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COMMENTARY

Behavioral and Psychological Manifestations Among People Living With Dementia: Current Challenges Related to Terminology, Their Implications, and a Way Forward

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1 | Introduction

People with dementia often present changes in the way they express their emotions or in the way they behave throughout dementia's trajectory (given the lack of consensus, we hereafter refer to these changes generally as "manifestations"). These manifestations can be considered positive or neutral, such as when the person appears to feel more comfortable in places or situations which used to be unpleasant for them. Often, however, these indicate distress or other forms of suffering, reflecting a negative impact on the wellbeing of the person and potentially others around them. The prevalence of this phenomenon varies greatly—from less than 5%–90% –, depending on their type or clinical classification (e.g., apathy, agitation, psychosis, depression, anxiety), context (e.g., care homes, hospitals, home settings), and type of dementia [1, 2]. Such manifestations have been considered for many years as intrinsic to dementia, and as something that should be invariably "fixed," controlled, or eliminated [3]. However, there is an increasing body of evidence indicating these are rather (and often) expressions of unmet needs, which could be prevented or ameliorated through effective care strategies [4].

The terminology and definitions used to refer to and to describe such psychological and behavioral manifestations can significantly influence research approaches and clinical practice, with profound implications for those affected by dementia [5]. People with this condition feel that terminologies can affect how they are viewed and treated, as well as their own self-perceptions [6]. In two recent studies, "unmet need" or "changed behavior" were overall their preferred choices because these indicate a need for an intervention, or/and are considered neutral [6, 7]. However, no consensus was reached among participants [6, 7]. Amid academics, there have been multiple attempts to establish an all-encompassing terminology to standardize and inform measurement, as well as improve clinical decision making, all of which have had pitfalls. Further reflection is required on the most suitable way to refer to this phenomenon, so that new knowledge in the field can be more accurate, and clinical guidelines can be both understood and adequately applied by health care providers and other knowledge users [8].

In this commentary paper, we first examine the challenges associated with the terminologies currently used, including how these may shape measurement, interpretation, and care management. We give examples of how language may impact social and healthcare experiences of people with dementia, as well as their social environment. Considering the existing understandings of dementia, we argue that establishing a universal terminology is probably unattainable and unhelpful. We then propose a reflexive and informed approach in which individuals may adopt relevant terminology depending on their circumstances and goals to favor the person with dementia's dignity and rights.

2 | Breadth and Complexity

There have been numerous attempts in previous studies to grasp the psychological and behavioral manifestations among people with dementia in a single umbrella term which could both sufficiently and adequately encompass this phenomenon. However, for several reasons, no terminology to date has been comprehensive and specific enough to capture the complexity and breadth of this phenomenon.

Most individuals have more than one manifestation at the same time (e.g., hallucinations and agitation), which may change in a matter of hours [3], and each can be caused by a complex range of extrinsic and intrinsic factors, as well as by the interaction between these [3, 9]. Noise as a behavioral manifestation, for instance, can indicate suffering (e.g., screaming due to fear or pain), or the person's attempt to communicate an unmet need because they either lack the ability to effectively communicate or fulfill these needs themselves [5, 10]. In some cases, it can be a coping strategy (e.g., verbalizing something repeatedly for reassurance), or a deliberate attempt of the person to make sense of their world and/or communicate with others, rather than something that requires intervening [11]. Though such noise may not necessarily mean that the person is in distress, it can be distressing or harmful to people around them, particularly in places where more than one person with cognitive impairment reside. For instance, such noise can be a source of psychological distress to other persons with dementia who live in the same nursing home, thus creating multiple dilemmas for those involved with the care provision. Any attempt to control this manifestation should thus take into account these multiple causal possibilities and consequences in each case.

Overall, broad and/or neutral terminologies (e.g., changed behaviors) do not capture this complexity, can be vague and may not work for their purpose (e.g., improve care, distinguish causes). As such, they may not accurately inform, nor clearly elicit an intervention. Other terminologies, which can indicate the need for action (e.g., behavioral challenges, signal behavior), pertain to what the behavior means to, or causes in, those around the person with dementia, thus lacking reference to the intentions or causes behind the behaviors, and therefore to the need(s) that drive the behavior, and which should be investigated thoroughly. Although such type of terminology can be helpful to ensure that at least some nonspecific actions can be taken when the causes of the manifestation are unclear or still under investigation (e.g., redirection techniques, providing comfort, or ensuring basic needs are met), they may not be adequate to elicit an investigation, nor care actions toward solving the root cause.

Further, terminologies which convey psychological and behavioral manifestations as "symptoms" can easily pathologize processes that are functional to any human being and ignore the role that these manifestations have in the person's experiences of the world. For example, delusions are often described as a psychotic symptom that manifests itself as irrational beliefs [11]. However, in some contexts, these so-called "irrational beliefs" may represent a functional response of the person's attempt to make sense of their situation or simply a reaction to an environment, for instance stemming from disorientation, loneliness, or boredom in an unstimulating environment [10, 11]. Labeling delusions as symptoms may lead to over-reliance on labels rather than seeking to understand the person's experiences.

3 | The Issues Related to the Terminology "BPSD"

A review by Watt et al. [4] identified 20 terms used in the literature, with Behavioral and Psychological Symptoms of Dementia (BPSD) being the most commonly adopted in clinical guidelines (58.3%). However, multiple concerns can be raised regarding its use. First, the psychological and behavioral manifestations considered as part of "BPSD" are present in several other psychiatric disorders and are not necessarily specific to dementia. Indeed, these can be exhibited by any person, even in the absence of a clinical condition. Referring to such manifestations as being "of" dementia can thus be misleading.

Second, the terminology BPSD indicates that behavioral and psychological manifestations among people with dementia are "symptoms" of dementia. However, the existing evidence shows that this is often not the case, and doing so can have multiple implications for people with dementia. For example, it may lead to disease overshadowing (e.g., focusing on the disease rather than on the person and their underlying health and social needs), having implications for the person's personhood and to the management of other underlying health issues (which may also cause these manifestations). It also ignores multiple possible causes beyond dementia itself which can be prevented and ameliorated with social care, health care, and environmental strategies. Although people with dementia can sometimes describe what is happening to them in terms of "symptoms", for instance with "irritability", formally classifying such expressions as symptoms may also lead to hyper-medicalization in people with dementia as it suggests a direct relationship between brain damage and behavior, with critical implications to care practices [8]. These concerns apply to other terminologies that include the word "symptoms", such as "Neuropsychiatric Symptoms" (NPS), which is widely used in some parts of the world.

4 | Negative Attributions and Their Implications

A key challenge has been to create an umbrella term that does not add negative attributes to an already highly stigmatized condition, which could unintendedly lead to further stigmatization and discrimination toward people with dementia [6, 12]. Evidence shows that, as cognitive impairment advances, clinicians increasingly adopt words that reflect negative emotion (e.g., hate, worthless, enemy), are anxiety-related (e.g., nervous, afraid, tense), or imply negation (e.g., no, not, never) to refer to people with dementia and their expressions, with a significant decrease of human-related words (e.g., person, experience, relationship) in cases of advanced dementia [13]. This reflects the important role and potential influence of implicit emotional reactions in the language used in everyday care and should be of concern.

Although behavioral manifestations are often functional, have meaning, and may reflect coping strategies, persons with dementia should not invariably be held responsible for these manifestations. Terms such as "aberrant behavior," "disruptive behavior," "disturbing behavior," and "problem behavior" hold negative attributes and may lead to attribution bias (e.g., "she is disruptive"), which all may directly or indirectly lead to people with dementia being shunned, shamed, and blamed for their condition within their immediate and broader social environments, as argued in previous studies [5, 6]. Coupled with other stigmatizing words linked to dementia, such as "demented" or "senile," such terms could have catastrophic social implications for the person's experiences and self-perceptions [6], with needs being unintendedly dismissed, overlooked, or ignored as a result in care contexts where these are frequently adopted [12–15].

Additionally, labeling psychological and behavioral manifestations as "behavior" can be inadvertently interpreted as deliberate. If these manifestations are perceived negatively, it can lead to social consequences for the person (e.g., blaming the person for their unintended actions). When such negative terminologies are then considered intrinsic to dementia (or "symptoms of dementia"), they also contribute to exacerbate the negative social reactions that already exist in relation to dementia, such as social avoidance and discrediting [12].

Alternative terms have been specifically proposed to mitigate stigma, such as "signal behavior" [8], "adjustment behavior" [16], "responsive behavior" or "reactive behaviors" [17]. Yet, these also have limitations in terms of comprehensiveness and specificity because they often cover only some behavioral and psychological manifestations and may be mainly applicable in residential care settings, where observing behavior is usually the starting point for analysis of these manifestations.

5 | Cultural Aspects and Language

The exact same terminologies can have slightly or majorly different meanings or relevance in different languages and contexts, which may elicit different interpretations and actions. For example, understandings of agitation have been shown to vary between different audiences and populations. The term agitation covers a broad range of behaviors, values and moral judgments, and the information provided is often not accurate enough to properly assess or provide treatment, nor to compare research studies [18–20]. Additionally, what might be considered a "symptom" for some people or groups could be a natural or even expected experience for another [21, 22]. In some cultures, what is classified as a "symptom" may be taken more seriously as a health issue than what is simply an "experience," and therefore adopting the word symptom may be helpful in some contexts to ensure that concerns related to psychological and behavioral manifestations in dementia are taken seriously. Such examples demonstrate that psychological and behavioral manifestations in dementia are therefore bound to a variety of cultural interpretations and reactions [23].

In particular, any terminology which specifies the word dementia, such as BPSD, is bound to the additional interpretations of what dementia currently means in different cultures and contexts, which is varied [12, 24–26]. Crucially, over 75% of all people with dementia around the world are undiagnosed, particularly in low- and middle-income contexts where numbers can be as high as 90% [27]. Terminologies that make a direct reference to dementia may thus lead to people with an "unnamed status" to be persistently underserved in terms of care options. This is because professionals may not *immediately* refer to the scientific evidence related to dementia to provide appropriate care in such contexts where awareness and diagnosis rates *currently* are extremely low. Adopting a more neutral terminology might be favorable so as not to contribute to widening the gap of access to care among people who do not have access to a diagnosis.

Measurement in any healthcare context is hugely influenced by cultural aspects and language, and therefore any terminology used should be relevant and sensitive to accurately inform how the phenomenon is assessed in different contexts. Currently, there is a serious dearth of research on the experiences of living with dementia in low-resource settings, partly due to this high underdiagnosis rate, and therefore existing evidence on psychological and behavioral manifestations and their measurement among people with dementia thus has limited external validity in such contexts. Likewise, research about this phenomenon has traditionally been conducted in care home settings and hospitals, with very limited data on home settings. More research is required to argue for universal terminology across settings.

6 | The Way Forward

Considering these arguments, we reason that establishing a universal terminology is probably unattainable and unhelpful. The psychological and/or behavioral manifestations exhibited by many people with dementia should be considered functional and thus as having meaning, often representing adaptive efforts of the person with dementia—which may not be successful, and/or may be distressing for others. These manifestations can communicate unmet needs or needs being met, alongside representing more intrinsic phenomena such as hallucinations or delirium [10]. Recommending an all-encompassing term thus risks increasing unmet needs among people with dementia because it may exclude important aspects of the phenomenon and may mislead care practices.

We argue that different words and definitions may be adopted depending on the context in which these are used to fit their purpose (e.g., clinical, care related, social/public/lay contexts), as long as these do not result in detriment to the care, experiences, and wellbeing of people with dementia (e.g., discrimination, missed opportunities of care) in any way, and that they actively elicit an action that aims to enhance the wellbeing of the person with dementia. It is necessary to consider the temporality of the manifestation, as well as the person's trajectory and circumstances which may require different levels or types of responses. This includes the period when the person has not yet received a diagnosis but nevertheless may still present behavioral and psychological manifestations that require attention. We therefore propose a reflexive, transparent, and informed approach in which professionals and individuals, including people living with dementia, may adopt relevant terms depending on their own circumstances, and on those of the person with dementia, as well as their goals. As a basis, we propose that any terminology adopted in any context or circumstance should apply five key principles to promote a dignity- and rights-based approach, while avoiding negative consequences and unfair treatment for people with dementia [28].

6.1 | Principle I. Protection of Rights

Terminology should be free of stigma and discrimination and should be respectful of every person's rights. Any action or intervention implemented in response to the psychological and behavioral manifestations among people with dementia should also adhere to this principle. For as long as they are able to, each person living with dementia should have the right to decide how they wish to refer (or others refer) to any psychological and behavioral manifestations they might experience.

6.2 | Principle II. Intersectionality

Terminology should result from an inclusive, intersectional view, representing a global range of characteristics of people with dementia. Research should be very explicit about sample characteristics and should be disaggregated by different sociodemographic and economic groups. Cultural sensitivity can help inform and facilitate respectful conversations.

6.3 | Principle III. Responsibility and Accountability

Terminology should reflect the context of the person living with dementia, including services and their physical and social environments, and should address the function of the manifestations of the person living with dementia, emphasizing the need to take action. Every person/professional should be aware of, as well as responsible and accountable for, the meanings and possible consequences of the terminologies they decide to use.

6.4 | Principle IV. Science and Evidence-Based Approach

Terminology should be based on the highest level of available evidence, which should be culturally relevant, and context informed. This includes, for example, understanding behavioral and psychological manifestations among people with dementia as ways to communicate (unmet) needs or to fulfill needs. Unmet needs can often be met with non-pharmacological interventions and environmental/social changes informed by thorough and meaningful needs assessment.

6.5 | Principle V. Multisectoral Collaboration and Universality

Terminology should be made explicit and should be explained in the contexts in which they are used. It should be comprehensible, understandable, and useful by the pertaining audiences, care contexts, professional/individual groups, and care goals (e.g., pharmacological treatment by medical doctors vs. care by family carers), with the goal of improving the lives of people with dementia everywhere. For instance, in acute healthcare contexts, a person with dementia may have a level of insight/awareness that justifies discussing their specific manifestations in terms of symptoms, for example, hallucinations may be specifically named as well as discussed as symptoms. In residential care settings, pertaining to a population with commonly more severe dementia, the cause of behavioral and psychological manifestations is often unclear, which makes describing the manifestations in terms of behavior a good starting point to enhance care.

7 | Conclusion

In this paper, we have discussed the multiple challenges that exist in attempting to establish a universal terminology for the psychological and behavioral manifestations exhibited by some people with dementia. Given the complexity of this phenomenon as well as the existing pitfalls of widely adopted terminologies, we argue that having an umbrella term is probably unattainable and unhelpful. We propose that any definition and their related terminology adopted in any context or circumstance should apply five key principles that promote a dignity- and rights-based approach, while avoiding terminologies that hold negative attributions. For example, clinicians from hospital settings in English-speaking countries may use the word symptom when referring to psychological and behavioral manifestations that hold neurobiological plausibility and where this terminology is culturally acceptable. On the other hand, for individuals in primary care, residential or homebased care, it may be preferable to use the term unmet need, behavior of concern, or behavioral expression with the attempt to understand what might be causing a manifestation that is generating distress to the person, and its possible solutions. When the cause is known, for example in cases of agitation due to pain, the terminology may then shift to ensure that the focus is on the management of what is causing that manifestation (i.e., pain-related agitation, agitation due to pain). Another illustration is that, in some cases, it can be reassuring for the person that a specific terminology is given to such manifestations and to know that these are common in their condition, for instance in cases of hallucinations.

Our proposal acknowledges that people from different countries and contexts will refer to behavioral and psychological manifestations in different ways, in line with what makes sense in their cultural and language contexts, but such a decision should always be respectful of the five key pillars proposed. Terminologies which embed negative attributes, or which reinforce stereotypes against people living with dementia, should be discontinued.

Ethics Statement

The authors have nothing to report.

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The authors have nothing to report.

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The authors have nothing to report.

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