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Review Article

A Comprehensive Review of the Quality and Feasibility of Dementia Assessment Measures: The Dementia Outcomes Measurement Suite

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A B S T R A C T

The diagnosis of dementia and the management of its associated symptoms are aided by high-quality assessment tools. However, there is disagreement on the optimal tools among abundant alternatives and lack of consistent quality standards across the different domains of dementia-related change (ie, cognition, severity, function, behavioral and psychological symptoms, delirium, quality of life). Standardization is difficult because the relevance of a measurement tool for health professionals may depend on the clinical setting and on the dementia type and severity. To address this need, we conducted a comprehensive and clinically relevant evidence-based review of dementia-related tools and present a set of recommended tools, the Dementia Outcomes Measurement Suite. The review revealed that considerable development has occurred in terms of assessment of persons with mild cognitive impairment, executive dysfunction, cognitively mediated functional change, and apathy. More research is needed to develop and validate tools to assess health-related quality of life and specific symptoms of dementia including anxiety, wandering, and repetitive vocalizations. This extensive overview of the quality of different measures may serve as a guide for health professionals clinically and for researchers developing new or improved dementia assessment tools.

High-quality assessment tools are important for the diagnosis and management of dementia and its associated symptoms. Early diagnosis of dementia by cognitive screens may enable the timely provision of care services and family education, and advance legal directives while the person still has capacity.[1] Measuring the functional ability of a person with dementia may facilitate the provision of appropriately targeted care services.[2] Tracking the effects of interventions to reduce the behavioral and psychological symptoms of dementia (BPSD) may help reduce distress and healthcare costs.[3,4]

Despite an abundance of tools for many domains of dementia-related change (ie, cognition, function, BPSD), consensus is lacking on which one should be used.[5] This may hinder effective communication between health professionals and could lead to misdiagnosis or mismanagement.[6,7] Some tools, such as the Mini-Mental State Examination (MMSE),[8] serve as a proxy "gold standard" but nonetheless have significant limitations (eg, to detect mild cognitive decline or dementia that present with executive dysfunction).[9–11] Several reviews have helped identify the most promising options to test cognition,[12] staging,[13] function,[14] BPSD,[3] or delirium,[15] and protocols such as the International Consortium for Health Outcomes Management[16] offer excellent breadth of coverage by recommending 1 standard tool per domain. However, less attention is paid to important qualitative variations in the clinical scenario including differences in practice setting, types of dementia, and levels of dementia severity.[17] Conversely, many reviews focus intensively on tools for specific clinical scenarios, such as dementia screening in

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primary care[18,19] or functional assessment in persons with frontotemporal dementia (FTD),[20] but lack broader integration with other affected domains. Thus, an acceptable trade-off is needed between standardization, and breadth and depth of coverage.

In 2007, the Australian Center for Health Service Development conducted an exhaustive review of tools used to measure the multidimensional changes associated with dementia, the Dementia Outcomes Measurement Suite (DOMS).[21] The underlying rationale was to encourage clinicians to use the same tools to enhance interprofessional communication, while flexibly accommodating for different clinical scenarios. A secondary goal was to use the review outcomes to identify gaps in research and clinical practice. Criteria with clinical relevance (eg, psychometric properties, cost, feasibility, user-friendliness) were used to select and rate a short-list of tools, and the same rating system was used across domains allowing for broader standardization. Since the original publication in 2007, however, there have been substantial advances in research on dementia assessment tools, including increased attention for mild cognitive impairment (MCI) and non-Alzheimer types of dementia.[22,23]

We present the updated DOMS, a set of recommended dementia-related tools based on a comprehensive evidence-based overview, which has been translated into a user-friendly online database for health care professionals at: http://www.dementia-assessment.com.au.

Methods

A steering committee of a diverse group of health professionals from clinical psychology/neuropsychology, general practice, geriatric medicine, mental health, nursing, and occupational therapy met during 2015 and 2016 to discuss the aim, scope, and primary target audience of the DOMS update. Although the original DOMS review was an exhaustive summary of dementia-related tools that led to a database of 844 instruments,[21] the update focused on integrating new evidence into this database and primarily targeted health professionals and secondarily, dementia researchers. Therefore, the update was restricted to the domains of cognition, staging, function, BPSD, delirium, and dementia-specific health-related quality of life (HRQoL). Although social isolation, multi-attribute utility measures and patient/carer treatment satisfaction were considered clinically important and associated with relevant research, they were not considered to be firmly integrated within current routine clinical practice. We also categorized tools within each domain to maximize the coverage of different clinical practice settings, contexts, dementias, dementia severities, and patient types (Supplementary Table S1).

Literature Search

Peer-reviewed articles, written in English, were identified by searching electronic databases (CINAHL, ProQuest, Scopus, PsychARTICLES, Biomed Central, EMBASE, PubMed, PsychINFO, MEDLINE, ScienceDirect, Web of Science, Cochrane Reviews) using the key word "dementia" combined with "assessment," "measure," "screen," "scale," or "rating" and the following MESH terms: "cognition," "staging," "global," "severity," "function*," "BPSD," "behaviour/behavior," "neuropsychiatr*," "delirium," and "quality of life," where "*" indicates a wild card. These searches were restricted to articles published after 2003, to ensure thorough coverage of articles on tools that were very recently published at the time of the 2007 review.

The reference lists of articles were also searched. Tool names relevant to dementia were identified by scanning titles and abstracts and additional searches using the key word "dementia" combined with the tool name were conducted. After removing duplicates, the general and tool-specific searches yielded 7764 titles in total (cognition: 2704; staging: 916; function: 1211; BPSD: 2378; delirium: 235; dementia-specific HRQoL: 320).

Selection Criteria

A short list of tools was compiled based on the recommendations in the initial 2007 DOMS review and on the current literature search, and if they met all of the following criteria:

- Content validity: the content of the tool must be appropriate for assessing dementia and the tool must not be designed for another specific purpose (eg, psychosis in persons with schizophrenia, motor impairment in persons with stroke), except if it has been shown to have clinical validity in dementia (see below). To reduce the number of (general) cognitive screening tools and maximize their clinical relevance with respect to current diagnostic guidelines,[24,25] only cognitive screens with at least 1 item testing recent memory and at least 1 item from another cognitive domain (executive, visuospatial, or language function) were included. This rule did not apply to tools specifically designed to detect types of dementia for which executive dysfunction was the primary presenting feature.
- Psychometric validity: evidence of the tool's inter-rater reliability and/or test-retest reliability (preferably in persons with dementia) from at least 1 peer-reviewed publication.
- Clinical validity: quantitative evidence in support of the tool's discriminant validity in a clinical context relevant to dementia (eg, in distinguishing persons with dementia from those without dementia, or from those with depression) when assessed concurrently (eg, sensitivity and specificity) and/or longitudinally (responsiveness).
- Affordability: free to use or at low cost
- Feasibility: <45 minutes of administration time, and no highly complicated scoring and/or administration procedures that would contraindicate use in a (typical) clinical context (eg, requirement for a computer or other special equipment and/or to perform a complex algorithm to calculate the score).
- Redundancy: for tools with multiple versions (eg, revised or abbreviated forms), only the version that best satisfied the selection criteria was included.

Tools that were short-listed and considered promising but did not meet our selection criteria are listed in Supplementary Table S2 with their respective failed selection criteria.

Rating System

Tools were rated based on 18 criteria scored 0–2 and with a weighting of 1 or 2, making up a maximum weighted total score of 60 (Table 1). Psychometrics (criteria 1 to 13) counted for two-thirds of the total rating, with validity and reliability making up three-quarters and one-quarter of the total rating for psychometrics, respectively. The remaining 5 criteria were weighted equally and included the tool's international adoption, administration time, ease of administration, professional qualifications, and cost of instrument/training. As the administration mode differed across scales, ease of administration (criterion 16) was rated differently for clinician-administered and self/informant-completed tools. To maximize the clinical usefulness of the rating system across all domains, validity criteria 1 to 6 could apply to a range of different clinical situations, ranging from diagnostic (eg, discriminating persons with vs those without dementia) to descriptive (eg, categorizing the severity of apathy). Partial scores were given when the evidence showed equal support for 2 scoring categories.

The criterion for responsiveness was based on recommendations that distinguished "external responsiveness" (the extent to which measured change relates to change in a reference measure of clinical or health status, such as progressing from MCI to dementia) as more clinically important than "internal responsiveness" (the ability of a measure to change over a prespecified time frame, often in the context