

## ADOPTING A DIARY TO SUPPORT AN ECOLOGICAL ASSESSMENT OF NEUROPSYCHIATRIC SYMPTOMS OF DEMENTIA

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**Abstract:** Neuropsychiatric symptoms (NPS) are one of the most challenging issues in the management and care of people with dementia. Their accurate assessment is thus crucial for properly approaching subjects with cognitive disorders in the clinical setting. In parallel, the correct evaluation of NPS is also particularly relevant in the research field where they serve as critical indicators for measuring the efficacy of interventions against cognitive disorders. However, the study of NPS is extremely challenging given their extreme inter- and intra-individual variability. Moreover, the available assessment tools are often inadequate to fully capture their complexity and phenotypic expression. Based on these considerations, novel modalities for the assessment and measurement of NPS may be important to identify and develop. In this regard, a promising alternative (or, at least, a complementary aid) to traditional scales and questionnaires might be constituted by diaries. In the present article, we discuss the potential advantages and implications that may result from the adoption of this kind of instruments for the ecological assessment of NPS in subjects with dementia.

**Key words:** Neuropsychiatric symptoms, dementia, narrative medicine, diary, assessment tools.

### Introduction

Neuropsychiatric symptoms (NPS) affect nearly 98% of individuals diagnosed with dementia at any disease stage (1). These disturbances are considered one of the most challenging issues in the management and care of people with dementia. They are associated with several adverse outcomes and poor quality of life. Moreover, NPS represent an important cause of stress for caregivers and major source of (direct and indirect) healthcare costs. It is thus evident why the accurate assessment of NPS is crucial for properly approaching subjects with cognitive disorders in the clinical setting. At the same time, their correct evaluation is also particularly relevant in the research field where they serve as critical indicators for measuring the efficacy of interventions against cognitive disorders (2).

Unfortunately, the study of NPS is extremely challenging for several reasons. NPS are characterized by extreme inter- and intra-individual variability. Furthermore, the NPS assessment tools are often inadequate to fully capture the complexity and phenotypic expression of these symptoms. In fact, most of scales and questionnaires address a number of pre-defined and fixed symptoms and/or are focused on specific NPS (e.g., agitation, apathy, depression) neglecting others. For example, major neuropsychiatric manifestations such as inappropriate sexual behaviours are often ignored or underestimated, despite the impact and prevalence observed in the routine clinical practice (3). In other words, available tools may be affected by a limited capacity of adaptation to the heterogeneity of the NPS and uniqueness of the patient (4). It is also noteworthy that the retrospective evaluation provided by most of these instruments limits the reliability of the assessment, making it

strongly influenced by many attributes of the responder (e.g., fatigue, mood, sleep, educational level, personal beliefs) at the time of administration. The ability to recall and summarize the past experiences within the few minutes of the test as well as the multiple behavioural modifications exhibited by the patient over the previous weeks can be extremely variable. In this context, another weakness resides in the inadequate capacity of many tools to consider the temporal fluctuations of NPS, that is the tendency of some symptoms at becoming overt at specific times of the day (e.g., sun-downing)(5). Finally, the diverse determinants and contributors that may trigger the onset of NPS or exacerbate/attenuate their severity (e.g., environmental modifications, concomitant medical events, lifestyle) are almost completely ignored or missed by traditional assessments (6).

For all these reasons, novel modalities for the assessment and measurement of NPS may be important to identify and develop. In this regard, a promising alternative (or, at least, a complementary aid) to traditional scales and questionnaires might be constituted by diaries. Such instruments are already widely adopted in different medical activities for recording quantitative and qualitative variables potentially confounding or explaining the results of a test. For example, diaries are completed by patients undergoing blood pressure, pain, diet, or glycaemic control for measuring the fluctuation of the parameter of interest over time with the final aim of supporting clinical decisions. NPS may represent an ideal condition for applying a diary-based evaluation, as already recognized in the DICE (Describe, Investigate, Create, Evaluate) approach, which encourages their use to describe of the heterogeneous manifestations of dementia (7).

The use of a NPS diary would have many advantages and practical implications. Fundamentally, it may consent a more

**Figure 1**  
Example of a diary for neuropsychiatric symptoms

DATE: 2nd October 2018					DATE: 3rd October 2018				
Hour	Description	Triggering factor	Duration	Resolution	Hour	Description	Triggering factor	Duration	Resolution
07					07				
08					08				
09					09				
10	He starts wandering around the house, opening cabinets and drawers. Very AGITATED and FRENETIC.	I told him that the water-treater broke down.	2-hours	He reassures himself and calms down as soon as the technician arrives to repair the fault.	10	He stays ALL DAY doing NOTHING. He does not want to go out as usual, he always wants to be on the couch.	I don't know	ALL DAY	None.
11									
12									
13					13				
14					14				
15					15				
16					16				
17					17				
18					18				
19 <sup>30</sup>	He becomes NERVOUS and IRRITABLE. He answers me badly.	I asked him to go and wash his hands before dining.	Few minutes	I avoid insisting.	19				
20									
21									
22					22				
23					23				
24					24				
01					01				
02					02				
03					03				
04					04				
05					05				
06					06				

Footnote: The figure shows the modified version (adjusted for colors and calligraphy) of two pages taken from a 30-page NPS diary filled up by the wife of a 78-year-old patient with Alzheimer's disease attending our memory clinic.

ecological and objective assessment of NPS. In particular, a diary may allow a more accurate description of the behavioural disruption and its main psychopathological dimensions. The approach may facilitate the identification of potential triggers (e.g., pain, changes in light exposure, noise, stressful events) as well as the ascertainment of possible solutions (e.g., reassurance, distraction, stimulations, administration of psychoactive drugs). All these aspects, whose identification inevitably implies a constant observation and monitoring, are crucial to enhance the effectiveness of the available treatment options. For instance, a diary may improve the management of NPS by suggesting possible factor sustaining the onset of an agitated behaviour or precipitating its clinical course. Such approach may thus allow to act on the environment of the patient, potentially limiting the prescription of (additional) medications for the behavioural control. In parallel, the accurate description of NPS in terms of time of occurrence, duration, and frequency may support the personalization of

the pharmacological intervention (e.g., modifying the time of administration of a given drug or choosing a prolonged-release treatment), thus increasing the possibility for a positive response. Moreover, the NPS diary might render the assessment more objective and less biased by the caregiver's conditions at the moment of the clinical interview. It might help at better differentiating those symptoms that may sometimes appear similar or overlapping (e.g., agitation, aggressive behaviour, irritability, and anxiety or apathy and depression), especially if occurred days or weeks before the evaluation. Last but not least, the benefits for caregiver possibly arising from the compilation of the diary should not be overlooked. In fact, completing the diary may promote a better understanding of the patient's behaviours as well as the participation and involvement of the caregiver in the intervention plan. All this through a sort of narrative medicine (8).

It is important for a diary to meet specific criteria in order to adequately serve in the assessment of NPS. First of all, it should

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be structured to help and not burden the caregiver. It should be designed to record the critical information in a useful, visually synoptic, and handy way. For instance, it might be organized as a weekly agenda where every day is organized by hours, thus allowing a clear and timely description of the disturbance. Enough space for describing the NPS, the possible predisposing and precipitating factors, the strategies used to solve/attenuate its manifestation, and their efficacy has to be foreseen. An example of a NPS diary is shown in Figure 1.

It is noteworthy that NPS diaries may also potentially benefit from novel technologies and facilitate exchanges between the caregiver and healthcare professionals. In this context, a digital version of the diary to record images, sounds or videos might even be considered (9). As above-mentioned, the use of diaries might also be of interest in the research setting for improving a more accurate monitoring of the interventions efficacy. Of course, this eventual use implies the need of transforming the collected information of diaries into “numbers”.

*Disclosure of conflicts of interest:* Authors have no funding source to disclose for the present study. Marco Canevelli is supported by a research grant of the Italian Ministry of Health (GR-2016-02364975) for the project “Dementia in immigrants and ethnic minorities living in Italy: clinical-epidemiological aspects and public health perspectives” (ImmiDem). Matteo Cesari has received honoraria for presentations at scientific meetings

and/or research funding from Nestlé and Pfizer. He is involved in the coordination of an Innovative Medicines Initiative-funded project (including partners from the European Federation Pharmaceutical Industries and Associates [Sanofi, Novartis, Servier, GSK, Lilly]). The other Authors have no conflict of interest to disclose.

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