulting in socially disruptive or morally unacceptable behaviors, such as repetitive and compulsive (vocal) behavior or hypersexual behavior.³ This type of behavior generally forms a source of psychological distress for health care professionals in long-term care facilities.⁴

Despite the high prevalence and its impact, guidance on the management of disinhibition is lacking. Pharmacologic treatment is often offered, but disinhibited behavior is difficult to target, and its

benefits are both questionable and outweighed by the risks of adverse effects and polypharmacy.⁵ Psychosocial interventions in long-term care have been reported but are often designed to provide education to the caregiver, with less focus on behavioral modifications itself.^{6,7} To support health care professionals in long-term care with managing disinhibited behavior, a structured, evidence-based, and personalized psychosocial approach is required. The aim of this article is to introduce such an intervention, outline the process of its development, and demonstrate its feasibility in practice.

Innovation

"Focusing" (Figure 1) is a pragmatic, multicomponent intervention to manage disinhibited behavior in bvFTD, developed over the last decade on a YOD special care unit of a long-term care facility in Nijmegen, the Netherlands, grounded in years of practical experience.⁷ The intervention is based on theory of automatic behavior and stimulus processing. Executive functions in the prefrontal cortex regulate cognitive processes that require our attention.⁸ Additionally, the salience network, a brain system with a central role in the detection of stimuli, is crucial for effective behavioral inhibition, as numerous stimuli compete for attention.⁹ In bvFTD, neurodegeneration in these structures disrupts behavioral inhibition, causing inadequate stimulus filtering and unmanageable automatic

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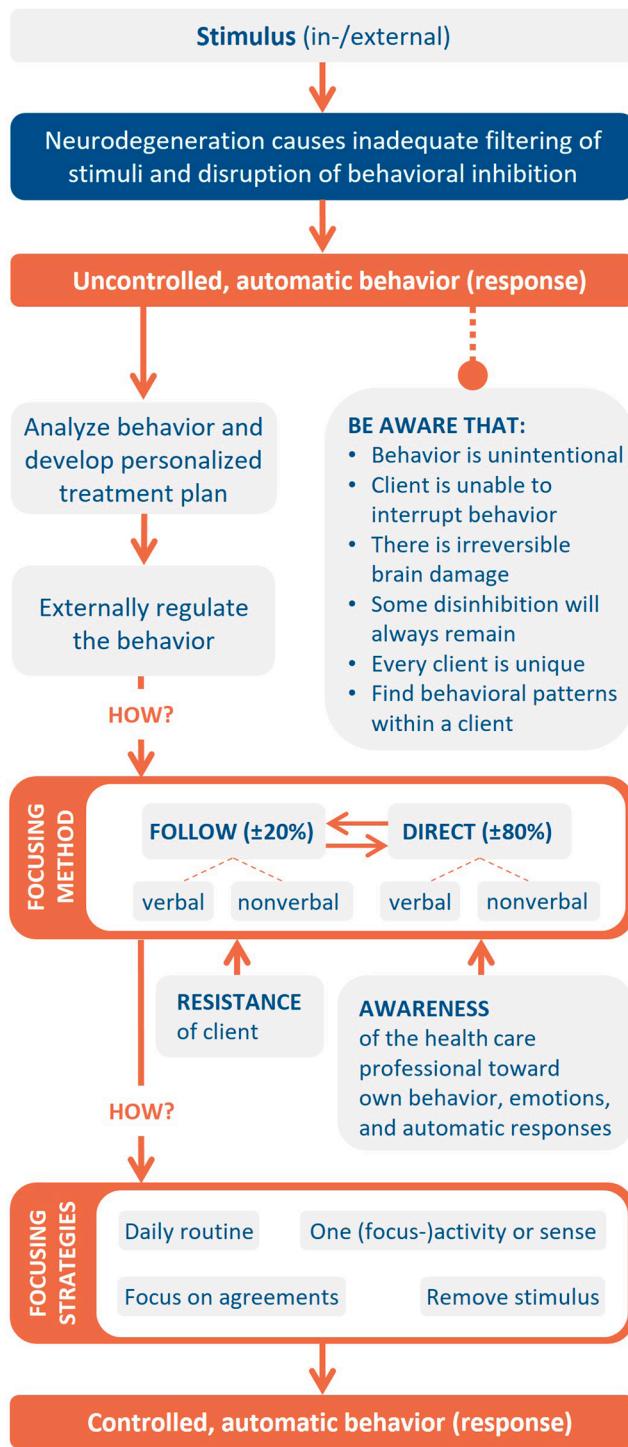


Fig. 1. Schematic overview of the components of the “Focusing” intervention.

behavior. “Focusing” compensates for this by adjusting interactions between resident, health care professional, and the environment, making the behavior manageable.

“Focusing” starts with observing a resident to identify and analyze unmanageable, automatic responses and the triggering internal and/or external stimuli that cause these. These observations help to map behavioral patterns, which are then used to develop a personalized treatment plan to be applied by all health

care professionals involved. Evaluation and adjustment of the treatment plan is done in a cyclic process. Usually, the psychologist is in the lead here. Strategies in the treatment plan can involve the following:

1. Provide a daily routine with dedicated time for activities and rest.
2. Focus on 1 (dominant) sense by offering specific activities.
3. Focus on 1 activity to replace unmanageable repetitive behavior with manageable repetitive behavior.
4. Remove stimuli to which a resident is inclined to respond.
5. Make clear agreements within the health care team on how to respond to behavior.

Another key element is the awareness of health care professionals regarding their own automatic behavior toward the resident. We differentiate between “following” the resident, that is, joining the resident’s experience and not intending to change behavior, and “directing” the resident, that is, using (non) verbal instructions to guide toward manageable behavior. In the interaction with residents with bvFTD, the focus is on directing, with a practice-based balance of approximately 80% directing and 20% following.

Evaluation

Guided by the model of Bowen,¹⁰ we performed a feasibility study to assess acceptability, demand, implementation, and limited efficacy. For the latter, a multiple-case study was performed in 6 purposefully selected residents with bvFTD at 2 YOD special care units, ensuring variation in age (range: 61–70 years), sex (2 female, 4 male), and time since diagnosis (range: 3–10 years) (Supplementary Table 1). We used a replicated single-case A-B design in which a 15-minutes period with no intervention (A-phase) was followed by a 15-minutes period during which the intervention was applied (B-phase), replicated within each case on 5 consecutive days. The presence of disinhibited behavior was scored by a single observer at a 15-seconds interval using partial-interval recording. Specific disinhibited behaviors that were scored during the observations were predefined for each case during a multidisciplinary meeting (Supplementary Table 2). In Supplementary Figure 1, the average of the 5 A-B observations per case are shown. Visual inspection indicates that a decrease in disinhibited behavior was observed following the introduction of the intervention in 4 of 6 cases (Supplementary Figure 1). Given the explorative nature, no formal statistical testing was performed. Interviews with health care professionals revealed that they felt more in control and experienced more positive interactions with residents. In 1 case, involuntary care could be discontinued as the behavior became manageable, improving the resident’s well-being. While recognizing limitations regarding internal validity [(single) observer bias, A-B design] and external validity (convenience sampling), these results do support further investigation to test effectiveness.

Implementation

To assess acceptability, demand, and implementation, we performed a process evaluation using interviews and questionnaires with health care professionals. Results led to the development of an implementation package for health care organizations, including a handbook, step-by-step implementation guide, and training (in Dutch). The handbook provides a detailed description of the methodology, whereas the implementation guide outlines prerequisites and steps for successful adoption. The training consists of a 3-day train-the-coach program for staff in coaching roles and a 1-day training for other members of the health care team. After the

training sessions, 95% (n = 19) of trained participants (n = 20) believed the method would provide sufficient control over disinhibited behavior, compared with 35% (n = 7) before the training. All participants reported feeling sufficiently (60%) or (very) well (40%) equipped to guide their team in applying the methodology (Supplementary Table 3).

In interviews, participants indicated that translating theory into practice as well as training their colleagues requires specific skills. The complexity of the intervention and the need for consistency demands motivation and commitment from the entire team. Frequent staff turnover and varying compositions in health care teams is therefore a barrier for implementation. The knowledge gained during the training and the use of a train-the-coach approach were seen as facilitators. The allocation of sufficient time is crucial for this. Another key facilitator is the availability of a structured team-based analysis of behavior to develop an intervention plan. The handbook was considered a valuable tool in guiding this process, with respondents reporting its frequent use in daily practice. Overall, participants indicated that they deemed the intervention highly relevant, as it provides them with practical tools to manage what they perceive as a complex problem.

Comment

The “Focusing” intervention was developed based on the principle that disinhibition in bvFTD can be regarded as an automatic response that is not inhibited. After first evaluation, the intervention seems feasible and acceptable. However, evaluation of effectiveness is needed, and should also consider well-being of residents and staff. In the future, it might also be valuable to explore applicability to other types of dementia. To date, the “Focusing” training has been completed by more than 500 health care professionals in the Netherlands, reflecting the high level of interest among health care organizations in acquiring tools to manage disinhibited behavior.

Declaration of Generative AI and AI-Assisted Technologies in the Writing Process

During the preparation of this work the authors used Co-Pilot in order to improve language and readability. After using this, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Disclosure

The authors declare no conflicts of interest.

Supplementary Data

Supplementary data related to this article can be found online at <https://doi.org/10.1016/j.jamda.2025.106084>.

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The pragmatic innovation described in this article may need to be modified for use by others; in addition, strong evidence does not yet exist regarding efficacy or effectiveness. Therefore, successful implementation and outcomes cannot be assured. When necessary, administrative and legal review conducted with due diligence may be appropriate before implementing a pragmatic innovation.