Is the *DSM-5* Change in Dementia Labeling Perilous for Research?

Language choices matter. In 2009, Garand, Lingler, Conner, and Dew published an article in this journal examining the stigma associated with the diagnostic term *dementia* and the possible effects of that stigma on individuals’ willingness to participate in clinical research. In 2013, the American Psychological Association (APA, 2013) replaced the diagnostic classification of dementia with the categories of *major* and *minor neurocognitive disorder* in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (*DSM-5*). These new terms are cumbersome, but, to give them their due, may decrease the stigma associated with the term *dementia*. In the past year, a flurry of articles, editorials, and blog posts have addressed the costs and clinical implications of these changes. But these categories also impact research and the locating and aggregating of research participants. I’d like to briefly explore four critical research challenges posed by the new *DSM-5* categories.

**CONCEPTUALIZING DISORDERS ASSOCIATED WITH COGNITIVE DECLINE AS PSYCHIATRIC MAY BE FUNDAMENTALLY FLAWED**

Classifying cognitive decline as a psychiatric disorder seems arbitrary and dated, given the diverse pathophysiology of illnesses associated with cognitive decline and the other deficits that typify these disorders. The illnesses associated with cognitive decline cause motor impairments, aphasia, and alterations in the immune system. The term *neurocognitive* includes the notion that neurological impairments are evident, but continues to place the emphasis on the cognitive declines at the expense of fully understanding and appreciating the experience. Conceptualizing these changes as mental illness can tether research to frameworks that lie within a limited psychiatric realm. Although nurse researchers see the need to understand components to improve care, they also value frameworks that focus on the whole person and the context of that person's experience. Sticking with a psychiatric conceptualization can obscure and exclude fresh theoretical perspectives that engender new research questions and scientific progress and are less entropic.

**NEW CATEGORIES MAY YIELD SUBSTANTIAL MEASUREMENT ERROR**

It is fair to ask if these categories are based on sound scientific evidence. Do major and minor neurocognitive disorders represent a conceptual concentrate of the experience that is accurate, stable, and meaningful? How do we know the defining attributes designated by the developing workgroup are those that are the most salient for us to consider when aggregating groups for research analyses? The designation of *mild neurocognitive disorder* is delineated by cognitive test performance in the range of one and two standard deviations below appropriate norms (i.e., between the third and 16th percentiles). Including individuals who are one standard deviation below norms may create many false positives. The new *DSM-5* criteria differentiate mild and major neurocognitive disorder by whether daily functioning is affected to a degree that independence is compromised (APA, 2013). One concern that has been expressed in relation to this differentiating criterion is the subjective nature of judging whether the cognitive deficits are insufficient to interfere with independence (Siberski, 2012). Measures of functional decline are notoriously subjective and unreliable (Kohler, Redmond, Dickson, Connolly, & Estell, 2010).

Field testing of the *DSM-5* categories is underway, and I hope that more information on the validity and utility of the new psychiatric classification of neurocognitive disorders will be forthcoming. Just as we have rubrics for rating
the quality of evidence about a research topic, it would be useful to develop and consistently use a system of rating the extent to which health care language classifications, criteria, and cut-off scores have been validated.

THE REDUCTION OF A WHOLE SPECTRUM OF SYMPTOMS TO TWO CATEGORIES OF NEUROCOGNITIVE DISORDER CREATES PRACTICAL CHALLENGES FOR RESEARCHERS

Researchers need to have some means of measuring the degree of cognitive impairment. Without our ability to aggregate and study subgroups of cognitive and functional decline, we would not be able to conduct sophisticated statistical analyses or make generalizations from one specific group to another situation or group. Nevertheless, as much of a benefit as summary health measures are, the resulting categories need to represent an important construct or set of constructs and be precise enough to distinguish level of impairments in meaningful ways. The terms major and minor neurocognitive disorder have reduced an entire spectrum of possibilities down to just two options, without any shades of gray in between. This leaves researchers with the need to either use these very broad categorizations or use other measures of cognitive and/or functional status to yield continuous variable scores. Using only two categories to distinguish impairment has the potential to statistically analyze, it is critical to include study samples with explicit inclusion criteria. If samples within studies are substantially different, the mixing of incommensurable studies will create sampling error that distorts and muddles results. Samples may need to be larger to detect meaningful differences, which will increase costs and delay scientific progress. Leaving researchers to choose from the battery of neurocognitive assessment tools to create more precise categories of impairment will make it difficult to compare data between studies. Moderator analysis is exceedingly important in producing knowledge on the differential effectiveness of clinical interventions for specific subgroups. Two categories of neurocognitive disorder may not provide sufficient variability to capture moderator effects.

Science progresses through the accumulation of knowledge from multiple studies. We use meta-analysis to synthesize the evidence from multiple research studies using precise quantitative methods. When conducting meta-analysis, it is critical to include study samples with explicit inclusion criteria. If samples within studies are substantially different, the mixing of incommensurable studies will create sampling error that distorts and muddles findings. Conducting meta-analyses that blend both old and new diagnostic criteria may increase the likelihood of error and compromise quality of the analyses.

CREATE LABELS WITHIN DISCIPLINARY SILOS IS UNTENABLE

No one person or group officially controls health vocabulary. The DSM-5 categories were developed by a workgroup of the APA’s DSM-5 Task Force. A pervasive problem in health care and health care research is the lack of common language and rubrics for measuring health status and health care information. For example, to identify potential research participants who have a cognitive disorder, researchers may use a variety of sources of information: the International Classification of Diseases (World Health Organization [WHO], 2010); the International Classification of Functioning, Disability and Health (WHO, 2001); the recently updated diagnostic criteria for Alzheimer’s disease (McKhann et al., 2011); the DSM-5 criteria (APA, 3); the Uniform Data Set neuropsychological test battery (Weintraub et al., 2009); or other batteries of neurocognitive tests. It is unclear how the terms major and minor neurocognitive disorder will interface with other classification systems currently being used.

The WHO Family of International Classifications was established to create internationally endorsed classifications to facilitate the storage, retrieval, analysis, and interpretation of data (Madden, Sykes, & Ustun, 2007). It is critically important to the use of a common language that groups collaborate and come to some consensus regarding terms and categorizations before publishing new guidelines. Classifications that include language and categorizations that are the same or contain rules for comparison facilitate the quality and efficiency of clinical and research processes. The use of consistent language makes it easier to compare data within populations over time and between populations at the same point in time, as well as to compile consistent data within nations (Madden et al., 2007).

CONCLUSION

The effort to oust the term dementia from our lexicon and replace it with major and minor neurocognitive disorders helps us see that the symptoms, disorders, and problems we create labels for are shaped in part by social, political, and economic beliefs and assumptions. These labels in turn influence the way these phenomena are researched and understood. People with changes in cognition are complex and diverse. It is critically important that our research vocabulary not only conceptualize cognitive changes as decline, but that strengths of the individual, compensatory opportunities, and the potential for continued quality of life are not negated. We must strive for ever-increasing clarity in the use of common language,
advocate for interdisciplinary perspectives and the inclusion of patient perspectives, and insist on evidence of the validity and utility of classification schemes. In time, we will learn if the terms major and minor neurocognitive disorder replace dementia. The current plans of Research in Gerontological Nursing are not to choose one label over another; dementia, neurocognitive disorder, and cognitive impairment are all still commonly used. We will, however, present the conceptual definition being used and criteria or measures used to determine the impairment in study samples described in our publications.

REFERENCES

Christine R. Kovach, PhD, RN, FAAN, FGSA
Editor

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