

# Delirium Diagnosis Methodology Used in Research: A Survey-Based Study

*Karin J. Neufeld, M.D., M.P.H., Archana Nelliott, B.S., Sharon K. Inouye, M.D., M.P.H., E. Wesley Ely, M.D., M.P.H., O. Joseph Bienvenu, M.D., Ph.D., Hochang Benjamin Lee, M.D., Dale M. Needham, M.D., Ph.D*

**Objective:** To describe methodology used to diagnose delirium in research studies evaluating delirium detection tools. **Methods:** The authors used a survey to address reference rater methodology for delirium diagnosis, including rater characteristics, sources of patient information, and diagnostic process, completed via web or telephone interview according to respondent preference. Participants were authors of 39 studies included in three recent systematic reviews of delirium detection instruments in hospitalized patients. **Results:** Authors from 85% (N = 33) of the 39 eligible studies responded to the survey. The median number of raters per study was 2.5 (interquartile range: 2–3); 79% were physicians. The raters' median duration of clinical experience with delirium diagnosis was 7 years (interquartile range: 4–10), with 5% having no prior clinical experience. Inter-rater reliability was evaluated in 70% of studies. Cognitive tests and delirium detection tools were used in the delirium reference rating process in 61% (N = 21) and 45% (N = 15) of studies, respectively, with 33% (N = 11) using both and 27% (N = 9) using neither. When patients were too drowsy or declined to participate in delirium evaluation, 70% of studies (N = 23) used all available information for delirium diagnosis, whereas 15% excluded such patients. **Conclusion:** Significant variability exists in reference standard methods for delirium diagnosis in published research. Increasing standardization by documenting inter-rater reliability, using standardized cognitive and delirium detection tools, incorporating diagnostic expert consensus panels, and using all available information in patients declining or unable to participate with formal testing may help advance delirium research by increasing consistency of case detection and improving generalizability of research results. (Am J Geriatr Psychiatry 2014; ■:■–■)

**Key Words:** Delirium, dementia, amnesic, cognitive disorders, reference standards, research design, data collection

Received November 1, 2013; revised March 5, 2014; accepted March 6, 2014. From the Department of Psychiatry and Behavioral Sciences (KJN, OJB), Department of Physical Medicine and Rehabilitation (DMN), and Department of Medicine, Division of Pulmonary and Critical Care Medicine (AN, DMN), Johns Hopkins University School of Medicine, Baltimore, MD; Department of Medicine (SKI), Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA; Institute for Aging Research (SKI), Hebrew Senior Life, Boston, MA; Department of Medicine, Division of Allergy, Pulmonary and Critical Care Medicine (EWE), Center for Health Services Research, Vanderbilt School of Medicine, Nashville, TN; Geriatric Research, Education and Clinical Center (EWE), Department of Veterans Affairs Medical Center, Tennessee Valley Healthcare System, Nashville, TN; and Psychological Medicine Service (HBL), Yale-New Haven Hospital, New Haven, CT. Send correspondence and reprint request to Karin J. Neufeld, M.D., M.P.H., Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, Johns Hopkins Hospital, Osler 320 General Hospital Psychiatry, 600 N. Wolfe St., Baltimore, MD 21287-5371. e-mail: [kneufel2@jhmi.edu](mailto:kneufel2@jhmi.edu)

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## INTRODUCTION

Delirium is a clinical syndrome characterized by an acute and fluctuating cognitive impairment, occurring over hours to days, primarily associated with inattention and other cognitive and behavioral changes.<sup>1</sup> Delirium occurs very frequently throughout the healthcare system and is associated with substantial suffering and loss of dignity,<sup>2,3</sup> longer hospital stays,<sup>4–6</sup> institutionalization at hospital discharge,<sup>7,8</sup> increased healthcare expenditures,<sup>9</sup> increased 1-year mortality,<sup>10–13</sup> and long-term cognitive impairment.<sup>14–17</sup>

Common to most diagnoses in the psychiatric literature, no pathognomonic test (e.g., laboratory, imaging, or biomarker) can identify delirium; therefore, the diagnosis is predicated upon the careful clinical examination. In addition to a thorough patient history and physical examination, a delirium diagnosis requires (1) history from collateral sources documenting an acute and fluctuating change in cognitive function and behavior from baseline, (2) examination of the patient's mental state documenting decreased attention and other associated cognitive and behavioral impairments (e.g., disorientation, impaired short- and long-term memory, perceptual disturbances, hallucinations, delusions, motoric abnormalities, and sleep disturbances), and (3) review of laboratory and other investigations (e.g., radiologic testing) that may help detect underlying cause(s) of delirium.<sup>18</sup>

Reliable and valid delirium diagnoses, using a reference standard, are crucial for the advancement of clinical research in this field. To better understand its epidemiology, risk factors, phenomenology, etiology, and prevention, accurate case detection is important. Given the fluctuating nature of its presentation, accurate and reproducible diagnoses are an especially challenging issue for delirium research of all types.<sup>19</sup> One particular type of study that must, by design, regularly use an independent reference rater evaluation to serve as the reference standard is the development and evaluation of delirium detection tools.<sup>20–22</sup> Details of these reference rater methods are scant in most research publications. Although reference standards are important in all types of delirium research, understanding the reference rater methodology that underpins the development of detection instruments is arguably the most important standard to characterize, because it underlies the assumptions made in studies where only the delirium detection instrument is used as evidence of the diagnosis.

Hence, the objective of this inquiry is to characterize the methodology used as a reference standard in studies evaluating delirium detection tools in hospitalized patients, using a survey-based study design.

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## METHODS

### Study Sample

A sampling frame of 37 unique investigators representing 39 studies, published between 1990 and 2012, were obtained from three systematic reviews of the literature evaluating delirium detection tools against a reference standard for delirium diagnosis.<sup>20–22</sup> Of these 39 studies, 16 (41%) were performed in intensive care unit (ICU) and 23 (59%) in non-ICU inpatient hospital settings (see [Table 1](#)).

### Survey Design and Testing

The survey was designed by coauthors with expertise in the clinical diagnosis of delirium, the development and use of delirium detection tools, and/or survey design methodology. The survey included questions about the following areas of reference rater methodology: (1) characteristics of delirium reference raters (number per study, professional background, training, and experience), (2) sources of information used in determining the delirium diagnosis (including use of standardized cognitive testing and delirium detection tools), (3) the use of consensus panels in making a final delirium diagnosis, and (4) methodology for evaluating patients who did not answer questions because of decreased arousal or patient refusal. The survey was pilot-tested with two delirium researchers and revised based on their feedback. A web-based version of the survey was developed using "SurveyMonkey" ([www.surveymonkey.com](http://www.surveymonkey.com)) and pilot-tested by two additional delirium researchers. As a token of appreciation, an electronically issued US\$50 gift card was offered to participants. This study was reviewed and approved by the Johns Hopkins University Institutional Review Board; all survey respondents provided informed consent.

### Survey Distribution and Response

In September 2012, an e-mail was sent to the corresponding author of each of the 39 studies eligible

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