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Editorial

The Difficulty With Studying Challenging Behavior

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The behavior of people with dementia has been a focus of both research and dementia care for decades, particularly behavior that is considered "challenging." As we will discuss below, this challenging behavior has appeared difficult to demarcate and define, resulting in many approaches and views about what it comprises, which consequently has resulted in many different measurement instruments. The striking consequence is that the field now has been provided with a pool of research results that are hard to interpret and combine into knowledge that really moves it forward. For instance, various terms, definitions, and descriptions of vocalizations[1–4] are currently used in existing literature, and a broad range of behaviors are qualified as being vocalizations, such as moaning,[5–8] constant request for attention,[6,7] crying,[9] complaining,[2,5] abusive language,[2,4,7,8] singing,[4,8] and verbal or nonverbal utterances.[5,8] Additionally, vocalizations are often regarded as part of vocally disruptive behavior[1,10] or verbal agitation.[11,12] As a result, diverging and overlapping classifications exist for the same behaviors.[1,3,4,13–15]

For exploring how researchers can improve their contribution to the knowledge about challenging behavior and to its treatment, we will discuss different viewpoints in the literature with regard to (1) the relationship between challenging behavior and dementia and (2) why behavior is considered challenging.

Relationship Between Challenging Behavior and Dementia

Approaches to challenging behavior vary in how they relate the challenging behavior to dementia. We will describe 3 groups of approaches, which we refer to as (1) behavior-focused approaches, (2) behavior-symptom approaches, and (3) function-focused approaches.

The first group, the behavior-focused approaches, are numerous and use various names, such as *agitated behavior*,[16–20] *problem behavior*,[21] *obstreperous behavior*,[22] *behavior disturbances*,[23] *disruptive behavior*,[13] and *challenging behavior*.[24] Behavior-focused approaches concentrate on behavior specifically occurring in people with dementia, irrespective of its cause. In other words, these approaches focus on issues that can be observed in a particular target group (people with dementia) but do not explain or address how this behavior is related to their condition (dementia). The definitions and measurement instruments used in these approaches vary according to the behaviors included.

The second group of approaches, among which are the *Behavioral and Psychological Symptoms in Dementia* approach,[25,26] the *Neuro Psychiatric Symptoms* approach,[27] and the *Behavioral Pathology* approach,[28] combine observable behaviors with symptoms of (conditions associated with) dementia. By including symptoms, these behavior-symptom approaches may induce a focus on challenging behavior as a *direct* result of dementia; challenging behavior as merely reflecting a dementia-symptom and having no meaning in itself.[29–31] Furthermore, these approaches result in measurement instruments with hierarchical structures (eg, NPI,[27] BEHAVE-AD,[28] DBRI,[32] BEAM-D[17]) that may lead to interpretation difficulties. For example, the symptom "delusions" is scored in the Neuro Psychiatric Inventory[27] when a nursing home resident with dementia is repeatedly hitting other residents while sometimes yelling that they have stolen her purse. However, "delusions" is a symptom, not observable resident behavior, and may be a *cause* of the behavior shown. Furthermore, this behavior may have other, or additional, causes.[29,30,33]

A third group of approaches addresses behaviors (and not symptoms) and considers behavior as an *indirect* consequence of dementia, from which follows that the behavior has a function, that is, is meaningful in itself. Viewing behavior as an indirect consequence having function implies that it is important to investigate what the cause of the behavior might be.[34] Important examples of these "function-focused" approaches are, for instance, the unmet-needs

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approach[33,35] and the lowered-threshold theory.[36] According to the unmet-needs approach, challenging behavior is (1) an expression of distress caused by unmet needs, (2) a means of communicating needs, or (3) a means of fulfilling needs—the needs being of a physical and/or psychological nature.[33] The theory of lowered threshold postulates that challenging behavior is the result of environmental stressors exceeding a stress threshold. This threshold is reached sooner in people with dementia as they are considered to be more vulnerable to stimuli, given their neurologic damage.[36,37] By articulating causes, these function-focused approaches demarcate challenging behavior as behavior that results from specific causes, for instance environmental stressors in the latter approach. Consequently, one of the approaches alone cannot explain all possible challenging behaviors. Causes can be internal (behavior results from a stimulus within the resident) or external (stimulus from social or physical environment), and a resident's behavior can very well be a result of various combinations and interactions of these internal or external causes. This implies, for instance, that optimal clinical treatment for 2 similar behaviors can vary tremendously.[34,38] Function-focused approaches stress the importance of functional analyses of observable behavior.[34]

Why Is Behavior Considered Challenging?

The question why behavior is considered challenging is about at least 3 features. First, it may be challenging because of its causes and/or consequences; second, because of the person(s) involved, that is, the resident and/or his social environment; and third, because of its properties, that is, intensity and persistence of the behavior.

The approaches described above differ on the first and second feature. Behavior-focused approaches regard behavior, and not its causes and consequences. However, as can be seen in many of the above-mentioned concept names, the behavior in question needs to be addressed because of its consequences for the social environment, such as in the negatively labeled terms *disruptiveness*[13] and *disturbances*.[23] Other terms, such as *challenging behavior*, imply that its consequences can be challenging for the person with dementia and/or the environment. In the behavior-symptom approaches, which include a focus on a direct relationship between dementia and behavior, the attention is directed toward symptoms and, thus, by definition, on the internal causes in the person with dementia and not so much on his or her environment.[30] In the function-focused approaches, such as the unmet needs and progressively lowered threshold approaches, the *causes* of the behavior are central, and they vary regarding the persons involved in these causes. Namely, the *internal and external (environmental) nature* of these causes are exemplified.

Neither the first feature (causes and consequences) nor the second feature (persons involved) are often considered in assessment instruments. Some instruments, however, address the consequences of the behavior (eg, distress) for nursing staff or informal caregivers (NPI-NH,[39] NPI-Q[40]). Apart from the severity scale of the NPI-instruments, consequences for the person with dementia have, to our knowledge, not been included in measures for challenging behavior. This also holds for the impact on other residents.

A third feature of why behavior can be challenging are the behavior's properties. Behavior may be challenging because of its high intensity. For instance, requesting the attention of a nurse once or twice a day is not considered challenging; however, doing this 40 times a day mostly is. Furthermore, hitting the table loudly to get a nurse's attention until the nurse responds may be considered challenging, whereas asking something at conversational volume will not. In general, the *intensity* of the behavior is addressed in assessment instruments to some degree. Usually, it is measured in terms of severity and/or frequency. Other intensity issues, such as the unexpectedness of the behavior, are commonly not addressed in measurement instruments. The property *persistence* is often included, and usually through the time frames used by the instruments. These explicate, for instance, that the behavior has to be scored over a period of 2 weeks or 1 month.

Implications

In nursing home care, "behavior" can be an expression of many issues. Most residents are very impaired and have difficulty communicating verbally, making the precise cause of their behavior often far from clear. Therefore, it is difficult, if not impossible, to formulate a comprehensive definition of the challenging behavior, as well as employing the cause of behavior in assessment and intervention strategies. However, what we can do, in line with the IPA consensus definition of agitation,[41] is start from the viewpoint that challenging behavior primarily reflects compromised well-being. We add that it therefore requires analyses of its causes and, furthermore, that it has consequences for the person with dementia and his or her social environment, also requiring explication.[34] Should researchers subsequently only use behavioral items to measure challenging behavior, it would be possible to systematically select items and distinguish scales based on specific behaviors and, through this, explicitly distinguish behavior from its causes—the latter not being measured with the same instrument. For instance, the frequent hitting and kicking by a resident who also has delusions may stem from these delusions, but may also be (partly) related to the resident having abdominal pain. By first exploring the behavior thoroughly and then searching for causes, the pain may be noticed sooner. Furthermore, these causes can then dictate the treatment.

We must acknowledge that this behavior-focused approach has been criticized by researchers aiming to classify behaviors into neuropsychiatric syndromes such as the Apathy Syndrome and the Dementia-Associated Psychotic Disorder.[42] Their argument is that individual behaviors co-occur and that a behavior approach is less applicable in milder dementia stages in which the person's mental state can be examined specifically. In contrast, we argue that although a specific clustering of behaviors may point to a particular syndrome being the cause, classification may be a problematic oversimplification of the meaning, causes, and consequences of particular behavior in individuals, especially in people who cannot communicate their needs.

Furthermore, researchers could also specifically explicate the features of the behavior in their studies and in the choice of the measurement instruments applied, for instance, by adding consequences of interest (eg, level of distress of the person with dementia) to standard response scales of measurement instruments. The interventions initiated could subsequently be directed by using the results of these additional response scales in a thorough analysis of possible causes and consequences in daily practice. Finally, replicating studies and comparing results would be greatly facilitated if we, as researchers, were to be transparent by reporting not only the choices made in the definition and measurement process but also the operationalization applied.

Conclusion

Challenging behavior is, first and foremost, relevant as it is an expression of the compromised well-being of the person with dementia. Optimizing the well-being of people with dementia can be considered the central goal of dementia care,[43] implying that managing challenging behavior should be a priority. In order to be able to compare research results—genuinely advancing the knowledge about challenging behavior further—it is recommended that researchers in their studies and reports;

- specify a definition for the behavior of interest using observable behavior;
- specify why they consider the behavior challenging in terms of causes and consequences;
- specify why they consider the behavior challenging in terms of the person(s) involved;
- specify the properties of interest, that is, intensity and persistence;
- specify the assessment instruments used; and
- specify how the properties are operationalized (eg, response scales, observation periods).

Supplementary Data

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.jamda.2019.01.148.

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