



Assessing adults with neuroatypical conditions suspected of having dementia

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Abstract

Dementia is increasing as nations' populations across the world age and older adults survive in increasing number. Dementia has various etiologies and forms of expression thus accurate diagnosis is always a challenge. Detection of any adult-age cognitive impairment in health care settings is difficult in general but can be especially challenging among adults with neuroatypical or neurodivergent conditions (NACs). Most clinical guidelines/protocols applicable to the general population for assessing mild cognitive impairment or dementia do not include considerations when assessing adults with NACs. This article addresses the obstacles to early detection and assessment of adults with NACs and recounts what one national group undertook to raise awareness of this obstacle. These conditions often present assessment challenges as adults with NACs often have problems with comprehension, oral communication, motor task performance, recognition of assessment related visuals, and comfort in testing situations. Clinicians assessing adults with NACs face challenges due to an inappropriateness of using standardized dementia assessment measures, are often untrained or unfamiliar with discerning pre-existing conditions from new cognitive impairment and are uninformed as to how to adapt the testing situation. The investigation into NACs and dementia assessment lead to a series of recommendations to raise awareness among clinicians, seek to enlist professional organizations in adapting existing instruments, and increase research into NACs and dementia.

Key words: *assessment, dementia, intellectual disability, neuroatypical conditions, protocols*

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1. Introduction

The rates of various dementias are increasing as nations' populations across the world age and older age survivors increase in number. The WHO's 'Dementia: A Public Health Priority' (2012) made much of this growing challenge in many countries and noted the need for upgrading abilities for early detection and diagnosis of dementia. The WHO clearly stated that this challenge exists because dementia is a syndrome that affects memory, thinking, behavior and ability to perform everyday activities, poses challenges for those affected due to debilitation, and it is overwhelming not only for the people who have it, but also for their caregivers and families. The WHO's report noted that "there is lack of awareness and understanding of dementia in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families, and societies physically, psychologically and economically." With statistics bearing the weight of this challenge, WHO has estimated that the number of people living with dementia worldwide is currently around 35.6 million and projects that this number will double by 2030 and more than triple by 2050.

Dementia is multifaceted, thus given its various etiologies and forms of expression accurate diagnosis is always a challenge when cognitive decline occurs. Most nations lack the collective clinical expertise to undertake early detection efforts and often confound organic factors resulting in dementia with more classic psychiatric disease conditions. In some countries (and via international professional organizations) standard protocols and instruments for early detection and diagnosis are emerging and efforts are being made to expand diagnostic facilities focusing on the general older population. Yet, these protocols generally do not address outlier groups, who present with pre-existing cognitive or sensory conditions. Thus, formal assessment and diagnostic processes are confounded by variations in symptom presentation, challenges posed by patient characteristics, and a dearth of clinically trained personnel experienced with outlier groups.

Detection of any adult-age cognitive impairment as part of any casual or targeted assessment in primary or health care settings is difficult in general but can be particularly challenging when the adults seen have a pre-existing neuroatypical or neurodivergent condition (NAC).

Such conditions include those that affect normative intellectual development and function (such as intellectual disability [ID]) and ID with conjoint psychiatric conditions); thought, moods, and cognition (such as severe mental illness); communication functions (such as conditions on the autism spectrum [ASD] and hearing/vision impairments); and brain and motor function (such as cerebral palsy and acquired [ABI] or traumatic brain injury [TBI]). In most countries clinical guidelines or protocols applicable to the general population for the assessment of cognitive impairment related to mild cognitive impairment (MCI) or dementia do not include specifications for the special considerations needed for the assessment of adults presenting with neuroatypical conditions.

Such is also the case in the United States. To examine this deficit and explore what nuanced clinical practices might be appropriate or applicable when a clinician attempts to assess for the presence of MCI or dementia, a consensus outcome effort was undertaken. An expert panel of clinicians and academic researchers was convened and was asked to examine the barriers to inclusion of such adults in existing regulatory authority policy and practices as well as in provider and clinical practices. The panel was also asked to examine: (1) the prevalence and risk for dementia in each NAC; (2) which NAC had a body of research on ascertaining MCI or dementia; and (3) what adaptations might be undertaken to make the examination process more productive in specific NACs. Implications for post-assessment plans of care or post-diagnostic supports were also considered. The rationale for this effort although guidelines existed for use with typical population of adults suspect of cognitive decline, there was an absence of professional organization or government guidance on assessment carried out with adults with NACs. Following consultation with national organizations and government authorities it was suggested that such an effort to define assessment issues with adults with NACs be undertaken.

The aim of this article is to bring to the forefront one significant obstacle to the appropriate early detection and assessment of adults outside the typical norm for persons presenting with dementia and recount what one national group has undertaken to raise awareness of this

obstacle and provide substantiation for other such national or professional organization efforts to provide for inclusive protocols that can appropriately address the diagnostic needs of adults with neuroatypical conditions.

2. Process

In the United States, a Neuroatypical Conditions Expert Consultative Panel representing clinicians and academic experts from the fields represented by the conditions was composed in the latter part of 2021 and tasked with examining what barriers existed and what special adaptations may be needed when examining adults with these NACs (see Janicki et al., 2022b). Panel members were drawn from nominations submitted by professional organizations, government authorities, and clinical peers. Especially sought out were clinicians and researchers who were familiar with MCI and dementia and how its effects were determined within specific disability groups. The process involved individual consultations with the experts by the project team; these were held via written material exchanges and virtual conferencing. Once the Panel was assembled, group virtual conferencing media were used (due to meeting restrictions in place due to the COVID-19 pandemic). This work took place over a period of four months in late 2021. Panel members contributed summaries related to specific NACs, were involved in the cross-cutting virtual discussions, helped with producing recommendations, and reviewed drafts of the report.

3. Findings

The Panel found that many such neuroatypical conditions did pose significant barriers for early detection and assessment, particularly in situations where the primary conditions masked changes in cognitive functioning or the geographic location lacked sufficiently informed clinicians knowledgeable of assessment nuances among adults with such conditions. The Panel also found that adults with NACs faced a variety of barriers to being accurately examined and having determinations made about whether they had a new/additional cognitive impairment. Further, the Panel recognized that most clinicians experience difficulties in discriminating current behavior and function from that which was pre-existing in some of the conditions, particularly those that include pre-existing cognitive deficits.

It was evident that many of the conditions posed challenges as such adults had problems with comprehension, oral communication, motor task performance, recognition of assessment related visuals, and comfort in testing situations. Adults with NACs were also noted to pose various challenges for clinicians as they complicated testing as the use of standardized dementia assessment measures was not beneficial to the testing situation; however, they benefited from the use of specialized instruments. For conditions with pre-existing cognitive issues, the use of standardized dementia assessment measures was not indicated unless the measures were significantly adapted or specially designed. For conditions with motor or sensory impairments, special adaptations related to compensating for the impairments were necessary to obtain valid scoring.

The Panel noted that some of the conditions had definable risk for MCI or dementia and were backed by a significant field of study; others were still beginning to be studied and presented with varied expectations for risk of dementia and inherent factors affecting cognitive decline. It was obvious as well as there were insufficient data on epidemiological factors associated with age-related decline for most of the NACs. Some had a richer history of research into aging-related factors (e.g., Down syndrome), but for most the extant data was sketchy at best. The research investment in Down syndrome due to its recognized high risk for Alzheimer's was pronounced and thus made available sizeable documentation for much of what is known about dementia in this group. This was also true to some extent with TBI due to the investment by governmental veterans' affairs agency into research associated with military-activity brain injuries and aging.

Instrumentation was another area that was examined by the Panel. The Panel noted that the variations in applicability of standard dementia assessment instruments and the risk factors associated with each of the NACs, as well as what modifications to existing instruments may be appropriate or which existing specialty instruments might be more appropriate to use (see Janicki et al., 2022a). The Panel remarked that to increase the accuracy rate in the assessments, practitioners should be aware of the nature of aging effects in these conditions, know the expectations for cognitive decline and risk of

dementia (and of what type), and be familiar with testing adaptations that can facilitate the examination process to generate meaningful data.

The epidemiology of dementia was noted to vary among the NACs with respect to focus and outcomes (Janicki et al. 2022a). Some, like Down syndrome and ABI/TBI, have a deeper base of scientific literature due to the association with genetics and brain injury to later life dementia – but their dementia etiology is at variance (i.e., Down syndrome is associated with Alzheimer’s disease, while ABI/TBI is associated with vascular dementia). Others as still on cusp of research, such as autism and severe mental illness, where workers are exploring the long-term effects of brain changes upon cognitive impairment. Some considerations at play may be the long-term effects of psychotropic medication use (with severe mental illness). Still others are outliers, such as cerebral palsy and sensory deficits, where some associations may be present in retrospect, but not the validation of clear trajectories of brain disease leading to dementia. Risk in these NACs was seen as higher when comorbidities, such as an intellectual disability, were present.

Financial aspects underwriting detection and assessment were also considered. One consideration was the nature and level of insurance payments to clinicians for performing examinations. While most examinations with adults with typical presentation usually fit within the visit time parameters for payment under most US insurance schemes, the extra time per visit and sequential visits needed to discern dementia among adults with NACs posed challenges for full-cost reimbursements. Also, with respect to national health care schemes, the Panel noted that when reimbursement was not available for assessments of adults with risk for younger-onset dementia (not yet age 65) this posed as a barrier to the effective and early detection among some younger-older adults, including those with cerebral palsy, Down syndrome, some ABIs and several of the other neuroatypical conditions (which were associated with younger-age onset dementias).

Although identifying key issues that may prevent or impair functional early detection or assessment/diagnosis of dementia among NACs, the process of affecting change in practices will be an on-going process, which will involve education, advocacy, and culture change to

ensure the inclusion of consideration of the needs of adults with NAC facing later-life decline and possible being affected by dementia. What follows are some recommendations made by the Panel in anticipation of actions that will need to be undertaken to fully include adults with NACs within the dementia detections and assessment endeavors being undertaken. As the WHO (2022) has noted, as “... dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people worldwide *** [it poses] physical, psychological, social and economic impacts, not only for people living with dementia, but also for their carers, families, and society at large.”

The WHO (2022) also has noted that among the principal goals for dementia care are early diagnosis to promote early and optimal management, and optimizing physical health, cognition, activity, and well-being. This calls for inclusive post-diagnostic supports. Thus, it is important to have a grounded understanding of the etiology for cognitive decline and possible presence of dementia (outside of any preexisting cognitive impairment stemming from disease, injury, genetics, or environmental deprivation). This can only happen if governmental regulatory bodies, clinicians, and professional organizations step up and provide matter for the technical aspects of early detection and assessment of NACs.

4. Recommendations

The Expert Panel’s recommendations addressed decreasing assessment inequities, increasing clinical accuracy, enhancing education and knowledge among examiners, and strategies for underwriting research endeavors by governmental research institutes and the private sector. Their recommendations, as applicable internationally, included the following:

Recommendation #1: Broadening national guidelines to include adaptations of assessment practices to accommodate NACs. Included would be (a) enhancing existing or developing new protocols and guidelines for examining adults with primary and/or secondary or compound NACs; (b) promoting the development of specially designed instruments specifically for initial and subsequent examinations; (c) encouraging professional societies to create and manage listings and

directories of clinicians who are expert in examining adults with NACs; and (d) advocating expanding local diagnostic resources and clinical services familiar with examining and treating adults with NACs.

Recommendation #2: Enhancing education for practitioners to increase knowledge of NACs, how to differentially diagnose MCI or dementia, and how to develop assessment-informed plans for post-diagnostic care. Included would be (a) expanding training opportunities to reach primary and health care practitioners who are unfamiliar with many of the NACs; (b) enlisting national professional and multidisciplinary organizations and associations to develop guidelines for examining and formally assessing dementia in adults with neuroatypical conditions; and (c) relating assessment findings to condition and post-diagnostic supports.

Recommendation #3: Expanding research to produce more evidence-based information on assessing NACs as part of cognitive impairment screenings. Included would be (a) expanding epidemiological and demographic research on adults to determine the prevalence, nature, and characteristics of select NACs in older age; (b) expanding clinical proof of practice and applied research on interventions of value following diagnosis and as part of plans of care; and (c) expanding research on reliability and validity of specialty instruments developed or in use in cognitive impairments assessments with select NACs.

5. Conclusions

Overall, adults with NACs present with varying degrees of risk for dementia. To increase the accuracy rate in the assessments, clinicians should be more aware of how older age affects each of the NACs, be familiar with expectations for cognitive decline and risk of dementia (and what type) and be facile with adapting testing situations and measures. Besides the challenges noted for clinical assessment for MCI and dementia, there is also a need for expanding research to produce more evidence-based information on assessing NACs for later life adult cognitive diseases/disorders and for planning subsequent post-diagnostic care. The Panel questioned

whether national organizations representing some of the diverse NACs are sufficiently looking after their clientele from a lifelong perspective. While most focus may be on pediatric or work-age adult issues, little focus is on older age issues. Much can be done by various national professional organizations to produce helpful materials, stimulate research to address many unanswered questions, and work toward legislative actions to produce a more inclusive national dementia diagnostics and care system. Clinicians would generally benefit from more information and guidance about these adult conditions when encountering adults with a NAC in their clinic.

Conflicts of interests

The author declares no conflict of interests.

6. References

- Janicki, M.P., Hendrix, J., & McCallion, P., and Neuroatypical Conditions Expert Consultative Panel. (2022a). Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments – Report of the Neuroatypical Conditions Expert Consultative Panel. The National Task Group on Intellectual Disabilities and Dementia Practices and the LuMind IDSC Foundation. <https://www.the-ntg.org/screening-assessment>. [Revision V. June 27, 2022].
- Janicki, M. P., Hendrix, J. A., & McCallion, P. (2022). Examining older adults with neuroatypical conditions for MCI/dementia: Barriers and recommendations of the Neuroatypical Conditions Expert Consultative Panel. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 14(1). <https://doi.org/10.1002/dad2.12335>
- World Health Organization. (2012). Dementia: A Public Health Priority. Geneva, Switzerland. <https://www.who.int/publications/i/item/dementia-a-public-health-priority>
- World Health Organization. (2022). Dementia. <https://www.who.int/news-room/fact-sheets/detail/dementia>