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Terms and Measures of Cognitive Health Associated with Dementia and Alzheimer’s Disease: A Scoping Review

Kelly Quinn*,

Department of Communication, University of Illinois at Chicago

Christina E. Miyawaki,

University of Houston

Raina Croff,

Oregon Health & Science University

Mia T. Vogel,

Washington University in St. Louis

Basia Belza,

University of Washington

Anita M. Souza,

University of Washington

Minhui Liu,

Johns Hopkins University

Valerie J. Edwards,

Centers for Disease Control and Prevention

Daniela B. Friedman

University of South Carolina, Arnold School of Public Health

Abstract

The Healthy Brain Initiative: National Public Health Road Map to Maintaining Cognitive Health (2007) called on the research community to disseminate its work on cognitive aging and cognitive health. The purpose of this scoping review was to (1) identify terminology that cognitive, social, and behavioral scientists use to describe cognitive aging and cognitive health, in association with dementia and Alzheimer’s disease, among older adults; (2) demonstrate how such terms are defined; and (3) illustrate how these constructs are measured in research settings. Empirical studies published 2007–2018 were examined for terminology, definitions, disciplinary orientation, and measurement mechanisms. Analysis of the corpus and a detailed review of the terms “cognitive impairment” and “mild cognitive impairment” reveal that formal definitions are provided infrequently and measurement of constructs ranges widely. Overall, the variability in terminology, definitions, and measures reflects a need for greater specificity in research communication, such that cross-disciplinary collaboration can be facilitated.

*Corresponding author Kelly Quinn, PhD, Department of Communication, University of Illinois at Chicago, 1007 W Harrison St, BSB 1140, MC132, Chicago, IL 60607, (312) 996-3187, kquinn8@uic.edu.

Keywords

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Two important calls for enhancing communication about cognitive aging and cognitive health have been issued in recent years. In 2007, *The Healthy Brain Initiative: National Public Health Road Map to Maintaining Cognitive Health* (“*The Road Map*,” 2007) was issued jointly by the Centers for Disease Control and Prevention (CDC) and the Alzheimer’s Association, and called on researchers to disseminate critical findings about cognitive health. More recently, the Institute of Medicine (IOM) issued its report, *Cognitive Aging: Progress in Understanding and Opportunities for Action* (2015), and included recommendations for improving communication around the concept of cognitive health, especially with respect to the public. To fulfill the mandates of these efforts, research on cognitive aging is being shared across disciplines, put into clinical practice, and used in public health messaging. However, this widespread dissemination has increased the opportunity for ambiguity and misinterpretation of terminology.

Disciplinary assumptions, whether epistemological, ethical, ideological, theoretical, or methodological, exist and influence terminology used to describe phenomena of study (Szostak, 2014). When terms are employed across disciplinary boundaries or translated into clinical practice, confusion, misunderstanding, and misinterpretation can occur (Koskan, Friedman, & Messias, 2010). Often, terminology does not translate easily. In cross-disciplinary contexts, researchers from various disciplines may attach different meaning to the same terms due to the inherent ambiguity in language. Though such ambiguity can be a positive force, by stimulating curiosity and leading to new research directions, it can also be negative, masking logical or theoretical inconsistencies (Griffiths & Stotz, 2014; Szostak, 2011). Scholarly attention to the use of terminology in the study of cognitive science is limited, despite its relevance to interdisciplinary research efforts on cognitive aging and cognitive health.

In an effort to highlight ways in which further clarification of terminology might be relevant to research dissemination efforts, this review aims to: 1) identify the shared terminology found in medical, nursing, and social science research literature to describe cognitive aging and cognitive health specifically in conjunction with dementia and Alzheimer’s disease among older adults; 2) demonstrate how such terms may be defined; and 3) illustrate the range of construct measurement practices being employed in research settings. We conclude with a practical call to provide evidence to support the adoption of common data elements and to develop interdisciplinary consensus around application of terms both clinically and in research, along with recommendations for future research.

Background

Prior to 2007, the burden of cognitive decline, in terms of care-related costs and health disparities, was rapidly rising, despite growing scientific evidence that healthy behaviors may reduce risk and the rate of decline. In response, CDC and the Alzheimer’s Association released the *Road Map* (CDC, 2007), the first nationally-coordinated effort to promote

cognitive health as a public health issue. Recommendations contained in the *Road Map* placed emphasis on research dissemination, translation into clinical practice, and policy implementation, among other factors. It set the goal of developing strategies to increase cognitive health awareness among providers, public health professionals, and service providers. While it did not provide a formal definition for the term, “cognitive health,” the *Road Map* called for standardized mechanisms for the measurement of neurological and behavioral health.

The National Alzheimer’s Project Act of 2011 prompted the development of a federal coordination strategy to address the burden of Alzheimer’s disease and other dementias. The *National Plan to Address Alzheimer’s Disease* (U.S. Department of Health and Human Services (USDHHS), 2012), first published in 2012 and updated annually through 2017, focused on prevention and research, but also on building public awareness and monitoring progress to drive improvement, prioritizing the role of communication as key for success, especially to enhance awareness of cognitive aging to healthcare practitioners, public health professionals, service providers, and the public. Little attention has been given, however, to the ways in which concepts of cognitive health are communicated among researchers, despite the inherent interdisciplinary nature of this work.

Interdisciplinary communication

Interdisciplinary approaches are growing more common as a heuristic mechanism for scientific progress (Porter & Rafols, 2009). Interdisciplinary research promotes innovation by developing new lines of questioning and expanding problem definitions (Frost & Jean, 2003). Linking fields of study enables researchers to more fully address critical questions (Aboelela et al., 2007) and builds common knowledge and methodologies to solve complex problems (Newhouse & Spring, 2010). However, communication beyond individual disciplines is complicated, as each relies on methodologies and terminology used within its boundaries (Frost & Jean, 2003). Although scholars tend to agree that there is no formal definition of “interdisciplinary communication,” it is a practice aimed at achieving some kind of reciprocal comprehension, or shared knowledge, among researchers from different disciplines (Holbrook, 2013).

Researchers use dialects that are specialized to their discipline (Wear, 1999). This creates translational difficulty between natural science fields, between natural and social science fields, and between qualitative and quantitative social and behavioral scientists (Bruce, Lyall, Tait, & Williams, 2004). Different disciplines can use the same word to mean different things (Szostak, 2014), and words that are used in everyday discourse by non-experts, particularly contributes to misunderstanding (Bracken & Oughton, 2006). An example of this may be found in terms such as “memory” and “recall,” which may seem to suggest equivalent concepts. The former often refers to a passive ability to retain information and the latter often refers to an active ability to retrieve information, yet these terms are frequently used interchangeably. Translation of terminology into clinical practice presents additional opportunities for misinterpretation. Groups of differing socioeconomic status or geographic proximity attach meaning to convey concepts commonly encountered by the group (Hebert,

Brandt, Armstead, Adams, & Steck, 2009), and these meanings may differ or conflict with meaning attached by other groups and/or researchers.

In healthcare, members of various disciplines may use the same words; however, subtle conceptual interpretations can lead to misunderstanding (Bonis, 2013). As an ideal, terminology enables a common understanding of concepts. In practice, however, this ideal often fails because a) in a scientific context, not every term is defined and assumptions are made about existing knowledge, or b) terms, even when clearly defined, pick up connotations in usage that “gradually separate its fine-grained meaning into potentially incompatible submeanings” (Wray, 2017, p. 82).

Further complications to achieving a common understanding arise in cross-language and/or cross-cultural research settings. Cross-translations of research instruments and research reports may not adequately capture subtle nuance and cultural connotation with precise equivalency across languages (Shklarov, 2007). Moreover, cultural contexts shape the semantic meaning of terminology (Goddard, 2014), even among a shared, common language. For example, though English is common to both the U.S. and England, the equivalency of patient-supplied terms and responses can vary between these contexts; differing healthcare systems, private and socialized, may influence the readiness of patients to admit to health problems, patient satisfaction, or compliance with medical regimens (Hunt & Bhopal, 2004). Thus, even comparability of datasets across languages and cultures is not always achievable, as concepts around health often are influenced by disparate expectations and cultural values (Hunt & Bhopal, 2004).

Terminology related to cognitive aging, specifically, presents challenges to interdisciplinary work, as the presentation of symptoms related to cognitive aging are highly variable. For example, the terms “dementia” and “mild cognitive impairment” are often used to represent a syndrome of maladaptive behaviors related to cognitive health, that vary both in the type of behavior (e.g., memory loss, sleep disturbance), as well as in the behaviors that occur together. Clinical practitioners may use a variety of measures in practice to render diagnosis of these conditions, as such variety helps to illuminate and differentiate gradation and progression. In scientific research settings, however, such variability is far less desirable, as its presence diminishes the ability to reproduce and compare findings. Inconsistent definitions and measurement mechanisms can limit the interpretability of research results and impede the potential for interdisciplinary research progression.

Given the emphasis placed on communication in both the *Road Map* (2007) and the IOM Report (2015), identification of basic concepts, terminology, and measurement practices related to cognitive aging may serve to overcome potential cross-disciplinary communication challenges and foster greater research collaboration. To assist in this process, we examined the terminology *used by researchers* in reporting their work on cognitive aging and cognitive health that specifically related to dementia and Alzheimer’s disease. We address the questions, “What are the basic concepts relied on by cognitive, social, and behavioral scientists to describe cognitive aging and cognitive health in their work on dementia and Alzheimer’s among older adults?”; “How are such terms being defined, if at all?”; and “How are these constructs being measured?” By demonstrating how

such terms are defined by researchers, and by illustrating the range of construct measurement practices being employed in research settings, we aim to highlight potential research terminology that might benefit by greater definitional clarity, and thereby enhance the potential for its use in interdisciplinary research settings.

Method

Scoping reviews enhance conceptual clarity about a specific topic or field of evidence (Davis, Drey, & Gould, 2009). They differ from systematic reviews in their emphasis on mapping a field of study, and do not evaluate the quality of the underlying literature (Levac, Colquhoun, & O'Brien, 2010); yet, by utilizing the techniques of systematic reviews, scoping reviews offer rigorous and transparent methods to identify and analyze relevant literature pertaining to a research question (Pham et al., 2014). This review examines peer-reviewed literature published between January 2007 and July 2018 to scope research nomenclature relating to cognitive aging and cognitive health and specifically concerning dementia and Alzheimer's disease among older adults. This selected period coincides with the publication of *The Road Map* (2007), which called for greater critical research dissemination on cognitive health.

Conceptual criteria

Search terms and targeted databases were determined by consensus and developed with the assistance of a health sciences librarian. The research team consisted of experts in nursing, social work, communication, psychology, gerontology, and public health. Embase, CINAHL, PsycINFO, and MEDLINE were searched, using the parameters summarized in Appendix 1 to search title, abstract, subject terms, and keywords. In addition to terms related to cognitive aging and health, supplementary terms related to public health were included to maintain a focus on research aligned with disease prevention and early diagnosis, consistent with *The Road Map's* aim of promoting cognitive health as a public health issue. This concentrated the dataset on studies that focused on the health of populations, outside of clinical settings, to capture the broad range of ways in which dementia occurs in the community.

Inclusion/exclusion screening

After reviewing for duplicates, 3,714 articles were selected for further screening of abstract and title information to ensure that articles met inclusion and exclusion criteria. To be included in the database, articles covered primary research, included terminology used by researchers and others related to dementia, Alzheimer's disease, cognitive aging, and cognitive health, and were published between January 2007 and July 2018. Reasons for exclusion included, for example, case studies, study protocols, and pharmaceutical studies. Studies performed outside of the U.S. were excluded in an effort to enhance the conceptual clarity of terminology being used in the research, and eliminate challenges associated with cross-language and cross-cultural contexts (Hunt & Bhopal, 2004). In an effort to maintain a focus on public health research, studies on basic science (e.g., biological studies) were excluded, along with studies that did not align with the focus of this review, such as cost of care studies and study proposals and study protocols. An illustration of the screening

processes is provided in Figure 1, and the full list of inclusion/exclusion criteria are detailed in Table 1.

Screening was conducted using the Covidence platform (www.covidence.org), a web-based tool developed for systematic reviews that enables a blind, random assignment of articles to the reviewer team. To ensure accuracy and consistency among reviewers, every article was screened by at least two team members, and all reviewers formally revisited inclusion/exclusion criteria after screening approximately every 50 articles. Two designated team members resolved conflicts in the screening process. In all, 3,034 studies were excluded in the abstract/title screening phase, leaving 680 articles available for data extraction.

Data charting

Once the initial screening process was completed, each article was obtained and distributed to team member dyads, or pairs of research team members, for data charting. Data were collected and managed using REDCap electronic data capture tools (Harris et al., 2009). Each dyad reviewed the full text of between 50 and 120 articles, with each member of the dyad charting information independently. Members of each dyad reconciled the charted data with one another after completing approximately 25 to 50 articles, with reconciliation events varying between one and four per dyad in total. Another 471 articles were excluded in this phase: 341 reported on international study populations; 33 reported on basic science (animal studies, neuroimaging, etc.); 21 articles were considered gray literature; 26 articles related to instrument testing; 14 articles were letters to the editor or opinion essays; and 36 articles were excluded for miscellaneous reasons (e.g., case studies, cost of care studies, focus on delirium; one unobtainable article and one duplicate). The following information was charted from the remaining 209 articles: study type; study purpose; descriptive sample data; specific use of the terms dementia, cognitive impairment, mild cognitive impairment, cognitive decline, and cognitive change; definitions for specified terms, applicable citations for specified terms, measurement of specified terms; other relevant terms related to cognitive health and/or cognitive aging, along with definitions, citations, and measurement processes; measurement instruments used in the study; and any other relevant conclusions, citations, and research recommendations related to terminology.

As a final step, the disciplinary orientation for each of the remaining 209 articles was assigned by examining the National Library of Medicine catalog entry for the Broad Subject Terms assigned to the publishing journal of each article.

Results

The following analysis provides descriptive information about the 209 articles in the dataset. We then offer a more detailed analysis of two specific terms, “cognitive impairment” and “mild cognitive impairment,” as these were commonly employed throughout the literature. Descriptive information on the dataset is summarized in Table 2.

We first note the significant acceleration in published literature regarding cognitive health over the period of review. Ten articles were included in the dataset for 2007 (a partial year), and 13 articles for 2008. By comparison, 25 articles were published in 2017 (the latest

complete year), with another 17 articles published in the first seven months of 2018. This significant rise in published literature demonstrates the increased attention to this field, likely in response to the calls of *The Road Map* and the IOM report.

Types of studies

The majority of studies in the dataset were observational in nature (n=134, 64.1%), and included longitudinal studies on neuropsychological measures and cognitive performance, and studies of the predictive power of performance on these types of measures (e.g., tests of executive function, visuospatial tests) and cognitive condition. A number of studies examined the relationship between physical behaviors and characteristics (e.g., sleep patterns, physical activity levels, body mass index, lower extremity function), psychological factors (e.g., apathy, pain reports, agitation, anxiety), or other health conditions (e.g., kidney or cardiovascular disease, anemia, presence of dental care) and cognitive health. The role of caregiving for persons with cognitive impairment also received attention, with several observational studies examining caregiver burden and the role of patient behaviors, the prevalence of anticipatory grief, and the reliability of caregiver reports on patients' cognitive state.

Experimental research (n=33, 15.8%) included studies on the efficacy of a variety of psychosocial interventions, such as interaction strategies, hypnosis, and support groups on memory and recall. Some studies also examined interventions aimed at preserving cognitive function, such as caregiver-supported in-home cognitive and mindfulness training. A third line of research encompassed the role of physical activity to cognitive health, comparing groups with and without structured physical activity programs.

The prevalence of qualitative protocols (n=21, 10.0%) was much more limited, and centered on the ways in which narratives arise around cognitive decline and Alzheimer's disease, how partners navigate intimate relationships in the face of cognitive loss, and the experiences of caregivers and their quality of life. A few qualitative studies examined the ways in which diagnoses are obtained, from both the perspectives of the caregiver and primary care provider. Mixed methods research (n=14, 7.0%) examined differences in mechanisms for reporting health information, the characteristics of caregivers, and cultural differences in common beliefs about memory loss and Alzheimer's disease.

Sample data

The majority of articles (n=181, 86.6%) centered on older community-dwelling adults as the subject of study. About 15.3% (n=32) of the articles concerned caregivers, including family members, spouses, and clinicians. Two studies examined document content, such as death certificates and advertisements. Somewhat surprisingly, over 12% (n=25) of the studies did not report age and/or gender information about the study sample and 35.4% (n=74) failed to report race and/or ethnicity information. Only twelve studies (6.0%) reported information about the duration or onset of cognitive decline and/or impairment.

Disciplinary representation

Disciplinary analysis was conducted on the dataset by examining “broad subject terms” listed in the National Library of Medicine catalog record for each article’s publication. In all, the dataset represented research in 31 disciplines, as noted in Table 3. Many journal titles are cross-disciplinary in nature: two disciplines were listed for about half of the articles in the dataset (n=101); one discipline was listed for 74 articles; three disciplines were listed for 15 of the articles; and eleven articles had no disciplinary information listed. Despite the interdisciplinarity of the underlying research, the majority of the articles in the dataset were published in journals circulated among geriatrics (n=95), neurology (n=81), psychiatry (n=65), and to a lesser degree, psychology (n=30). Other disciplines that might be expected to contribute, such as nursing and public health (n=6 and n=4, respectively), had substantially lower levels of research reporting on the topics. Fewer than six articles were represented by any other field. The majority of the articles appeared in journals devoted to geriatrics, neurology, and psychiatry is perhaps unsurprising. More notable is the absence of work in other relevant areas such as social work and sociology.

Measurement tools

By far, the most frequently used measurement tool for assessing cognitive status was the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975). In its various forms (modified, revised, the Consortium to Establish a Registry for Alzheimer’s Disease adaptation), the MMSE was used in n=120 (57.4%) of the 209 studies in the dataset. Other tools used to assess cognitive function included the Clinical Dementia Rating scale (CDR) and its variants (n=35, 16.7%), and a variety of phone or practitioner assessments. Tests of executive function included the Trail Making test (n=39, 18.7%), the digit span forward and backward test (n=26, 12.4%), and a variety of the Wechsler Adult Intelligence Scale subtests (n=22, 10.5%).

Terminology

A variety of terminology was used to describe cognitive health and cognitive aging, though most of the terms extracted from the articles reflected cognitive deficiency. The full list of terms is catalogued in Appendix 2 and includes 1,160 references to cognitive function and cognitive health. For analysis purposes, the terms were loosely grouped by topic; these centered on terms describing Alzheimer’s disease and related disorders, dementia, cognitive impairment, mild cognitive impairment, cognitive change and decline, cognition and cognitive function, memory, executive function, and cognitive aging. There were few references to cognitive health or cognitive improvement.

Within each of these categories, terms that described related concepts were grouped. For example, the group surrounding “memory” also included phrases such as “memory complaint,” “memory loss,” and “subjective memory impairment.” Frequently, definitions of such terms were not included in the research report. For example, of the 158 (75.6% of the dataset) articles that mentioned “dementia” only twelve (8.0% of the dementia articles) articles defined the term. Measurement of constructs, similarly, were poorly outlined and, if a measurement mechanism was offered, varied widely among articles. Again, using the term “dementia” as an example, measurement was described in a scant 33 articles (20.9% of the

dementia articles), and varied widely between use of the MMSE, the National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria, a participant's "prior diagnosis of dementia," the CDR, or by a participant's "subjective memory complaint in the absence of functional impairment" (Koppel, et al., 2012).

To offer a more nuanced perspective on this wide-ranging nomenclature and the ways in which terms are defined and measured, the terms "cognitive impairment" and "mild cognitive impairment" are offered as detailed examples, as these were two frequently used terms.

"Cognitive impairment"

The term, "cognitive impairment" was used in a majority (n=132, 63.2%) of the articles. However, out of these, only one article defined the term as, "a spectrum of conditions ranging from mild cognitive impairment to full dementia" (Gurgel & Ward, 2014). Frequently, researchers used measurement instrument scale readings to define "cognitive impairment" within their studies, but these more quantitatively-oriented definitions varied widely in both the instruments that were used, as well as the cut points that were employed to determine an impaired cognitive status.

The measurement tools used as proxies for definitions of cognitive impairment included more widely employed instruments, such as the MMSE, Montreal Cognitive Assessment, the Blessed Orientation Memory and Concentration Test (BOMC) (Katzman, et al., 1983), the CDR, and Cumulative Illness Rating Scale for Geriatrics (CIRS-G) (Miller, et al., 1992), as well as researcher-improvised mechanisms. These improvised mechanisms ranged widely. Researchers used interviews (Rovner, Casten, Arenson, Salzman, & Kornsey, 2012), devised their own batteries of neuropsychological measures such as language, executive function, praxis, and reading ability to assess participant's cognitive impairment (e.g., Lee & Wu, 2015), or considered participants cognitively impaired when they "failed" a screening test (Bailey & Arab, 2015). One study used performance difficulty on items such as tracking current events, paying attention, and remembering people and addresses (Bass, et al., 2012) to determine cognitive impairment. Researcher-improvised assessments, while likely providing valid indication of impairment, may be unhelpful for cross-disciplinary use, as the outcomes of study may necessarily be tied to levels of impairment which cannot be reliably assessed in other settings.

Some studies attempted to employ more universal mechanisms, such as by defining cognitive impairment as falling at least 1.5 standard deviations below available age-corrected normative data in a standard neuropsychological test battery (Eggermont, et al., 2010). Yet these too can make comparison more challenging because of varying assessment mechanisms, despite such comparison's importance to cross-disciplinary work.

Even when more conventional tools were used, relevant cut points to demonstrate cognitive impairment deviated broadly between studies. For example, as shown in Table 4, the MMSE was frequently employed as an instrument to measure cognitive function, but scores to designate cognitive impairment ranged widely. One study defined cognitive impairment as

participant scores of between 20 and 30 (Beard, Sakhtah, Imse, & Galvin, 2012), while other studies considered participants to have significant cognitive impairment with MMSE scores of less than or equal to 23 (Clarke, Ko, Lyketsos, Rebok, & Eaton, 2010) or less than 19 (Morrow, Snitz, Rodriguez, Huber, & Saxton, 2009). Other, widely available tools, such as the CDR and the BOMC, evidenced similar discrepancies.

“Mild cognitive impairment”

A total of 131 articles (62.7%) used the term, “mild cognitive impairment.” Definitions for this term were more prevalent in these articles than in those that used the term “cognitive impairment,” but still meager, with only 33 articles (25.1%) providing any kind of definition. Similar to cognitive impairment, there was a wide variety in definitions provided. Mild cognitive impairment (MCI) is well-established as a precursor to dementia (Petersen, 2004), and is seen as a clinical syndrome that may intercede in the neuropathological progression between normal aging and Alzheimer’s disease (Petersen et al., 1999).

Citation analyses of terms revealed many (n=15, 45.5%) of these definitions were based on Petersen and colleagues’ work (1999, 2001, 2004, 2009), which evolved from the work of Braak and Braak (1991, 1995). Other definitions included MCI as “an initial state of [Alzheimer’s disease] or prodromal [Alzheimer’s disease]” (Tappen & Hain, 2014) and “a transition state between normal aging and dementia and predicts progression to dementia, particularly [Alzheimer’s disease]” (e.g., Lingler, Terhorst, Schulz, Gentry, & Lopez, 2016), or a disorder often thought to be a transitional phase between cognitive health and Alzheimer’s disease (e.g., Kirchberg, et al., 2012). People with MCI have subjective concerns about cognition and perform poorly on cognitive tests (Winblad et al., 2004) and/or experience impaired test performance (Plassman, et al., 2011). Mild difficulties in complex everyday tasks can commonly be seen among people with MCI (Giovannetti, et al., 2008); however, they are able to perform and preserve their normal activities of daily living skills, and therefore, do not meet the criteria for dementia disorders (Petersen, et al., 2001).

Measurement of MCI, like that of cognitive impairment, varied among a number of instruments, both singly and in combination. The MMSE was the most frequently used instrument (n=14, 16.0%), and was often used in tandem with the CDR (e.g., Kirschberg & Cohen, 2012) or Dementia Rating Scale-2 (CDR-2, Jurica, Leitten, & Mattis, 2001) (e.g., Seidenberg, et al., 2009; Tremont & Alosco, 2011). While the CDR was used as a stand-alone assessment in some studies (e.g., Albert, Moss, Blacker, Tanzi & McArdle, 2007), others used a standard battery of neuropsychological tests, such as tests of memory and executive function (Hall, Pennington, Swicegood, & Winter, 2012), or the presence of subjective memory complaint (Koppel, et al., 2012).

Cut points to define MCI again varied widely, and are shown in Table 4. For example, two studies defined participants with MCI as having MMSE scores between 21 and 30 (Dawson, et al., 2008; Rose, et al., 2011), while others used cut points of a score of 20 or higher (Lingler, et al., 2008), 24 or higher (Kirchberg, et al., 2012), and 25 and higher (Giovannetti, et al., 2008). In some cases, the MMSE was used to assign gradations of cognitive impairment, such as for making distinctions between MCI and moderate or severe cognitive impairment (Rose, et al., 2011). When using the CDR, researchers were similarly

inconsistent in their determinations: some used a defining score of 0 to 0.5 (Hall, et al., 2012) and others a score of greater than 0.5 (Albert, Moss, Blacker, Tanzi, & McArdle, 2007). Comparison to normed data was also employed, consistent with the Petersen definitions, using 1.5 standard deviation units below that of individuals with comparative age and education (e.g., Kirchberg, et al., 2012).

Discussion

Multiple specific clinical diagnoses fall under the umbrella of dementia, but all clinical representations indicate maladaptive behaviors and deficits in cognition. A challenge of dementia and cognitive decline is the insidious nature of its onset. Its early stages are where researchers and clinicians frequently grapple to define terminology and employ measurement tools to capture the variability of symptoms present in patients. Under such circumstances, it is understandable that variation in expression arises. Terminology changes over time as well, perhaps in response to more nuanced grappling. Yet, the deliberate development of common vocabulary and corresponding operationalization is essential to interdisciplinary research efforts, and even efforts within disciplines, to solve the complex problems presented by dementia and cognitive decline.

Our review of terminology used to describe cognitive aging and cognitive health among older adults (see Appendix 2) demonstrates wide variation in what is employed in a research reporting context. To date, studies which examine these discrepancies have been limited, despite the importance of language to advancing interdisciplinary research efforts. Research on dementia and MCI is extensive and ongoing, and yet many studies offer limited opportunity for comparability or interpretation in the collective, because of the ways in which terminology and measurement tools are utilized. This review highlights some ways in which further clarification of language might be relevant to enhancing research endeavors.

Six terms stand out as most frequently used: dementia (n=158); cognitive impairment (n=132); mild cognitive impairment (n=131); Alzheimer's disease (n=57); cognitive decline (n=55) and cognitive deficit(s)(n=55). The prominence of these terms signals not only their significance to research efforts, but also that a shared, common understanding of these terms is imperative. Other scoping reviews research indicate similar findings and recommendations. Friedman and colleagues (2015) examined risk and protective factors for Alzheimer's disease and related disorders and found several definitions; however, there was a lack of common definitions, measures, and instruments across studies. Given that work in this area is so vast in nature, it is recommended that a next step could be establishing an interdisciplinary task force of investigators in key areas where this work is being published (geriatrics, neurology, psychiatry, and psychology) to discuss how to proceed with the study of these key areas through a common lens. The field would benefit from clear specification of these terms to better communicate within and across disciplines.

Closer examination of the terms "cognitive impairment" and "mild cognitive impairment" reveals that such common understanding does not yet exist. Our review uncovered that when using these terms, few authors offered definitions. When definitions appeared, there was no consistent application across studies or, more surprisingly, within disciplines. Furthermore, it

was common for researchers from various disciplines to have technically distinct definitions of terms, especially when the terms were used in the vernacular. In the articles we reviewed, there was more clear and consistent terminology used, once a specific etiology was confirmed.

In addition, there was substantial variation in the measurement tools used to quantify participants' level of cognitive impairment and MCI, and inconsistency in interpreting results of these tools, especially with respect to various stages of cognitive decline. For example, the MMSE was the most used measurement tool to identify cognitive impairment. Yet, the MMSE is a screening tool and not intended for diagnosis (Monroe & Carter, 2012). The widespread, individualized interpretation of MMSE scores by researchers highlights the limited utility of this tool to capture the early spectrum cognitive impairment.

Part of our assessment of methodological rigor in this review was to determine whether standard demographic information was reported in the articles in our dataset. We found inconsistent reporting on race and ethnicity, gender, income level, and time since diagnosis. When data were collected about ethnicity and race, the datasets revealed a lack of ethnic and racial diversity in the samples. Because not all studies included this information, it is unclear whether they indeed lacked diversity; however, such information is essential to understanding the broader patterns of social determinants of health as they relate to cognitive aging. Moreover, universally collecting and reporting demographic information is critical to producing credible research and drawing appropriate conclusions.

Finally, based on journal classifications, research from a variety of disciplines was represented in our dataset, with geriatrics, neurology, and psychiatry featured prominently. Less represented were journals specific to the disciplines of social work, nursing, and sociology. Because of the significance of cognitive aging and cognitive health as key public health issues, readers of all health-related professional journals would benefit from articles on these topics.

Suggestions going forward

Findings from this scoping review have important research and practice implications, and indicate the importance of moving toward agreed upon definitions and measurement for cognitive disorders impacting older adults. First, researchers should include a definition and citation for the term(s) used for cognitive health description (Petersen, et al., 2014), as such precision will aid in the ability to compare, reproduce, and interpret results. Moreover, more research is needed to uncover whether consistency in terminology exists within disciplines such as geriatrics, neurology and psychiatry, as inconsistent use of terminology can hinder communication within disciplines as well. If such consistency is present, researchers should state the disciplinary-specific definition and its measurement for the benefit of those working in other disciplines. Second, journals should consider promoting consistent usage and definitions of cognitive health terms. This scoping literature review highlights the need for future research, such as use of the Delphi method, to establish definitions of these terms. Third, well-established and psychometrically strong measurement tools should be developed and used in ways that enable consistent interpretation of results across studies. As noted in our findings, screening tools such as the MMSE have limited utility for capturing the

spectrum of cognitive impairment, especially in its early stages. Finally, it is also important for the field to identify common data elements to be reported in all research studies about these topics, including demographic information of samples. Such standards would help ensure scientific rigor and transparency as multiple disciplines join together to improve the cognitive health of older adults.

Governmental funding research mechanisms, professional associations, and publishers can play a key role in this effort by providing authorship guidance that aims for greater consistency in research language and reporting requirements. Substantial efforts have been made in this direction with the 2011 update of clinical guidelines for diagnosis, which have more clearly delineated the clinical differences that exist on the cognitive continuum (e.g., Albert, DeKosky, Dickson, et al., 2011; McKhann, Knopman, & Chertkow, 2011). In clinical practice, having clearer and agreed upon definitions of cognitive impairment and MCI may help facilitate diagnosis and treatment. Additionally, discussing terms with consistency might serve to legitimize the subjective experiences of individuals in the early stages of cognitive change.

There were several limitations of this scoping review. Due to the nature of the search strategy, the dataset may have inadvertently excluded some articles due to the specific nature of the search terms and inclusion/exclusion criteria. The review was limited to studies conducted in the United States due to an effort to preserve conceptual clarity. We anticipate that an analysis incorporating international research reporting might surface additional deviations in language and terminology, due to the introduction of translational and cultural influences. In addition, basic science articles were excluded from the dataset because of a focus on public health, yet extensive research on dementia and Alzheimer's disease is being conducted in this area, along with research in areas related to cognitive training and intervention. Future studies might expand inquiry into each of these directions. Our search was reliant on the indexing of the four databases employed, Embase, CINAHL, PsycINFO, and MEDLINE. Also, our approach did not include a review of author disciplines, only the discipline of the journal in which a study was published, thereby limiting the view of the disciplinary representation of research.

We found few terms describing research on healthy cognitive status; rather, most of the terminology focused on cognitive decline and many of the identified terms had negative valence. This absence of terminology surrounding positive cognitive outcomes of aging suggests an important area for future research. Further work could also include additional analytical strategies, such as semantic network analysis or automated forms of topic modelling of the corpus of articles, to further expand on the variety of terminology and themes used in describing research on these topics. Likewise, an analysis of how terminology has changed over time may be a fruitful avenue for exposing the nuanced and positive changes that have occurred in response to more detailed studies of cognitive aging. In addition, researchers could examine other terms related to cognitive health and cognitive aging (see Appendix 2), beyond that of cognitive impairment and MCI, as well as terminology employed in other settings, such as clinical and caregiving settings.

Conclusion

In sum, with society’s aging population, work on understanding and improving cognitive health is of utmost importance, and researchers from across disciplines have joined this mission. Though some ambiguity can be helpful to research innovation, the disparities in definitions of cognitive impairment and MCI ultimately hinder cross-disciplinary communication. This limits opportunities for broader research collaboration to meet the challenges of cognitive aging and impedes dissemination of research on a wider scope. If researchers aim to make progress toward improving cognitive health among all older adults, it would be helpful to have more specificity and clarity around definitions, along with greater consistency in the use of measurement tools to assess the conditions of study.

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Appendix 1: Search parameters

Term	Public Health Focus Term
Alzheimer*	Physician patient relations
Dementia*	Public health
Cognitive impairment	Health promotion
AND Alzheimer*	Health education
AND dementia	Health information
Cognitive disorder*	Consumer information
AND Alzheimer*	Intervention*
AND dementia	Prevention

Term	Public Health Focus Term
Cognitive change *	Patient communication *
AND Alzheimer *	Patient education
AND dementia	Community health
Cognitive decline	Health messag *
AND Alzheimer *	Public awareness
AND dementia	Health communication *
Cognitive health	Campaign
AND Alzheimer *	Public service
AND dementia	Attitude *
Cognitive aging	Knowledge
AND Alzheimer *	Belief *
AND dementia	Perception *
Cognitive status	
AND Alzheimer *	
AND dementia	
Brain health	
AND Alzheimer *	
AND dementia	
Healthy brain	
AND Alzheimer *	
AND dementia	
Memory loss	
AND Alzheimer *	
AND dementia	
Senile	
AND Alzheimer *	
AND dementia	
Senility	
AND Alzheimer *	
AND dementia	

(*) Note. The asterisk refers to the use of a wildcard, or a placeholder for one or more characters; it is used in searching for related terms such that messag* would return items that include message, messages, and messaging.

Appendix 2: List of Abstracted Terms

Terms	Frequency
AD continuum	1
advanced dementia	1
age-related cognitive decline	1

Terms	Frequency
age-related cognitive deficits	1
alcoholic dementia	1
alcohol-related dementia (ARD)	1
Alzheimer Disease/Alzheimer's/Alzheimer's disease (AD)	57
Alzheimer's dementia	3
Alzheimer's disease and other dementias	2
Alzheimer's disease and related disorders (ADRD)/Alzheimer's disease or related cognitive disorders (ADRDs)	2
Alzheimer's disease or related dementia	1
amnesic mild cognitive impairment/amnesic MCI	12
Anosognosia	2
anticipatory grief	1
brain aging	2
brain health	3
caregiver burden	1
cognitive complaint(s)	3
Cognition	10
cognitive ability	1
cognitive aging	1
cognitive change	390
cognitive competence	1
cognitive decline	55
cognitive deficit(s)	8
cognitive deterioration	1
cognitive difficulties	1
cognitive disorder(s)	3
cognitive dysfunction	8
cognitive factors	1
cognitive flexibility	2
cognitive function(ing)	5
cognitive health	4
cognitive illness	1
cognitive impairment	132
cognitive impairment no dementia (CIND)/cognitive impairment no dementia (CIND)/cognitive impairment without dementia (CIND)/cognitive impairment, not dementia (CIND)	7
cognitive loss	4
cognitive mastery	1
cognitive performance	1
cognitive problems	2
cognitive reserve	1
cognitive status	3
cognitively intact	1
cognitively normal	4

Terms	Frequency
concept formation	1
declining cognitive function	1
delirium superimposed on dementia	1
Dementia	158
dementia of the Alzheimer's type	2
dementing illness	1
early stage cognitive difficulties	1
early stage memory loss	1
early-stage dementia	3
executive dysfunction	1
executive function	1
executive function deficits	1
familiarity impairment	1
five domains of cognitive function	1
frontotemporal dementia	1
functional ability	1
functional decline	2
functional deficit	1
global cognitive function(ing)	2
impaired cognition	1
improved cognitive function	1
incipient dementia	1
Korsakoff syndrome or Korsakoff amnesic syndrome	1
Lewy body dementia	1
loss of cognitive and functional abilities	1
loss of functional capacity	1
MCI executive	1
MCI nonexecutive	1
memory complaints	1
memory decline	1
memory disorder	1
memory impairment	5
memory loss	8
memory problems	2
mental stimulation	1
mild AD	2
mild AD dementia	1
mild Alzheimer's disease	2
mild Alzheimer's disease dementia	1
mild cognitive change(s)	2
mild cognitive decline	1
mild cognitive deficit(s)	4

Terms	Frequency
mild cognitive disorder	1
mild cognitive dysfunction	1
mild cognitive impairment (MCI)	131
mild cognitive symptoms	1
mild dementia	2
mild impairment	2
mild memory impairment	1
mild neurocognitive disorder	1
mild neurocognitive impairment (MNCI)	1
mild to moderate cognitive impairment	1
mild/moderate dementia	2
minor cognitive impairment	1
moderate AD	1
moderate AD dementia	1
moderate cognitive impairment	1
moderate to severe dementia/moderate/severe dementia	2
multidomain MCI	1
neurocognitive degeneration	1
neurocognitive disorder	1
nonamnesic MCI	1
nondemented but mildly impaired	1
normal aging	1
normal cognition	3
normal cognitive aging	2
normal cognitive function	1
normal memory loss	1
objective cognitive impairment	1
pre-dementia cognitive changes	1
probable AD	2
probable dementia	2
processing speed	1
prodromal AD	1
psychometric MCI	2
quality of life	1
recollection impairment	1
semantic dementia	2
staying sharp	1
subjective cognitive complaints	2
subjective cognitive decline	3
subjective cognitive impairment	1
subjective memory concerns	1
subjective memory impairment	1

Terms	Frequency
transient cognitive impairments	1
vascular dementia	7
very mild AD	1
visual spatial skills	1
Wernicke-Korsakoff	1
Wernicke's encephalopathy	1
Total	1,163

Appendix 3: Complete List of Articles Included in the Dataset

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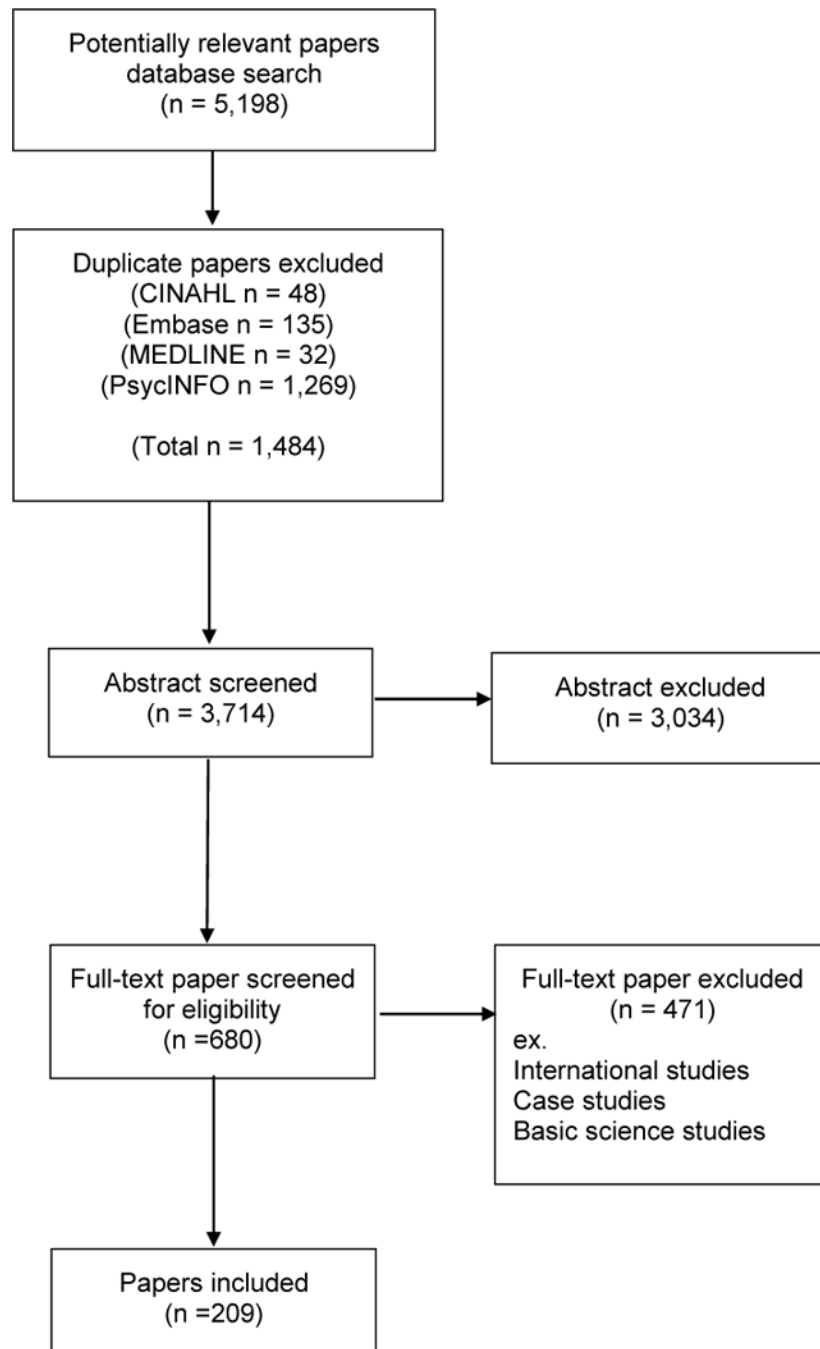


Figure 1.
Screening process flow chart

Table 1.

Inclusion and exclusion criteria

Inclusion criteria	
Article type	Primary research
	Data including terminology used by researchers, participants, or others for concepts related to dementia, Alzheimer’s disease, cognitive aging and brain health
Publication information	Studies with a public health focus
	Published in English
	Published from January 2007 through July 2018
	Study conducted in the United States
Exclusion criteria	
Article type	Focuses on perceptions in general (not specific to dementia, Alzheimer’s disease, cognitive aging, and brain health)
	Basic science study
	Focuses on delirium, developmental disorders or other
	Gray literature or review
	Pertains to cost of care/cost of treatment study
	Proposed studies, study protocols
Setting	Studies conducted in clinical settings (don’t have a public health focus) [†]
	Studies/data collection conducted outside the U.S. (international studies)
Participants	Less than 10 participants
	Younger than 18 years old

[†]Clinical settings was defined for the purposes of this study as those which included hospital inpatients and/or residents of skilled nursing facilities as participants.

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Table 2.

Descriptive summary of dataset

	Articles	
	n	%
Individuals studied [†]		
Individuals	181	86.6
Caregivers	32	15.3
Other	2	
Types of studies		
Observational	134	64.1
Experimental	33	15.8
Qualitative (interviews, focus groups)	21	10.0
Mixed methods	14	7.0
Other	7	3.5
Publication year		
2007 [*] –2009	35	16.7
2010–2012	61	29.2
2013–2015	55	26.3
2016–2018 [*]	58	27.8

[†]Totals may not add up to 100% because of multiple samples within a given study.

^{*}Indicates partial year.

Table 3.

Disciplinary representation

Discipline	Number of articles
Brain	3
Drug Therapy	3
Geriatrics	95
Health Services	2
Health Services Research	2
Internal Medicine	4
Medicine	5
Neurology	81
Nursing	6
Primary Health Care	3
Psychiatry	65
Psychology	30
Psychophysiology	4
Public Health	4
Science	3
Social Sciences	5
Therapeutics	2
Vascular Diseases	2

Disciplines appearing only once: Acquired Immunodeficiency Syndrome; Behavioral Sciences; Cardiology; Critical Care; Epidemiology; Medical Informatics; Nephrology; Neurosurgery; Nutritional Sciences; Otolaryngology; Physical/Rehabilitation Medicine; Pulmonary Medicine; and Transplantation.

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Table 4.

Assessment tools used to define terms

Term: Cognitive Impairment (CI)		
	MMSE	CDR (subscale, if stated)
Beard & Sakhtah (2012)	20–30	
Clarke & Ko (2010)	23	
Lee & Bliwise (2007)	16 = moderate CI	
Morrow & Snitz (2009)	18 = significant CI	
Tolea, Morris & Galvin (2015)		.5
Term: Mild Cognitive Impairment (MCI)		
	MMSE	CDR (version, if stated)
Albert, Moss, Blacker, et al. (2007)		>.5
Dawson & Singer (2008)	21–30	
Darby, Brickhouse, Wolk, & Dickerson (2017)	24–30	=.5 and =.5 (memory box)
Dodge, Mattek, Gregor, et al., (2015)		=.5
Giovannetti, Magouirk, & Bettcher (2008)	25	
Hall, Pennington, Swicegood, et al. (2012)		.5
Jefferson, Gifford, Acosta, et al., (2016)		.5
Kirchberg & Cohen (2012)	24	=.5 (global)
Lingler & Hirschman (2008)	20	
Marshall & Rentz (2011)	24–30	=.5 and .5 (memory box)
Rose & Beck (2011)	21–30	
Rovner, Casten & Hegel (2012)	>24	
Seidenberg et al. (2009)	>23	
Sundermann, Biegon, Rubin, et al. (2017)	24–30	=.5
Tolea, Morris & Galvin (2016)		=.5

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