

# Disconnect between clinical and research terminologies regarding behavioral symptoms of dementia

Ladislav Volicer<sup>1</sup>, Elizabeth Galik<sup>2</sup>

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Behavioral and psychological symptoms of dementia are very common and a recent study found that they occur in up to 90% of people living in residential care facilities [1]. These symptoms are often more disturbing than cognitive impairment and are associated with increased healthcare use, earlier institutionalization [2], excess morbidity and mortality, greater caregiver distress and depression [3].

Development of strategies for the effective management of this problem is hindered by confusing terminology. Many investigators consider behavioral and psychological symptoms of dementia to be a singular phenomenon using abbreviations of BPSD. This approach assumes that all of these symptoms may be improved by the same strategy.

**Table 1** The clinical evaluation of behavioral symptoms of dementia.

Minimum Data Set MDS 3.0	Proxy reports		Direct observational scales
	Neuropsychiatric Inventory (NPI-NH)	Cohen-Mansfield Agitation Inventory (CMAI)	
A. Physical behavioral symptoms directed toward others (e.g., hitting, kicking, pushing, scratching, grabbing, abusing others sexually).	C. AGITATION/AGGRESSION Does the resident have periods when he/she refuses to let people help him/her? Is he/she hard to handle? Is he/she noisy or uncooperative? Does the resident attempt to hurt or hit others?	Physical / Aggressive Hitting (including self) Kicking. Grabbing onto people. Pushing. Throwing things. Biting. Scratching. Spitting. Hurting self or others. Tearing things or destroying property. Making physical sexual advances	Restiveness to Care – Dementia of the Alzheimer Type (RTC-DAT) scale
B. Verbal behavioral symptoms directed toward others (e.g., threatening others, screaming at others, cursing at others).  Did the resident reject evaluation or care (e.g., blood work,		Verbal /Aggressive Screaming. Making verbal sexual advances. Cursing or verbal aggression	

taking medications, and ADL assistance) that is necessary to achieve the resident's goals for health and well-being?

A. Other behavioral symptoms not directed toward others (e.g., physical symptoms such as hitting or scratching self, pacing, rummaging, public sexual acts, disrobing in public, throwing or smearing food or bodily wastes, or verbal/vocal symptoms like screaming, disruptive sounds).	H. DISINHIBITION Does the resident do or say things that are usually done or said in public? Does he/she seem to act impulsively without thinking? Does the resident say things that are insensitive or hurt people's feelings?	Physical /Non-Aggressive Pace, aimless wandering. Inappropriate dress or disrobing. Trying to get to a different place. Intentional falling. Eating / drinking inappropriate substance. Handling things inappropriately. Hiding things. Hoarding things. Performing repetitive mannerisms. General restlessness	Scale for Observation of Agitation in Persons with DAT [dementia of the Alzheimer type] (SOAPD)
J. ABERRANT MOTOR BEHAVIOR Does the resident have repetitive activities or "habits" that he/she performs over and over such as pacing, wheeling back and forth, picking at things, or winding string?		Verbal/Non-aggressive Repetitive sentences or questions. Strange noises (weird laughter or crying). Complaining. Negativism. Constant unwarranted request for attention or help	

Other investigators call all behavioral symptoms of dementia agitation. Using factor analysis, they divided these symptoms into physically aggressive, verbally aggressive, physically non-aggressive and verbally non-aggressive agitation. This system has two problems. First, it is unwieldy, using four categories of behaviors and second, it labels people with dementia aggressive. This "aggressive" behavior is in most cases triggered by the individual's rejection of care, when the person with dementia does not understand the need for care, does not understand the carer instructions, cannot communicate concerns verbally, struggles with the performance of self-care due to motor apraxia, and/or misinterprets the

<sup>1</sup>School of Aging Studies, University of South Florida, Tampa, FL and 3rd Medical Faculty, Charles University, Prague, Czech Republic

<sup>2</sup>University of Maryland School of Nursing, Lombard St., Baltimore, MD 21201, USA

Correspondence: Ladislav Volicer, School of Aging Studies, University of South Florida, Tampa, FL and 3rd Medical Faculty, Charles University, Prague, Czech Republic, Tel: 8135971402; E-mail: lvolicer@usf.edu

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carer's intention or approach due to agnosia. If the carer insists on providing care, the person with dementia defends herself from this unwanted attention and may become combative. This is actually a reactive aggression in contrast to proactive aggression which is defined as behavior that anticipates a reward and involves planning and premeditation [4]. Persons with dementia exhibit rarely proactive aggression because their executive function is impaired. [5]. Additionally, individuals with dementia have a heightened fight or flight response where care becomes perceived as a threat and limbic fear response is less able to be overridden by a cerebral cortex that has sustained significant neuro-degeneration due to the underlying dementia [6].

The situation is further complicated by the Neuropsychiatric Inventory (NPI) which is commonly used in clinical research trials. The NPI labels one item Agitation/Aggression. The probing questions for this item are "Does the resident have periods when he/she refuses to let people help him/her? Is he/she hard to handle? Is he/she noisy or uncooperative? Does the resident attempt to hurt or hit others?" which may indicate that the item is actually asking about rejection of care that may sometimes escalate into reactive aggression. Behaviors that represent actual agitation are measured in this scale by items called Disinhibition and Aberrant Motor Behavior.

Should the term agitation be avoided in research and clinical care because of the confusing and overlapping definitions? Fortunately, the clinical evaluation of behavioral symptoms of dementia, prescribed by the Minimum Data Set 3.0, does not use the terms agitation and aggression (Table 1). It separates the behavioral symptoms into those directed toward others and those that are not directed toward others. The behavioral symptoms directed toward others could be reactive aggression evoked by rejection of care, while the symptoms not directed toward others could be the real agitation. This approach indicates that the difference between agitation and aggression is in the circumstances of this behavior. Aggression by definition occurs during interaction of person with dementia with another person or object, while agitation occurs when there is no interaction and the person with dementia may be solitary.

The distinction between rejection of care and agitation is very important because non-pharmacological management strategies differ in these two conditions. Agitation and apathy is decreased by providing stimulation and meaningful activities for nursing home residents with dementia [7,8], while rejection of care may be decreased or prevented through the use of effective and individualized communication strategies and modification of care approaches that are person-centered and actively involve individuals with dementia in their own care 8. Providing care "with" an individual with

dementia rather than "for" the individual decreases misinterpretation of carer's actions and fear while providing opportunity for meaningful engagement in care.

The main problem with the broad definition of "agitation" is that it may be used as an indication for pharmacological treatment. Agitation and reactive aggression may be influenced by different medications and treatment of both syndromes by the same medication may be inappropriate. Unfortunately, some of the current investigations studying the effect of medications on behavioral symptoms of dementia use scales that do not distinguish clearly between agitation and aggression.

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