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Hypothesis

A Multidimensional, Person-Centered Framework for Functional Assessment in Dementia: Insights from the 'What', 'How', 'To Whom', and 'How Much' Questions

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Abstract. Dementia is a syndrome characterized by cognitive and neuropsychiatric symptoms associated with progressive functional decline (FD). FD is a core diagnostic criterion for dementia, setting the threshold between its prodromal stages and the full-blown disease. The operationalization of FD continues to generate a great deal of controversy. For instance, the threshold of FD for the diagnosis of dementia varies across diagnostic criteria, supporting the need for standardization of this construct. Moreover, there is a need to reconsider how we are measuring FD to set boundaries between normal aging, mild cognitive impairment, and dementia. In this paper, we propose a multidimensional framework that addresses outstanding issues in the assessment of FD: i) *What activities of daily living (ADLs)* are necessary to sustain an independent living in aging? ii) *How to* assess FD in individuals with suspected neurocognitive disorders? iii) *To whom* is the assessment directed?

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and iv) *How much* does FD differentiate healthy aging from mild and major neurocognitive disorders? Importantly, the *To Whom Question* introduces a person-centered approach that regards patients and caregivers as active agents in the assessment process of FD. Thus, once impaired ADLs have been identified, patients can indicate how significant such impairments are for them in daily life. We envisage that this new framework will guide future strategies to enhance functional assessment and treatment of patients with dementia and their caregivers.

Keywords: Activities of daily living, Alzheimer's disease, dementia, disability, functional dependence, functional independence, functional status, person-center care, functional ability

INTRODUCTION

Dementia, or major neurocognitive disorder, is a syndrome that encompasses multiple etiologies defined by specific cognitive and neuropsychiatric symptoms that interfere with the individual's functional abilities to perform activities of daily living (ADLs) [1]. Although dementing disorders differ in their clinical expression and prognosis, they share a set of common characteristics, including progressive cognitive and functional decline (FD), defined as a deterioration in the ability to perform ADLs. Despite the advent of novel biomarkers, FD remains crucial in both clinical and research settings for neurocognitive disorders. FD is considered a characteristic that sets the boundaries between normal aging, mild cognitive impairment (MCI) or mild neurocognitive disorder, and dementia or major neurocognitive disorder. Besides diagnosis, FD is fundamental in monitoring disease progression, evaluating burden associated with care delivery and delivering adequate comprehensive treatment [2]. Such a role makes assessment of FD a crucial role both for clinical diagnosis and treatment. In clinical diagnosis, assessment primarily focuses on evaluating an individual's capacity to perform ADLs. By doing so, the examiner can determine the level of functionality within the individual's environment and establish whether objective criteria for diagnosing neurocognitive disorders are met. When it comes to treatment, a thorough evaluation of FD is essential. It contributes to designing person-centered strategies aimed at supporting both individuals with dementia and their caregivers [3].

Research evidence shows that FD correlates negatively with quality of life and increases the risk of institutionalization [4–6]. Timely and effective assessment of FD enables healthcare providers to determine the dementia severity, design interventions to maintain functional abilities, help patients and caregivers plan the journey, and provide legal and safety counseling [7, 8]. A significant leap in the understanding of FD in dementing disorders was triggered by the categorization of ADLs into three main subdomains according to the compromised function, complexity, and neurocognitive substrate [9]. The classification considers 1) basic activities of daily living (BADLs); 2) instrumental activities of daily living (IADLs); and 3) advanced ADLs (a-ADLs). There remains a question concerning the amount of FD that should warrant a dementia diagnosis.

According to the National Institute of Neurologic, Communicative Disorders and Stroke – Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) [10], dementia is diagnosed when cognitive and neuropsychiatric symptoms interfere significantly with the individual's functional abilities to perform ADLs. Nevertheless, in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [11], the concept of "significant" FD was not retained. The DSM-5 introduced the concept of independence in daily life as the pivotal point to pose the diagnosis of dementia, i.e., the diagnosis is warranted when cognitive and neuropsychiatric symptoms interfere with the functionality necessary to maintain independence in daily life. The diagnosis is justified when cognitive and neuropsychiatric symptoms interfere with the functionality necessary to maintain independence in daily life.

The adjustment of the threshold shows how difficult it is to define and operationalize the amount of FD needed to arrive at a diagnosis of dementia [12]. The functional construct of ADL scales continues to generate a great deal of controversy and debate in clinical and academic contexts [13]. For instance, after the reconceptualization of MCI based on FD, Morris [14] applied the revised criteria to their cohort and found that 99.8% of individuals diagnosed with very mild Alzheimer's clinical syndrome (ACS) at the dementia stage could be reclassified as MCI, based on their level of impairment in the Clinical Dementia Rating domains for performance of IADLs in the community and at home. The author highlighted that the categorical distinction between MCI and the very mild stages of dementia in the ACS has been blurred by the revised criteria. However, the author also noted that the resulting diagnostic overlap supports the premise

that "MCI due to Alzheimer's Disease" represents the earliest symptomatic stage of Alzheimer's disease, hence calling for better ADL scales to reliably identify the prodromal stages of the ACS [14].

In clinical practice, FD is usually determined by the clinical judgment of an expert, who usually takes as reference the information of a caregiver or family member. This information is often influenced by emotional factors, so clinical judgments may lack the necessary impartiality [1]. In addition, the tools available to evaluate FD do not usually consider the basic neurocognitive mechanisms necessary to carry out each of the daily activities. For instance, asking if someone retains the "Ability to use the telephone" and considering the ability impaired when the person "Does not use telephone at all" overlooks subtle yet important functions needed to perform this activity (e.g., knowledge of mobile phone uses, visual-motor abilities, etc.). Nor do these tools consider the context in which the person lives [15]. A person may have the cognitive and physical abilities to perform an action in a context with different possible contingencies. However, when that context is not part of the subject's usual environment, the activity loses its meaning as important to independent living. For instance, a person who lives in the city and frequently uses public transport does not need to drive. These limitations point to important gaps in "how" FD is being formulated and interpreted by available assessment tools, even if important advances have been made to pick up more subtle cognitive deficits and better capture the level of difficulties in performance on ADLs [16].

To contribute to a more appropriate diagnosis and treatment of people with dementia [8], there is a clear need to rethink how we assess FD. This involves considering both objective measures of FD (referred to as 'objective FD' hereafter), which are rooted in the biomedical definition of dementia, and person-centered and meaningful measures of FD (referred to as 'meaningful FD' hereafter), aligning more closely with the psychosocial perspective of dementia. As a result, meaningful FD needs to assess elements that hold significance for individuals and their caregivers. Importantly, due to the complexity of FD, there exists an overlap between the biomedical and person-centered measures, as we will elaborate in the manuscript.

Addressing this matter and current gaps in assessment of FD, as explained below, requires a comprehensive or multidimensional assessment of FD. In this manuscript, we propose a framework to design a multidimensional assessment of FD, including both objective FD and meaningful FD, underpinned by four questions, represented in Fig. 1: i) What ADLs are necessary to sustain an independent living? The What Question also encompasses evaluating what ADLs are objectively impaired and identifying observable changes in ADLs. ii) *How* to assess FD in individuals with suspected neurocognitive disorders? iii) *To Whom* is the assessment directed? The *To Whom Question* fundamentally refers to what is relevant and meaningful for a person with dementia and its caregivers, such as their interests or purpose; and iv) *How Much* FD differentiates healthy aging from mild and major neurocognitive disorders? Indeed, responses to the *What* and *How Much* questions are strongly related to the response to the *To Whom Question*. To respond to these questions, and more specifically, to the *To Whom Question*, we propose to expand objective assessment of FD incorporating the perspectives of patients and caregivers in clinical workups and to bring to the fore the notion of "meaningfulness" in FD, i.e., meaningful FD, as a means to support person-centered care in dementia [17]. Importantly, the goal of our multidimensional, Person-Centered Framework for Functional Assessment in Dementia is to propose a methodology for enhancing the assessment of FD, including an objective and person-centered approach. This is particularly important considering the lack of consensus on the diagnosis of dementia, as illustrated, for example, by different definitions on the concept of timely diagnosis in the biomedical or biopsychosocial paradigm on dementia [18]. Diagnosis based only on meaningful FD assessment presents the risk of underdiagnosing dementia or delaying its diagnosis. In this sense, both objective and person-centered measures of FD are critical in the process of diagnosis and treatment processes of dementia. On the one hand, objective measures of FD are necessary to properly quantify the amount of assistance needed in daily living, independently of the value the person or their caregiver places on the FD. On the other hand, meaningful FD is very relevant to plan treatment and could also contribute to enhanced assessment of FD in the diagnosis process when there is doubt regarding FD with objective assessment. In this context, assessment of FD needs to consider the goal of assessment, i.e., diagnosis and/or treatment. See Table 1 for a summary.

To raise awareness about the need to address these outstanding issues in the assessment of FD, we propose a new framework. To this aim, this paper will first set the context of functional assessment in dementia by briefly reviewing the evolution of the

Table 1
Methods for assessing functional decline in people with dementia

Objective assessment of functional decline	Meaningful assessment of functional decline
Answer to the questions: What, How and How much	Answer to the question: To Whom and How much?
Based on the biomedical model of dementia	Based on psychosocial model of dementia and person-centered care
Diagnosis and treatment oriented	Treatment oriented
Measures based on questionnaire, performance-based tests, and information and communication technology assessment	Measures based on the report of meaningfulness of ADLs.
	Meaningfulness of functional decline in the person with dementia and caregivers beyond objective functional decline and considering specific ADLs.

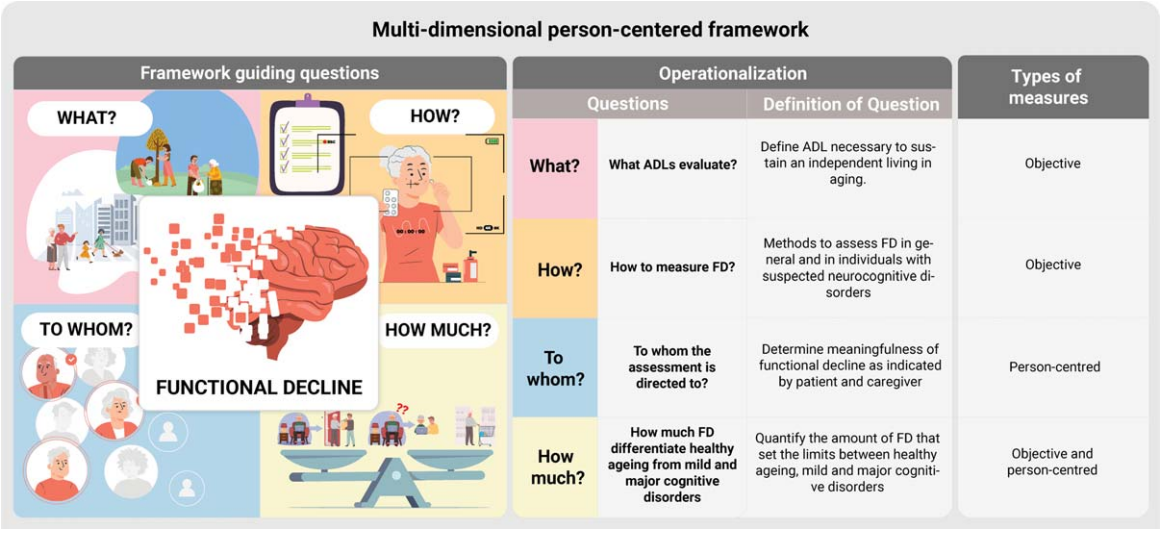

Fig. 1. A Multidimensional and Person-Centered Framework for Assessing the Functionality of Individuals with Dementia. Illustration of the multidimensional framework underpinned by four questions aimed at addressing outstanding issues in the assessment of functional decline. FD, functional decline; ADLs, activities of daily living.

concept of FD in brain disorders and discussing current understanding of their neurocognitive underpinnings. We will then discuss the rationale behind the four questions motivating our new framework highlighting the limitations of current objective assessments of FD. Finally, we will discuss a model on which the new framework would rely, envisaging that this will motivate strategies that can help overcome barriers in the functional assessment of dementia.

HISTORY OF QUESTIONNAIRE ASSESSMENTS OF FUNCTIONAL DECLINE IN DEMENTIA AND MILD COGNITIVE IMPAIRMENT

Functional assessment with objective measures began in the late 60 s and was aimed at institutionalized older adults [12, 15, 19]. However, due to factors such as stereotypes and social stigma linked to aging, the clinical evaluation of functionality was limited to BADLs. BADLs, also called physical or self-maintenance ADLs, focus on physiological and basic personal care and are essential for survival (e.g., eating, going to the bathroom, dressing, etc.). The emergence of dementia as a public health issue fostered the conceptualization of IADLs to describe an earlier and milder stage of FD [19]. In 1969, Lawton and Brody [14] published a questionnaire for the assessment of self-maintaining ADLs, i.e., BADLs and IADLs. IADLs are more complex ADLs related to interacting with the environment and necessary for independent living in the community in which a person lives (e.g., managing finances, shopping, handling medications or using public transport, etc.)

Subsequently, the description of dementia as a continuum that begins with a long and silent (presymptomatic) phase, and the description of MCI as an intermediate (prodromal) stage of cognitive impairment led to the inclusion of more complex ADLs, such as a-ADLs in functional assessment [20]. a-ADLs are more complex activities that are not essential to maintain an independent life and include activities necessary for complex interpersonal or social functioning [21]. a-ADLs require higher levels of cognitive, physical, and social functions, specifically they require greater attentional resources and are less automatic and more volitional than IADLs (e.g., employment, internet access, computer use, etc.) [12]. MCI is frequently, but not always, a transitional phase from cognitive alterations associated with normal aging to those with dementia [22]. The introduction of a-ADLs enabled the characterization of mild neurocognitive disorders that are distinct from those seen in the normal course of aging and still different from those found in major neurocognitive disorders (i.e., dementia). The initial operational criteria of MCI excluded functional impairment, evidence emerged suggesting that patients with MCI may have subtle impairments in complex ADLs, mainly a-ADLs, which do not undermine the abilities needed to live independently [20]. Noticeably, other authors proposed alternative classification of ADLs such as basic or complex ADLs [23, 24]. Finally, more recently, alternatives to objective assessment of FD have emerged. Newer scales have been designed to capture earlier and more subtle functional deficits that may impact performance of IADLs and a-ADLs. Examples of recent approaches to ADL scale development include assessing for i) the cognitive processes that are required in different ADLs [e.g., Everyday Cognition Scale (ECog)-[25]], ii) more subtle functional changes that may be reflected in the time, efficiency, error types or frequency with which tasks are completed (e.g., Alzheimer's Disease Cooperative Study Activities of Daily living Prevention Instrument (ADCS-ADL-PI) [26]), iii) increased use of compensatory strategies that often occurs in the beginning stages of functional decline (e.g., Instrumental Activities of Daily Living- (IADL-C) and Everyday Compensation (EComp) Questionnaire) [16, 27]), and/or iv) a-ADLs that involve modern technology use like internet or computer use (e.g., Technology-Activity of Living Questionnaire (T-ADLQ) [2]; Instrumental Activities of Daily Living Questionnaire (A-IADL-Q) [28]).

It is important to note that besides self- and informant-rated questionnaires, other methodologies have been proposed to enhance the validity of assessment of everyday functioning. These measures will be discussed in more detail later. For now, the evolution of ADLs included in the FD questionnaires is used to illustrate that the assessment of mild FD has gained importance over time. Furthermore, the absence of methodological consensus in the evaluation of FD emerges as a critical issue in the field.

A relevant issue in the era of the biological definition of dementia *in vivo* relates to the mapping of these various levels of FD to the underlying pathology. We address this in the next section.

NEUROCOGNITIVE CORRELATES OF FUNCTIONAL DECLINE IN DEMENTIA

Two theoretical approaches have underpinned studies on neurocognitive correlates of FD in dementia. One approach is driven by studies of FD based on ADLs. These studies explored neuropsychological factors and brain regions associated with impairment in global FD or by domain of ADLs (i.e., BADLs, IADLs, and a-ADLs), or in specific ADLs. Briefly, these studies suggest that different neuropsychological factors and brain regions were associated with different levels of ADL impairment and domain of ADLs supporting the notion that ADLs differ in terms of complexity [9, 29, 30]. Regardless, a review of these studies is beyond the scope of this paper, some studies are worth highlighting. For example, in mild and moderate Alzheimer's disease and people with healthy cognition, FD in IADLs and a-ADLs, were associated with memory impairment, whereas BADLs was associated with impairment in global cognition. Furthermore, these three domains of ADLs were underpinned by different, although partially overlapping, brain regions [9]. Low scores in BADL scales correlated mostly with frontal atrophy, low scores in IADLs with more widespread frontal, temporal and occipital atrophy and decline in a-ADLs with occipital and temporal atrophy, including the bilateral parahippocampal region [9]. In behavioral variant frontotemporal dementia, the presence of apathy was associated with FD in BADLs, IADLs and a-ADLs. However, disinhibition was an important contributor to FD in BADLs while FD in IADLs was also associated with deficits in executive function and emotion recognition [29]. In people with healthy cognition, divergence in the neuroanatomical

substrate of a-ADLs, specifically leisure activities, has been reported according to the type of activity involved, i.e., physical, or social activity [31]. More recently, subtle difficulties in some IADLs were associated with mildly higher amyloid burden and worse cognition in cognitively normal elderly [32].

The second approach is driven by theoretical models explaining neurocognitive processes that support everyday actions, i.e., the goal control model of FD. In this model, neuropsychological and neural correlates of FD are inferred from the analysis of errors observed in performance-based tests and their correlation with neuropsychological deficits and their neural correlates in neuroimaging studies [33]. From this perspective our question framework can help disentangle transition stages from normal to severely impaired functional abilities and in so doing provide more meaningful behavioral evidence that contributes to the evaluation of FD.

RELEVANT QUESTIONS ABOUT THE ASSESSMENT OF FUNCTIONAL DECLINE

The What Question

The first question poses the following problem: *what* ADLs are necessary to sustain independent living as we age, and more importantly, as we depart from the normal aging path? To answer the *What Question*, it is necessary to consider several relevant points.

First, the World Health Organization (WHO) defines healthy aging as "the process of developing and maintaining the functional ability that enables older people to do the things that matter to them" [34, 35]. This capacity can be compromised by factors associated with the individual and the environment. Secondly, while BADLs are essential for survival and IADLs for maintaining independent living, the three domains of ADLs (i.e., BADLs, IADLs, and a-ADLs) are culturally driven and subject to variation based on the following variables:

(1) Inter-country variability: living facilities are heterogeneous. There are important differences between the support environments found in high- and low-income countries [36, 37]. For example, assistive technologies that can compensate for FD and prolong independent living are becoming more readily available in high income countries [38].
(2) Intra-country variability: there are differences between rural and urban areas in the same country, as well as the support received by some ethnic groups (e.g., indigenous population) [39]. For example, in the Everyday Abilities Scale for India designed for assessing dementia in illiterate rural elderly, one of the IADLs is the ability to work in group activity which requires different roles from people due to the importance of collective labor in agriculture [40].
(3) Inter-individual variability: daily performance may vary according to age, sex, educational level, social class, and work history [41]. For example, the food preparation, housework, or laundry items of the Lawton Instrumental Activities of Daily Living Scale are still very gender-biased in many countries even if households are becoming more egalitarian [42].
(4) Cultural evolution: culture shapes the environment wherein we function, which in turn determines how we perform some ADLs. For instance, the emergence of information and communication technologies is one of the most important drivers of cultural changes to which IADLs and a-ADLs need to constantly adapt [43]. Indeed, the T-ADLQ [2] and more recently the ADCS-ADL-PI [26] included technologies related to ADLs such as internet access or ATM use in the T-ADLQ [2]. Nevertheless, technology-related IADL items do not yet hold cross-cultural validity as access to and reliance on technologies are still uneven across high- and low-income countries.

These variables explain that IADLs and a-ADLs relevant to sustain an independent life could vary as a function of time, inter-subjects, intra-country, and inter-country variability, thus creating challenges in the design of such instruments [42, 44]. Additionally, these variables also influence how BADLs are executed. Assessment tools that do not consider this variability could lead to an inaccurate evaluation of FD and potential errors in the diagnosis of dementia.

A good practice model incorporating these variabilities comes from the study of Fillenbaum et al. [40]. These authors proposed an appropriate and ecological measure of ADLs aimed at assessing functional loss among illiterate people with dementia in rural areas of India. An item from the questionnaire illustrating this validity for this population is: "Is he / she able to remember important festivals such as Holi, Diwali?" Other instruments such as the Iden-

tification and Intervention for Dementia in Elderly Africans (IDEA) study – Instrumental Activities of Daily Living (IDEA-IADL) [45], the Central African – Daily Functioning Interference (DFI) scale [46] or the Thai ADL measure have also been developed and adapted to specific cultures [47] (for a recent review see Yemm et al. [37]). Nevertheless, the development of culturally specific instruments raises the issue of the trade-off between generalizable or culturally specific measurement of functionality.

An ancillary issue regarding this question is in what domain of ADLs to rate impairment in ADLs. For example, the T-ADLQ measures 33 different ADLs captured with seven subscales (self-care, household care, employment and recreation, shopping and money, travel, communication and information and technology), and in three subdomains (BADLs, IADLs, and a-ADLs) [2]. It provides a global FD score, and FD by types of activities and subdomains. The Disability Assessment for Dementia (DAD), an informant-based questionnaire that includes 40 ADLs (17 related to BADLs and 23 to IADLs), assesses the components of performance during action, i.e., initiation, planning, or execution, and the extent to which impairment in such components account for FD [48]. However, although these instruments collect the degree of involvement of ADLs and the process associated with FD, there is no consensus regarding which domains, and more specifically, what ADLs must be altered to deem a person unable to sustain independent living due to functional impairments.

As we discussed previously and will further emphasize the personalized approach in assessment when considering the To *Whom Question*, the *What Question* raises the trade-off between a generalizable or tailor-to the person assessment. Generalizable assessment could foster the development of standardized and reliable metrics of functional decline. Nevertheless, the *What Question* could also be posed in the framework of the *To Whom Question* enriching assessment by incorporating specific ADLs relevant to the person being assessed.

Reflections on the What Question

The *What Question* is among the most central inquiries in functional assessment, aiming to define what ADLs determine the capacity to live independently. We hypothesize that two main factors that impact functional abilities are critical to determine what ADLs to evaluate to infer the capacity to maintain an independent life: external and internal factors. External factors are contingent upon features of the environment defined in a broad sense, i.e., the natural world but also the collective social and cultural conditions that influence an individual's life [49, 50]. As explained above, external factors are related to the place where the person lives, i.e., a where subquestion. For example, in certain cultures elderly people are expected to be able to manage their finances while in others there are cultural expectations that older adults engage in more social activities while younger people would manage the financial matters [37]. Internal factors consist of biomedical variables such as age, gender, and physical or cognitive abilities of individuals, which could explain the inter-individual variability among people living in the same place [35]. Indeed, ADLs needed to maintain an independent life could vary depending on the life stage. For example, the ability to work could be considered critical for independent living before retirement age. Finally, the goal of the assessment is a very important factor that could help answer the What Question. Identifying impaired ADLs for a diagnostic purpose, using objectives measures, could be different from identifying impaired ADLs for treatment purposes where ADLs that are meaningful for an individual with dementia and their caregiver could be critical for more person-centered care. For example, an older adult may have difficulty remembering how to do laundry. This behavior would initially be recorded by the examiner as a "functional deficit in home care activities." However, despite this, it may happen that this reported loss does not pose difficulties or psychological discomfort for that person since, for different reasons, it is not important to them.

To advance in this field, interdisciplinary research encompassing psychosocial, cultural, and biomedical aspects is required. This research should result in the creation of new tools that facilitate the selection of ADLs in accordance with the aforementioned factors, thereby simplifying the response to the What Question.

However, it is not only necessary to know what functional activities are necessary for an independent life, but also to consider how the information is collected.

The How Question

The second question we suggest needs to be considered is How to assess FD in individuals with suspected dementia.

Broadly, standardized instruments for the evaluation of FD could be divided into two main types: instruments that assess one specific category of ADLs such as "managing finances" or "use of technology" and instruments that several categories of ADLs [50, 51]. There are three main approaches for the evaluation of FD: i) questionnaire, ii) performance-based tests, and iii) technology-based assessment [52].

Questionnaires can be filled in by the informant (family member, friend, caregiver, etc.) or by the patient him/herself. They are often called "subjective evaluation" of functional abilities because they rely mainly on the subjective perspective of the person that completed the questionnaire. This perspective encompasses thoughts, memories, impressions, and emotions tied to various experiences under different conditions. The informant can offer an opinion that is biased by factors such as emotional burden or willingness to accept or report the changes [53]. Likewise, cultural factors linked to aging such as social stereotypes (also called "ageism") can reduce the reliability and accuracy of the assessment of FD [54, 55]. The most frequent assessment in clinical practice uses informant-based questionnaires, since patients with dementia frequently present anosognosia limiting the reliability of their report [56]. The instruments usually rely on Likert-type scales, in which at one end there is complete independence and at the other end there is an absolute disability or a complete loss of the ability to carry out certain activities. Due to its ease, simplicity, and speed, it is usually the most widely used assessment approach. Currently, there are several questionnaires that differ in the type of ADLs assessed, the response options used to collect the information and the methods used to quantify FD (for a review of these instruments, see [28]).

Performance-based tests offer an objective and accurate method of assessing functional capacity. They consist of direct observations of performance as the person completes ADLs required by the examiner (e.g., locate a number and make a telephone call) [16, 57]. Example tests include the Direct Assessment of Functional Status (DAFS), consisting of eight IADLs [58], and the Revised Observed Tasks of Daily Living (OTDL-R), composed of nine everyday tasks [59]. Despite addressing some of the drawbacks of questionnaires, these scales carry other challenges to be used in clinical practice. For instance, they are time consuming and require more resources. Yet, they can be useful for predicting, for instance, the types of behaviors that are contributing to impaired functional performance such as omissions, substitutions, or irrelevant actions as the process by which the individual completes the tasks can be observed and coded [57]. However, their ecological value could be questioned, since performing a task in a well-structured laboratory or clinic environment would significantly differ from performing a task in a real-life setting, which is ill-structured. Moreover, the laboratory or clinic is typically devoid of everyday environmental cues and typical compensatory supports that may be used in the real-world environment. These kinds of evaluation also do not include all ADLs, and typically involve assessment of IADLs, with some newer performance-based tasks assessing a-ADLs such as performing banking transactions [60], filling a prescription by phone [61], or preparing for a night out [62].

Technology-based assessment has recently emerged as a new alternative to the assessment of ADLs. For example, virtual and augmented reality (VR/AR) technologies are creating opportunities to overcome barriers in the ecological assessment and intervention of functional abilities within the laboratory [63]. Furthermore, it is now possible to monitor IADLs continuously and unobtrusively in the everyday environment using sensors that can be fixed in the environment (e.g., motion sensors in smart homes), attached to the person (e.g., smartwatch) or to equipment the person uses (e.g., car, phone) [52]. These technologies can capture typical functioning, as compared to functioning under optimal laboratory conditions, and can be paired with other methods such as ecological momentary assessment to further explore the effects of contextual and time-varying influences on performance [64]. Pill box use, vehicle driving performance, activity level in the home, and sleep interruptions are examples of behaviors that have been monitored with sensors placed within the real-world environment [65, 66]. Although there are challenges associated with this work, ranging from batteries that need to be frequently charged to large amounts of data that must be analyzed, these technologies offer new opportunities to enhance functional assessment.

Regardless of the method used to assess functional impairment, answers to the *How Question* are far from clear-cut. Objective assessments fail to establish a consensus regarding how to evaluate different ADLs. In other words, the material and economic resources involved, time constraints in clinical settings, lack of association between performance-based measures and informant-based measures, as well as the lack of demonstrated ecological valid-

ity of some instruments reinforce the notion that the various edges to the *How Question* need a more comprehensive approach. Although technology-based assessments, including ambient and wearable sensors and ecological momentary assessment, hold promise for evaluating ADLs and understanding the effects of contextual factors on performance within the everyday environment, more research is needed. It is also expected that the data derived from these newer technologies will lead to the development of improved clinic-based measures that can provide a more ecologically valid assessment of FD [67].

Reflections on the How Question

We hypothesize that limitations of current assessment of FD could be explained by the fact that typically information is collected mainly from one source. On the one hand, informant-based questionnaires are generally completed by one caregiver, omitting characteristics of caregivers (e.g., caregiver management styles; depression), which may influence the evaluation of functionality [53]. On the other hand, informants are being asked to provide a score for each ADL, which may not reflect the variability in performance on an ADL that can occur across time and context. Similarly, performance-based tests typically examine the capacity to complete one or a limited number of ADLs at one time under standardized conditions in an environment that is devoid of typical environmental supports. Also, as description of FD across the continuum from healthy aging to major neurocognitive disorders has become more precise, the use of compensatory strategies has emerged as an important dimension in the evaluation of functionality. These strategies are defined as internal (e.g., repetition of information, mnemonic) or external (e.g., memory notebook, alarm) methods developed to cope with impairments in cognition and to maintain functionality. This is illustrated by the recent availability of questionnaires on the use of compensatory strategies in everyday life [16, 27]. In the field of dementia, it is crucial to distinguish between individuals with FD who have the capacity to compensate and those who lack this capacity and require care support and assistance to deal with FD. Although this distinction may be challenging, enhancing our ability to do so could improve diagnoses by defining the threshold between those who can be independent in daily living and those who cannot. Furthermore, it could improve treatment and promote patient functional independence where appropriate. Importantly, as proposed by the International Classification of Disability, the type of compensation strategies and support, as well as their success, depend both on the capacity of individuals and the environment (see the 'how much' questions for further discussion on this point) [68].

Finally, current assessments generally do not combine different methods of assessments, such as informant and performance-based assessments [50]. We hypothesize that to overcome these limitations there is a need to design instruments that integrate different sources of information and are not restricted to one time and one context. This could be achieved by including the perspective of different proxies via informant-based questionnaires, by asking both the patient and the caregiver to use an "ADLs performance diary" and rate performances across different times and context, by adding informant and performance-based assessments or including newer technologies to continuously monitor ADLs in the everyday environment. This strategy could yield outcomes that can better reflect the real capacity of patients in real life. Certainly, this strategy is more time consuming. Like using cognitive screeners to determine whether an in-depth neuropsychological assessment is warranted, we recommend that a multidimensional assessment could be reserved for cases where it could improve clinical management. For example, cases where assessment could contribute to clarifying diagnosis when current instruments are not sufficient and/or cases where a more comprehensive assessment of FD, including meaningful FD, could benefit treatment and recommendations for use of compensatory strategies and support maintenance of functional independence.

Beyond the *What* and *How Question*s, a multidimensional assessment of FD must effectively incorporate the viewpoints of the person with dementia, caregivers, and other significant individuals. In the *To Whom* question, we explore ways to enhance the assessment by including these perspectives. How the person interacts with the environment will also depend on their personal priorities, which indicates the need for a new approach to the evaluation of FD that could complement objective assessments [69].

The To Whom Question: the person-centered model and meaningful functional decline

As mentioned earlier, assessment of FD is a complex construct that must consider not only the relationship between the capacity of the subject and

support from the environment, but also to whom the assessment is directed. In other words, understanding the person as an active agent of the process of change and decision-making [70]. This appraisal is concordant with the recommendation to incorporate in the clinical assessment ways of gauging how meaningful a clinical output or a change is for patients and their caregivers [71]. This perspective has led to the development of new theoretical approaches that complement objective models. One of the best-known models in the field of applied research corresponds to person-centered care. This model is defined as a care approach in which health care providers partner with patients to co-design personalized care that responds to people's needs [72]. Person-centered care is grounded on one hand, in the bioethical principles of autonomy, participation, individuality, and social inclusion, among others. On the other hand, it relies on empirical evidence, that is, research that has shown the benefit of care in improving people's quality of life [73, 74]. As proposed by Mast et al. [75], in dementia, person-centered care offers a broader and more integrative view of the person, creating opportunities for more personalized assessment and intervention planning.

For example, a person with early-stage dementia may have difficulty with banking. Objective FD will show impairment in this ADL. However, this task may never have been relevant to that individual, as they usually preferred to delegate that task to someone else. Moreover, some cognitively and functionally impaired individuals may not experience the psychological consequences of FD in everyday life because they have external support that will help them compensate for their functional loss [76]. Similar experiences are observed in older people who do not have cognitive decline but who have never carried out certain tasks [71]. From this perspective, the classical functional assessment approach, which is based on objective assessment of FD, would provide information on the impact that the disease has on an individual's abilities. This information is essential for diagnosis and treatment. While in our framework, objective FD is complemented by the newly proposed meaningful FD, aiding in the incorporation of person-centered care into treatment and care plans [75].

Importantly, this approach needs to consider that persons with dementia may present with anosognosia, i.e., lack of insight into their impairment, even in preclinical or early phases of dementia [77, 78]. Moreover, anosognosia usually increases throughout the progression of the disease when FD becomes more significant, representing an important challenge on how to integrate the perspective of the person with dementia into meaningful FD. This opens a discussion on the limits to the person-centered approach in dementia and questions whether meaningful FD focused exclusively on the person with dementia without considering the caregiver's perspective would be sufficiently informative and reliable [79]. We propose that both the perspective of the person with dementia be included along with the caregiver in assessment of meaningful FD. Although anosognosia limits the reliability of self-report measures of functionality [79], even in the presence of anosognosia, the perspective of the patient is an important dimension in assessment of meaningfulness. For example, Stoner et al. have shown that patients with dementia can evaluate their social independence [80]. In addition, strategies have been devised to reduce the influence of anosognosia through the way the question is phrased when considering the patient's perspective [79]. Even in absence of anosognosia, the meaningfulness surrounding how a specific FD is viewed could differ between the person with dementia and their caregiver. For example, the person with dementia might not feel a loss in an ADL like cooking if it is taken over by the caregiver; however, this loss could be overwhelming for the caregiver who must now take on an additional responsibility. Indeed, FD in patients is associated with self-reported increased burden by caregivers [81].

Weinfurt [82] raised the need to distinguish between "noticeable changes" and "valuable changes". The first corresponds to the changes perceived by the person or the caregiver, so they refer to those behaviors that the person clearly cannot do as before (or can do with greater difficulties). The second refers to those changes that are significant for the person and/or their caregiver. Specifically, this author points out that there is a lot of ambiguity when asking what constitutes a clearly significant change, especially when the aim is to obtain measures of performance and perception.

With current assessment methods, the diagnosis of dementia can have a negative and clinically significant impact on patients' self-esteem and self-efficacy, which can constitute a barrier to both seeking help by patients and their caregivers and to the disclosure of a dementia diagnosis by healthcare professionals. This can be underpinned by the feeling that nothing can be done, even if current evidence sug-

gests the benefit of access to diagnosis [83]. In this sense, including meaningful FD in diagnostic assessments could help address barriers to diagnosis and limit potential harms of diagnosis disclosure [84–86].

Identifying FD with objectives measures and incorporating meaningful FD can greatly contribute to the process of evaluation, diagnosis, and development of person-centered interventions to promote functionality, such as goal-oriented intervention [87]. This can improve people's physical and emotional well-being. However, it should be noted that this new approach should complement objective assessment, enhancing assessment of FD as a continuum from diagnostic to treatment. This is particularly important since objective functional assessment allows for detection of FD that may not be reported as problematic by informants but rather attributed to other factors, such as the normal phenomenon of aging [86].

Several instruments that consider the needs of patients have been developed. One of the most widely used is the Goal Attainment Scale (GAS) [88], which measures the achievement of goals during the intervention process in a mental health context. The GAS requires that the objectives of the individualized intervention are first clearly defined, then regular monitoring is carried out and summarized according to a formula that classifies the degree of achievement of the selected objectives. The GAS has been widely used across different pathologies, including dementia, with clear improvements in treatment expectations among patients, caregivers, and clinicians [88]. For example, Jennings et al. [89] reported that patients with dementia and their carers included in GAS the capacity to perform self-care activities, household and daily activities, and recreational activities. While the GAS has incorporated much-needed measures of change in clinical assessment, it lacks evaluation of the value of each goal for patients and empirical evidence supporting the psychometric properties of reliability and validity [89]. Another widely recognized instrument is the Canadian Occupational Performance Measure (COPM) [90]. This semi-structured interview facilitates the evaluation and prioritization of everyday issues that can limit an individual's participation in daily living. Although it was not primarily designed for dementia, it enables the identification and prioritization of issues and problems related to personal care, leisure, and productivity. However, it is important to note that the COPM does not provide an objective evaluation of FD [91].

Reflections on the To Whom Question

Given the aforementioned evidence, there is a pressing imperative to expand the application of the person-centered model in the assessment, timely diagnosis, and treatment of individuals with dementia. This involves prioritizing their personal motivations and using them as drivers to navigate challenges posed by the environment. In the case of functional assessment, this approach would facilitate the development of strategies to tailor clinical information to the needs of the person and the caregiver, considering their priorities and avoiding as much as possible further emotional, psychological, and functional impairment. Importantly for our framework, researchers grounded in the person-centered model have demonstrated that individuals with dementia maintain their personal identity even when experiencing significant cognitive impairments [70, 92]. This evidence suggests that the meaningfulness of ADLs is preserved despite the individual losing the ability to realize it. When assessing FD, the standardized approach is to ask patients about their ability to perform different ADLs independently. If we use the principles underpinning the person-centered model to complement this assessment, once the patient has reported their difficulty in, for example, "remembering to take the medication", the meaningful functional evaluation should raise the following question "How meaningful is this ADL to this person?". Importantly, a comprehensive answer to the *To Whom Question* requires including in the evaluation of FD specific ADLs that are meaningful both for the person with dementia and their caregivers.

With this methodology, the examiner would have an indication of the person's self-appraisal of his/her FD, so that the patient becomes an active agent during the process of disclosing the diagnosis. On the other hand, difficulties with medication could be significant and overwhelming for the caregiver (e.g., time consuming, caregiver availability) who must now take on an additional responsibility. Nevertheless, the individual with dementia, aided by external support such as reminders from a carer or assistive technologies, will not experience significant disruption in their daily life despite their functional loss. Additionally, as we discussed previously with the *What Question*, the *To Whom Question* needs to go beyond the generalizable approach of ADL questionnaires. From this perspective, the multidimensional assessment of FD, including both objective and meaningful FD, would assist in the diagnosis (i.e., patient "is not capable of

dispensing own medication" and in treatment (i.e., to mitigate caregiver burden).

Current trends in the diagnosis of dementia have shifted towards the new biomarker framework. Available biomarkers do not reliably predict the progression of MCI to dementia at the individual level [93]. Hence, reliance on biomarker evidence can lead to misdiagnosis, which can ultimately have devastating consequences for patients and their caregivers [94]. Indeed, current diagnosis with biomarkers is mostly recommended for research contexts and not for routine clinical practice [93]. This, together with the growing consensus in the field of public health regarding the need for a timely and personalized diagnosis of dementia, suggest that the incorporation of "meaningfulness" to any action undertaken as part of the diagnosis, would increase the effectiveness of diagnostic and treatment [95]. This is because the way in which the diagnostic process occurs can significantly influence the emotional wellbeing and the willingness of patients to receive treatment [96, 97].

Finally, a significant challenge lies in improving the quantification of FD. A more precise measurement of functionality, ranging from no functional impairment to total dependency, could substantially contribute to a more accurate evaluation, thereby reducing the risk of underdiagnosis or overdiagnosis of neurocognitive disorders. Furthermore, it's essential to discuss the relevance of quantifying FD when assessing meaningful FD. In the *How Much Question*, we delve into the challenges associated with the quantification of FD.

The How Much Question

This question relates to the issue of how much FD is necessary to undermine someone's ability to sustain previous levels of functionality or impede independent living. The response to this question requires a more precise measurement of functional abilities to enhance differentiation between healthy aging and mild and major neurocognitive disorders, considering the variability in living contexts.

Answering this question will help to define the boundaries more clearly between healthy cognitive aging, mild, and major neurocognitive disorders. Indeed, in the context of clinical evaluation, it has proved difficult to define the threshold of FD for the diagnosis of dementia. Typically, this threshold is defined by a clinician who collects information reported by a family member, a caregiver or from other sources, and whose clinical judgment will depend on factors such as knowledge of dementia and confidence with the diagnosis [94]. In this context, the amount of FD to warrant the diagnosis of dementia is a controversial issue whose answer remains open to scientific and methodological debate.

We propose to consider two main issues to answer the How Much Question. First, even healthy older people with intact cognitive function could present functional impairments. For example, Muñoz-Neira et al. [2] reported that a cut-off points of 29.25% of functional impairment in the T-ADLQ presents the optimal balance between sensitivity and specificity to differentiate between controls and dementia. This result suggests that even healthy older individuals with normal cognitive functions could present with FD and highlights the need to establish standardized cut-off values and validate such thresholds against standardized clinical criteria. Second, as highlighted by Cohen et al. [69], determining whether functional status has declined to the extent that a dementia diagnosis is warranted could be less clear-cut than determining the severity of cognitive dysfunction. Even more difficult is determining a threshold for when independent living is no longer viable. However, determining this threshold will depend fundamentally on resolving the following equation: the ratio between the functional ability of the person to perform ADLs necessary for independent living and the demands of the environment (see Fig. 2). In this equation, functional ability is dependent on the intrinsic characteristics of the person, such as the cognitive capacity to perform ADLs and use compensatory strategies, if necessary, while the environment refers to the living contexts in which the person functions such as cultural characteristics and available supports (for example, the relevance of information and communication technology for everyday life, the architecture of buildings, homes, facilities, etc.).

The key objective of the evaluation process is to identify the ratio between the functional ability of the person and the demands of different environments. These environments are going to demand different ADLs that will depend on neurocognitive abilities, so if there is not a correct tuning between the elements of the equation, the person will experience significant difficulties correctly performing ADLs. One way to ensure the equation would yield informative outcomes would be to know with certainty the functional ability required of the various environments wherein an individual operates.

The cross-sectional view depicted in the figure suggests that in cases 1 and 2, the individual

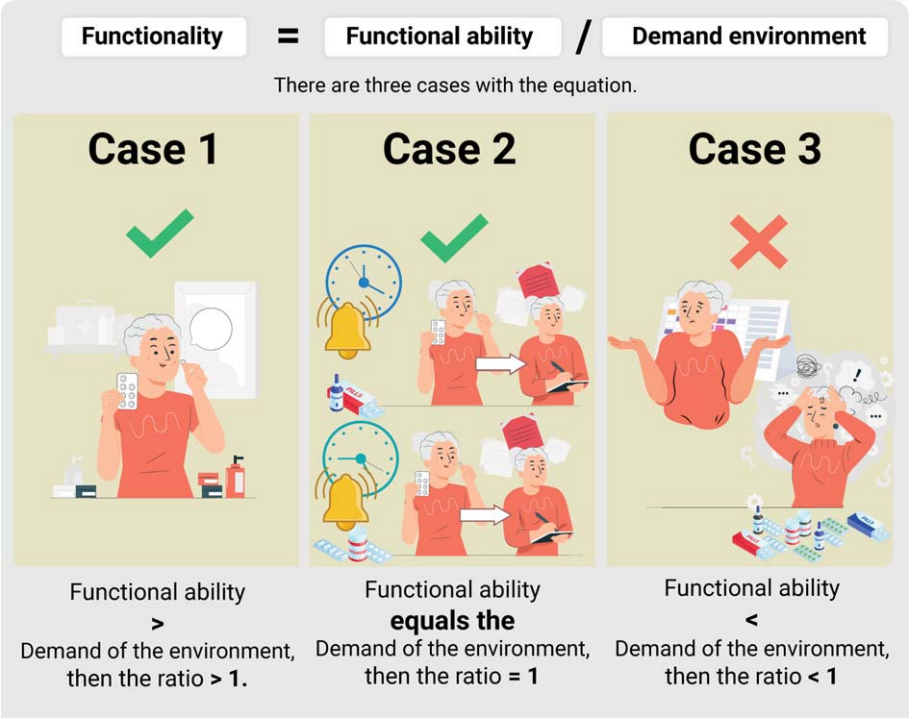

Fig. 2. Equation of the How Much question.

is functionally capable of taking prescribed pills. Specifically, in case 2, the individual demonstrates the ability to employ compensatory strategies to cope with increased environmental demands. When viewed longitudinally, it becomes easier to assess transitions from cases 1 and 2 to case 3, and to determine whether these shifts are attributable to changes in abilities or the environment.

Interpreting the results of the equation, particularly the threshold that differentiates between healthy aging and mild or major cognitive disorders, is challenging due to the multidimensional nature of FD in neurocognitive disorders. Despite these challenges, we propose that a more accurate quantification of FD, considering environmental factors, could reduce the risk of overdiagnosis or underdiagnosis. It is crucial to note that the threshold used to differentiate between healthy aging and mild or major cognitive disorders requires validation through suitable psychometric studies. This is to establish the optimal balance between sensitivity and specificity for diagnostic purposes [98]. Also, as previously discussed, the *How Much Question* may be more relevant for standardized FD than for meaningful FD. At the very least, its relevance could vary depending on the goal of the assessment, such as diagnosis or treatment. The *How Much Question* raises several issues for future research.

Reflections on the How Much Question

Our hypothesis is that, to address the *How Much Question* future researchers should investigate how to map the diversity and complexity of the environment with the ADLs required for navigation in diverse environments. This study should also consider factors associated with the use of compensation strategies, along with the cognitive, motor, and behavioral abilities necessary for effective ADLs performance. For example, the functional ability to use public transportation could vary according to the complexity of the system of public transportation and compensatory strategies used to assist with navigation. Such mappings will help not only to predict levels of FD but to anticipate the impact of such decline and implement timely actions to mitigate it. We also need more research on how the environment affects performance on ADLs. For example, Camino et al. [99] showed that persons with dementia performed better on ADLs at home compared to a well-organized environment in a research laboratory. A better understanding of this relationship could lead to the design

of new instruments to assess functionality, including the capacity of a person to perform ADLs using compensatory strategies and under varying contextual factors. We hypothesize that such a strategy could lead to the implementation of the equation presented in Fig. 2 in functional assessment improving standardized measurement of FD. Given the significant environmental and cultural influences on FD, it is essential to comprehend the constraints of quantifying FD when staging neurocognitive disorders and deducing other disease facets, such as the burden of brain lesions, cognitive impairment, and neuropsychiatric symptoms [100, 101].

EXPAND CLASSICAL FUNCTIONAL ASSESSMENT APPROACH WITH MEANINGFUL FUNCTIONAL ASSESSMENT

The standardized process of evaluation and diagnosis of people with dementia has focused primarily on identifying clinical symptoms, neurocognitive impairments, and impairments in functional abilities. Currently, when cognitive deficits undermine the independence of the person to perform ADLs, the clinician diagnoses the patient with dementia. Assessment of FD has, therefore, a significant weight in the decision-making process.

Identification of brain-behavior signatures of functional abilities aligns with the classification of ADLs into distinct categories [9]. Important advances in functional assessment are represented by the development of tools and technologies that are sensitive to earlier and more subtle changes in functional skills [8]. Despite important advances in the assessment of FD, four important questions remain unanswered.

(1) What ADLs are necessary for an independent life during aging?
(2) How to assess FD in general and in individuals with suspicion of neurocognitive disorders?
(3) To whom the assessment is directed.
(4) How much FD is necessary to ascertain a departure from normal aging and establish the boundaries between healthy cognitive aging, mild and major neurocognitive disorders?

The objective assessment of FD needs to be enhanced to address these questions. We propose that meaningful FD assessment would significantly complement current methods of FD assessment by includes person-centered perspective in FD, i.e., assessment of personally relevant aspects of the FD, considering both the person with dementia and their caregiver. This will enrich the evidence drawn from objective dementia assessment practices (see Table 1).

This new methodology derives from a perspective centered on the person and has at its heart fundamental principles of human dignity. Future research should consider the inclusion of meaningfulness in the evaluation process to develop appropriate instruments for individuals with different vulnerabilities and to overcome limitations associated with objective methods. Person-centered care in dementia is challenging, among other reasons, due to lack of insight understanding impaired abilities in persons with dementia, difficulties expressing needs by individuals with dementia, and the minimization of symptoms of dementia due to ageism [55, 70, 102].

CONCLUSION

Controversies and debate around the operationalization of FD underscore the need to reconsider how we are measuring FD to set boundaries between normal aging, mild cognitive impairment, and dementia. Here we propose a multidimensional framework that encompasses both objective and meaningful measures of FD, built around four relevant questions: what? how? to whom? how much? In response to the *What Question* our hypothesis is that the selection of the most pertinent ADLs for evaluation should consider the environments in which the individual lives (external factors), the characteristics of the individuals themselves (internal factors), and the goal of the assessment.

On the *How Question*, we hypothesized that limitations of current assessment of FD could be explained by the fact that they collect information mainly from one source. To overcome these limitations, we highlighted the need to design instruments that integrate different sources of information (informant, performance-based, technology-based) and are not restricted to one time and one context. In response to the *To Whom Question*, we stress the immediate necessity of including a person-centered model for evaluating and treating dementia patients. However, given that adhering strictly to a person-centered approach could potentially result in the neglect of dementia patients, it is crucial to consider the challenges of implementing this approach in dementia care to ensure the needs of dementia patients and their

caregivers are neither minimized nor overlooked. In response to the *How Much Question*, we emphasize the need for further research on how the environment impacts ADLs performance. This could lead to the development of context-sensitive assessments, potentially improving predictions of patients' abilities to perform ADLs.

Despite several models proposed to explain FD in aging and dementia since the seminal work of Lawton and Nahemow [103], assessing FD in dementia remains a challenge. Methods are needed for a comprehensive evaluation of FD that consider both biomedical and psychosocial models of dementias. Addressing this need, the objective of our Person-Centered Multidimensional Framework for Functional Assessment is to provide a methodology to enhance the evaluation of FD for the diagnosis and treatment of people with dementia and their caregivers. Our methodology aims to identify gaps in currently available assessment methods and to design a multidimensional functional assessment, encompassing both objective FD and meaningful FD, while considering the heterogeneity of individuals with dementia and their diverse sociocultural contexts.

GLOSSARY

Terms	Abbreviation	Definition
Functional decline	FD	Impairment in in the ability to perform activities of daily living.
Objective assessment of functional decline	Objective FD	Conventional assessment of functional decline. Uses questionnaire, performance-based tests, and technology-based tests. It is usually diagnostic-oriented.
External factors		The demands of the environment including the natural world, social and cultural aspects.
Internal factors		Biomedical aspects of the subjects
Meaningful functional decline	Meaningful FD	Deterioration of the abilities to perform daily activities that are important to the person.

AUTHOR CONTRIBUTIONS

Andrea Slachevsky (conceptualization; funding; writing - original draft, review and editing), Mario A. Parra, Fabrissio Grandi and Maureen Schmitter - Edgecombe (conceptualization; writing - original draft, review and editing); Daniela Thumala (funding, writing- review); Sandra Baez and Hernando Santamaria - Garcia (writing - review and editing).

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CONFLICT OF INTEREST

Andrea Slachevsky and Sandra Baez are an Editorial Board Members of JAD but were not involved in the peer-review process nor had access to any information regarding its peer-review.

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