Chapter 5
Mood and behavioural assessment

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Key points

- Psychological symptoms associated with cognitive decline can be part of the disease process but may be reactions to what is happening.
- Depression is a common symptom in early dementia.
- Behaviours such as agitation, paranoia, aggressivity, sleep disturbances usually occur well after the diagnosis of dementia is made but can be present in earlier stages.
- The term anosognosia refers to limited awareness of cognitive and functional deficits, but also to impaired awareness of emotional changes.

This is a chapter of the *World Alzheimer Report 2021, Journey to a Diagnosis of Dementia* which can be accessed in full at: https://www.alzint.org/resource/world-alzheimer-report-2021/

General background

Given the ongoing and prospective adjustments that cognitive decline may have on a person's day-to-day life, it is hardly surprising that an increase in psychological symptoms may also be witnessed. These may consist of depressive feelings, paranoia, anxiety, apathy and irritability. Whether it be characteristic of the condition's progression or a reversible reaction to the changes taking place, the person seeking a diagnostic assessment should anticipate questions about their psychological state during the history taking. As this is meant to gain a better understanding, provide an accurate diagnosis and orient treatment, one should not be upset or surprised if the family member or friend accompanying them is also asked to provide their observations about such symptoms. Both of you may want to express your opinions in private to allow for open and direct communication.

Background for clinicians

Non-specific mood and behavioural changes may precede dementia or even overt cognitive decline; this is the theory behind the new diagnostic criterion of Mild Behavioural Impairment (MBI), measured by the MBI-Checklist (Table 1). Depression is the most common first symptom encountered in early dementia. However, it is necessary to be able to differentiate apathy due to dementia, often presented as a disinterest in the activities of daily living, versus the symptoms of depression. Global informant-rated scales such as the NPI-Q (2) or MBI-C (3) can identify such symptoms.

> **The person seeking a diagnostic assessment should anticipate questions about their psychological state.**

Table 1. Mild Behavioural Impairment Checklist as an example of a structured questionnaire about mood and behavioural changes in early dementia

Mild Behavioural Impairment Checklist (MBI-C)

Date:

Rated by: ☐ Clinician ☐ Informant ☐ Subject

Location: ☐ Clinic ☐ Research

Circle 'Yes' **only** if the behaviour has been present for at least **6 months** (continuously, or on and off) and is a **change** from her/his longstanding pattern of behaviour. Otherwise, circle 'No'.

Please rate severity: **1** = **Mild** (noticeable, but not a significant change); **2** = **Moderate** (significant, but not a dramatic change); **3** = **Severe** (very marked or prominent, a dramatic change). If more than 1 item in a question, rate the most severe.

	YES	NO	SEVERITY
This domain describes interest, motivation, and drive			
Has the person lost interest in friends, family, or home activities?	Yes	No	1 2 3
Does the person lack curiosity in topics that would usually have attracted her/his interest?	Yes	No	1 2 3
Has the person become less spontaneous and active – for example, is she/he less likely to initiate or maintain conversation?	Yes	No	1 2 3
Has the person lost motivation to act on her/his obligations or interests?	Yes	No	1 2 3
Is the person less affectionate and/or lacking in emotions when compared to her/his usual self?	Yes	No	1 2 3
Does she/he no longer care about anything?	Yes	No	1 2 3
This domain describes mood or anxiety symptoms			
Has the person developed sadness or appear to be in low spirits? Does she/he have episodes of tearfulness?	Yes	No	1 2 3
Has the person become less able to experience pleasure?	Yes	No	1 2 3
Has the person become discouraged about their future or feel that she/he is a failure?	Yes	No	1 2 3
Does the person view herself/himself as a burden to family?	Yes	No	1 2 3
Has the person become more anxious or worried about things that are routine (e.g., events, visits, etc.)?	Yes	No	1 2 3
Does the person feel very tense, having developed an inability to relax, or shakiness, or symptoms of panic?	Yes	No	1 2 3
This domain describes the ability to delay gratification and control behaviour, impulses, oral intake and/or changes in reward			
Has the person become agitated, aggressive, irritable, or temperamental?	Yes	No	1 2 3
Has she/he become unreasonably or uncharacteristically argumentative?	Yes	No	1 2 3
Has the person become more impulsive, seeming to act without considering things?	Yes	No	1 2 3

Does the person display sexually disinhibited or intrusive behaviour, such as touching (themselves/others), hugging, groping, etc., in a manner that is out of character or may cause offence?	Yes	No	1 2 3
Has the person become more easily frustrated or impatient? Does she/he have troubles coping with delays, or waiting for events or for their turn?	Yes	No	1 2 3
Does the person display a new recklessness or lack of judgement when driving (e.g. speeding, erratic swerving, abrupt lane changes, etc.)?	Yes	No	1 2 3
Has the person become more stubborn or rigid, i.e., uncharacteristically insistent on having their way, or unwilling/unable to see/hear other views?	Yes	No	1 2 3
Is there a change in eating behaviours (e.g., overeating, cramming the mouth, insistent on eating only specific foods, or eating the food in exactly the same order)?	Yes	No	1 2 3
Does the person no longer find food tasteful or enjoyable? Are they eating less?	Yes	No	1 2 3
Does the person hoard objects when she/he did not do so before?	Yes	No	1 2 3
Has the person developed simple repetitive behaviours or compulsions?	Yes	No	1 2 3
Has the person recently developed trouble regulating smoking, alcohol, drug intake or gambling, or started shoplifting?	Yes	No	1 2 3
This domain describes following societal norms and having social graces, tact, and empathy			
Has the person become less concerned about how her/his words or actions affect others? Has she/he become insensitive to others' feelings?	Yes	No	1 2 3
Has the person started talking openly about very personal or private matters not usually discussed in public?	Yes	No	1 2 3
Does the person say rude or crude things or make lewd sexual remarks that she/he would not have said before?	Yes	No	1 2 3
Does the person seem to lack the social judgement she/he previously had about what to say or how to behave in public or private?	Yes	No	1 2 3
Does the person now talk to strangers as if familiar, or intrude on their activities?	Yes	No	1 2 3
This domain describes strongly held beliefs and sensory experiences			
Has the person developed beliefs that they are in danger, or that others are planning to harm them or steal their belongings?	Yes	No	1 2 3
Has the person developed suspiciousness about the intentions or motives of other people?	Yes	No	1 2 3
Does she/he have unrealistic beliefs about her/his power, wealth or skills?	Yes	No	1 2 3
Does the person describe hearing voices, or does she/he talk to imaginary people or 'spirits'?	Yes	No	1 2 3
Does the person report or complain about, or act as if seeing things (e.g. people, animals or insects) that are not there, i.e., that are imaginary to others?	Yes	No	1 2 3

Based on the ISTAART-AA Research Diagnostic Criteria for MBI ©2016 (3) as a precursor to cognitive decline and dementia. Mild Behavioural Impairment (MBI) describes neuropsychiatric symptoms (NPS) of any severity, which are not captured by traditional psychiatric nosology, persist for at least 6 months, and occur in advance of or in concert with mild cognitive impairment. The detection and description of MBI has been operationalised in the International Society to Advance Alzheimer's Research and Treatment – Alzheimer's Association (ISTAART-AA).

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The most troublesome behaviours such as agitation, paranoia, aggressivity and sleep disturbances usually arise well after the dementia diagnosis is confirmed. However, visual hallucinations early on may suggest dementia with Lewy bodies while the loss of social inhibition is indicative of a frontotemporal dementia. As dementia progresses into the moderate stage, other structured questionnaires such as the Neuropsychiatric Inventory are useful.

Behavioural symptoms associated with dementia have a significant healthcare impact on carer fatigue, depression and possible burnout. These factors accelerate the need for additional at-home resources. Early symptom occurrence is a predictor that advanced transfer and admission to long-term care facilities may be needed.

Survey results

1,111 multidisciplinary clinicians indicated their preference when asking about mood and behavioural changes. Most disclosed that they use a semi-structured approach to question the person with dementia complaints as well as the individual accompanying them, while the remaining clinicians use a structured questionnaire completed before or during the consultation.

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Expert essay

Measuring mood and behavioural changes as part of a complete dementia assessment

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Mood and behaviour changes in dementia are almost universal, occurring in up to 97% of people with dementia in the first five years after diagnosis (1). Termed neuropsychiatric symptoms, or behavioural and psychological symptoms of dementia, these changes include apathy, emotional dysregulation, agitation/impulse dyscontrol, disinhibited social behaviour, and psychotic symptoms. Neuropsychiatric symptoms are associated with greater functional impairment, accelerated cognitive decline, poorer quality of life, increased carer burden, higher rates of long-term care facility placement, greater mortality, and more neuropathological markers of dementia (2). Despite the clinical significance of behavioural changes, neuropsychiatric symptoms may be overlooked in a cognocentric dementia paradigm, where assessments focus on cognitive testing. However, awareness of non-cognitive markers of dementia is increasing (3), with inclusion of neuropsychiatric symptoms in this complementary symptom axis. Indeed, Canadian clinical guidelines emphasise the inclusion of neuropsychiatric symptoms for more thorough dementia assessments (4), as part of the cognition, behaviour, and function triad (5), all important factors to measure in clinical visits.

Other obstacles exist to fully assess the changes in mood and behaviour associated with dementia. These include clinician apprehension about causing distress, the perception that information may not be accurate, or an insufficient appreciation of the underlying neurobiology of neuropsychiatric symptoms – with an attendant belief that these changes are reasonable or simply attributable to cognitive impairment. Indeed, intervention, both pharmacological and non-pharmacological, is often required. The choice and implementation of treatments should be informed by appropriate and thorough assessments, grounded in the principles of measurement-based care.

Given the distress already associated with dementia, and/or a clinician's desire not to further upset the person during consultation, the path of least resistance may be to avoid inquiring about emotional or neuropsychiatric symptoms at all. On the face of it, this approach may appear kind and sensitive. However, failing to investigate these symptoms fundamental to their internal world, further diminishes the individual's personhood. Dementia can rob someone of their personhood by altering thoughts, feelings, and social behaviours. Understanding mood, behaviour, and emotion is essential to discerning the multifaceted aspects of dementia; neuropsychiatric symptoms are core dementia symptoms.

Notwithstanding the potential loss of decisional capacity as the condition runs its course, circumventing the assessment of neuropsychiatric symptoms can also diminish agency, namely the ability to influence their own personal circumstances. In fact, behavioural symptoms may very well be their attempt to communicate or exert agency (6). Assessing, exploring, and understanding these behaviours may contribute to better person-centred care. Conversely, if under-detected or untreated, neuropsychiatric symptoms can interfere with agency. Apathy, anxiety, poor frustration tolerance, impulsivity, suspiciousness or persecutory delusions can influence decision-making and an individual's ability to interact with the environment, possibly in contrast to long-standing habits. Assessing the neuropsychiatric symptoms can restore agency, allowing a person with dementia to influence their environment, more consistent with their pre-dementia selves.

Agency aside, the role of an informed carer, a family member, friend or formal carer (if in long-term care placement), is often overlooked when assessing neuropsychiatric symptoms. Indeed, who provides information is an important aspect of dementia care. Dementia is often associated with anosognosia, a lack of insight, which is linked with structural and functional changes in multiple brain regions, especially frontal and midline brain structures (7). Anosognosia can refer to limited awareness of cognitive and functional deficits, but also to impaired awareness of emotional changes, termed affective anosognosia (8). Research investigating report discrepancies between the person with dementia symptoms and the informant (respective carers or nurses) found that the person with dementia greatly underrated the severity of their depression symptoms (8). Thus, an approach that simply utilises a clinical interview, or that uses a measure that relies on personal endorsement

or self-reported symptoms may not accurately identify depressive symptoms, apathy, psychosis or behavioural disturbances associated with dementia. This insufficient appreciation of the extent or magnitude of neuropsychiatric symptoms can result in ongoing suffering or distress. If neuropsychiatric symptoms worsen and are only initially identified when exhibited in a crisis situation, a loss of autonomy, a change in living situation, or emergent pharmacotherapy may be required, none of which are optimal outcomes. Thus, early and ongoing assessment for neuropsychiatric symptoms is a component of good clinical care.

For some, a prevailing belief is that behavioural and psychological symptoms in dementia are 'noise', distracting from more concrete issues. However, an ever-increasing evidence base has elucidated the neurobiology of neuropsychiatric symptoms in dementia, with cortical and subcortical structures implicated, as well as traditional dementia markers of amyloid-β and tau (2). Indeed, the latest evidence suggests that dementia-related neuropsychiatric symptoms can emerge ahead of dementia, in prodromal or preclinical phases, associating with known dementia biomarkers (9). These findings again support the role of neuropsychiatric symptoms as core dementia features, necessitating assessment and monitoring, much the same way a clinician would assess and monitor cognition and function (2,5).

Clinically significant mood and behaviour changes in dementia require a cautious yet evidence-based treatment approach, grounded in measurement-based care. Scales for neuropsychiatric symptoms are recommended for routine screening, at the very least to identify a global neuropsychiatric burden (for example, the informant-rated Neuropsychiatric Interview Questionnaire), and to track these symptoms over time. Distress, safety issues, or impact on function point to neuropsychiatric symptoms that are clinically significant. First principles of behavioural changes in older adults apply, such that reversible causes first need to be ruled out, followed by non-pharmacological interventions, and then short-term pharmacological treatment if necessary (10). Frequent follow-up and measurement are required, balancing safety and efficacy, to optimise cognition, behaviour, function, and quality of life.

Therefore, while possibly uncomfortable or challenging, it is of utmost importance to regularly assess neuropsychiatric changes in a person with dementia. These mood and behavioural symptoms are a fundamental part of the dementia process, considered core criteria in dementia, associated with known dementia biomarkers, thus leading to poorer outcomes. Leveraging the knowledge and observations of an informed carer, as well as asking the person with dementia themselves about neuropsychiatric symptoms, is a person-centred approach to dementia, and should be routine practice.

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Conclusions

Given the significant impact of dementia on an individual's quality of life, an increase in mood and behavioural symptoms such as depressive feelings, paranoia, anxiety, apathy and irritability may become present. These neuropsychiatric symptoms, whether associated with changes to the brain or an emotional reaction to current circumstances, need to be assessed in a comprehensive manner. In fact, these symptoms may precede dementia but are often overlooked when the focus is on cognitive testing.

Also frequently overlooked is the role of an informed carer who is understandably well-placed to observe these symptoms. When anosognosia is factored in, the impaired awareness of cognitive and emotional changes, this makes a carer's feedback even more relevant. Thus, a combined approach of self-reporting and informant interview and/or questionnaire will yield a more complete picture. This may occur in a semi-structured interview setting and/or by using a structured tool such as the MBI-Checklist.

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