

How Is Literacy Being Defined and Measured in Dementia Research? A Scoping Review

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Abstract

Literacy plays an important role in Alzheimer's disease and related dementias (ADRD); however, less is known about how literacy is being used and defined in ADRD studies. This study reviewed terminology being used to describe types and definitions of literacy and instruments used to assess literacy in ADRD research. Among the 219 studies retrieved from 3 databases, 50 met our inclusion criteria. Literacy terms used in ADRD studies varied: literacy ($n = 28$), health literacy ($n = 9$), and dementia literacy ($n = 7$) were the most often used terms, followed by financial literacy ($n = 4$), dementia knowledge ($n = 3$), AD knowledge ($n = 2$), mental health literacy ($n = 2$), AD literacy, digital literacy, health literacy about incontinence, and financial knowledge ($n = 1$ each). Thirty studies did not define literacy terms used. Among the 20 studies defining literacy, definitions were inconsistent across studies even when they used the same term. Surveys ($n = 30$), open-ended questions, vignettes, or focus groups ($n = 10$), self-perceived ($n = 3$) or interviewer assessed ($n = 1$) literacy levels were used to assess literacy. Ten studies did not specify literacy measurement. Various literacies have been examined in ADRD research with unclear definitions and some inadequate measures. Well-defined terms with valid measures are needed to better understand the role of literacies in ADRD research.

Keywords

Alzheimer's disease, dementia, literacy, health literacy, review

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Introduction

Alzheimer's disease (AD) is the most common type of dementia and the sixth leading cause of death in the United States (Alzheimer's Association, 2018). About 5.7 million Americans are currently living with AD and related dementias (ADRD), and the prevalence of ADRD is increasing as baby boomers continue to age (Alzheimer's Association, 2018). ADRD is impacted by more than genetics; lifestyle factors, such as diet, physical activity, and socioeconomic status may also play a role in the development of ADRD (Alzheimer's Association, 2018).

Literacy often refers the ability to read or write. Beyond this fundamental literacy, literacy includes a broad range of abilities such as oral skills, numeracy, and how to access, learn, and apply knowledge and information (United Nations Educational, Scientific and Cultural Organization, 2005), and multiple domains of literacy have been proposed in various field. For example, the Institute of Medicine (Nielsen-Bohman, Panzer, & Kindig, 2004) viewed that health literacy includes individuals' capabilities of writing and reading, speaking and

listening, cultural and conceptual knowledge, and numeracy. Others also included fundamental literacy (reading, writing, speaking, and numeracy), scientific literacy, civic literacy, and cultural literacy (Zarcadoolas, Pleasant, & Greer, 2009), and media and Internet literacy as components of health literacy (Norman & Skinner, 2006; Nutbeam, 1998; Zarcadoolas et al., 2009). Given that different type of literacies may link to different role of literacy in people's ability to understand and utilize information, defining literacy is important to understand the role and impacts of literacy on people's health.

Literacy is suggested to be an important predictor of cognitive decline and ADRD due to its relation to cognitive reserve (Manly, Schupf, Tang, & Stern,

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2005). The cognitive reserve theory hypothesizes that individuals with different cognitive reserve, preexisting cognitive capacity, have different brain functions and thus their brains react differently to brain changes such as ADRD (Stern, 2002). This theory explained that individuals with more cognitive reserve can cope better with ADRD and maintain effective brain function than those with less cognitive reserve when brain changes are the same. Level of cognitive reserve is often measured by literacy. Commonly used instruments for literacy measurement include the Wide Range Achievement Test (WRAT), Rapid Estimate of Adult Literacy in Medicine (REALM), and Test of Functional Health Literacy in Adults (TOFHLA), which test various components of literacy ranging from word recognition, pronunciation, reading comprehension, and numeracy (Friedman & Hoffman-Goetz, 2006). Literacy has been investigated in ADRD research to understand the role of literacy in ADRD, and previous studies showed that literacy level may predict cognitive decline or ADRD (Boyle et al., 2013; Lee et al., 2016; Manly et al., 2005).

In addition, health literacy, defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000) has received much attention in recent years. Individuals with low health literacy are more likely to have negative health outcomes including cancer, diabetes, and ADRD (Bailey et al., 2014; Oldach & Katz, 2014; Yu, Wilson, Schneider, Bennett, & Boyle, 2017) as well as higher hospitalization rates, poor knowledge of health issues, and lower utilization of preventive services (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Diviani, Putte, Giani, & Weert, 2015). Improving health literacy has become increasingly important as health information and services including those related to ADRD have become more complex (Centers for Disease Control and Prevention, 2009). However, more than half of Americans over the age of 65 are considered to have a below-basic level of health literacy, and about 98% have health literacy skills that are below the proficient level (Kobylarz, Pomidor, & Pleasant, 2010). Limited literacy skills may hinder older populations from engaging in prevention and early detection of diseases, including ADRD, and from appropriate communication with health care providers and use of health care services (Suka et al., 2015; Suri, Majid, Chang, & Foo, 2015).

Although many aspects of literacies need to be considered to address ADRD, the term literacy and its multiple domains often used in different ways in each study. To better understand potential roles of various aspects of literacy in ADRD and compare results over previous research, it is important to understand how literacy is being used, defined, and measured in ADRD research. Thus, the purpose of this study was to examine types of

literacy, literacy definitions, and instruments used to assess literacy in ADRD research.

Research Design

Search Strategy

A scoping review of studies on ADRD and cognitive health with a literacy component was conducted. In September 2016, we searched PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL)[®] Complete, and PsycINFO using the following combination of search terms: “Dementia” OR “Alzheimer’s disease” OR “Cognitive health” OR “Cognitive impairment” OR “Cognitive decline” AND “Literacy.” The search of titles and abstracts yielded a total of 270 abstracts across the three databases. After excluding duplicate studies, 219 studies remained.

Inclusion and Exclusion Criteria

We included studies that were (a) written in English, (b) empirical research examining literacy in studies of ADRD and cognitive health, and (c) published in a peer-reviewed journal. Studies were excluded if they were (a) written in other languages; (b) focused on other diseases; (c) reviews, editorials, letters, essays, case reports, conference abstracts, or dissertations; and (d) conducted specifically for the purpose of instrument or validity testing. We did not exclude studies based on publication year.

Study Selection

An initial review of titles and abstracts were done by two reviewers. They each reviewed half of abstracts and reviewed the same random 10% of abstracts independently. Any discrepancies between the two reviewers were discussed until a consensus was reached. If disagreement remained, another author served as a tie-breaker. After excluding 154 studies from the abstract reviews, the first author reviewed full texts of remaining studies and further excluded 15 studies that did not meet inclusion criteria. Of the 169 studies excluded, 36 studies focused on instrument testing, eight studies were not in English, 32 studies were not focused on or directly related to literacy (e.g., used education level as an indicator of literacy), 77 studies were not focused on dementia/AD/cognitive health, and 16 studies were reviews/editorials/letters/dissertations. A final total of 50 studies were included for analysis. The study selection process is presented in Figure 1.

Data Extraction

One author completed full-article coding of the 50 studies. Another author reviewed a 20% random sample of the studies to ensure quality coding. For each study, we

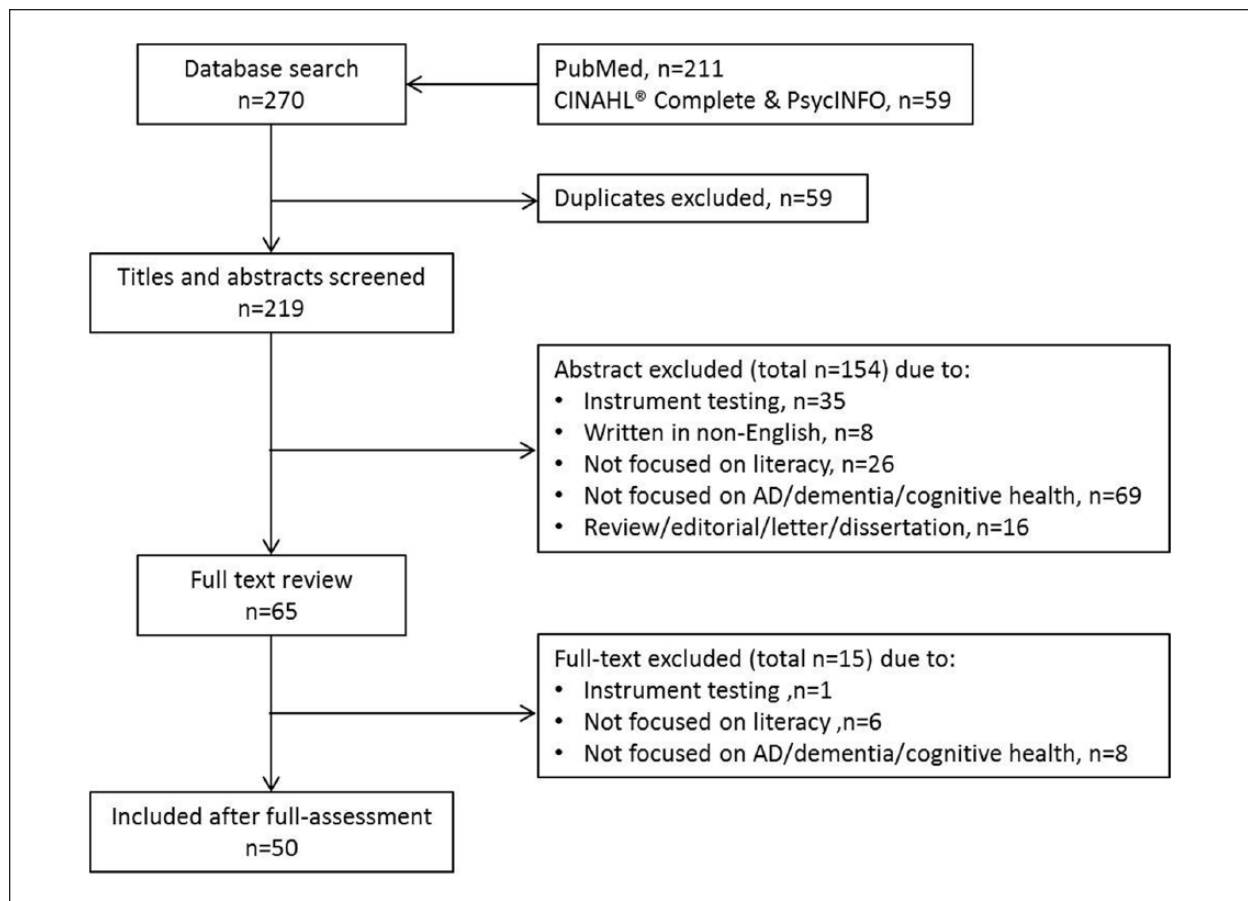


Figure 1. Flow diagram of the literature search.

identified what type of literacy was defined (e.g., literacy, health literacy, dementia/AD/cognitive health literacy, financial literacy) and if and how it was measured. Disease focus (e.g., dementia, AD, cognitive health), study location, and other characteristics of study populations, including sample size, age, sex, and rate of inadequate literacy, were coded during the full-text review.

Results

Characteristics of the studies reviewed, including literacy terms, definitions, and measurements used in each study, are presented in Table 1.

Characteristics of Studies Reviewed and Study Populations

Thirty-one studies were conducted in the United States, five in Australia, four in India, and three each in England and Brazil. Three studies were conducted in more than one country. Study populations were mainly community members/general population that might include ADRD patients ($n = 45$). Two studies each specifically focused only on individuals with mild cognitive impairment or AD and caregivers of individuals with ADRD. Two

studies included African American clergy. Only one study included health care professionals, and two included more than one population.

Most studies included older adults (aged 65 years or more; $n = 21$) or individuals middle aged or older (aged 50 years or older; $n = 16$). Four studies included only adults (aged 18-65 years) and six studies included both adults and older adults. Only one study focused on only children. Sample size in each study varied with the smallest having nine participants and the largest study including 12,887 participants. The mean number of participants across studies was 1,789. Thirty-two studies reported percentages of low or inadequate literacy among study populations; percentages of low or inadequate literacy varied greatly in each study ranging from 4.0% to 88.4%.

Disease Focus

The disease focus was mainly cognitive impairment or cognitive health ($n = 22$) and dementia ($n = 15$). Fewer studies focused on AD only ($n = 8$), both dementia and AD ($n = 4$), and both AD and cognitive impairment/health ($n = 1$). Two studies discussed dementia and AD interchangeably.

Table 1. Literacy Terms, Definitions, Instruments, and Study Characteristics in Alzheimer's Disease (AD) and Related Dementias Research (n = 50).

References	Study location Population Age range ^a Sample size	Disease focus	Definition of literacy	Instrument(s) used to assess literacy	% low/inadequate literacy
AD literacy					
Sun, Gao, and Coon (2013)	The United States Community members/general population 55-100 385	AD	People's knowledge and beliefs about AD	24 AD knowledge items and 10 Chinese cultural beliefs of AD items	—
AD knowledge					
Stansbury, Marshall, Harley, and Nelson (2010) Valle, Yamada, and Matiella (2006)	The United States Community members/general population African American clergy 36-90 9-111	AD Dementia		AD knowledge: 6 questions A vignette depicting an elder man experiencing symptoms of AD	11.1%
Dementia literacy					
Diamond and Woo (2014) Kim, Sargent, Cox, and Anstey (2015) Loi and Lautenschlager (2015) Low and Anstey (2009) Low et al. (2010) Millard, Kennedy, and Baune (2011) Noble, Hedmann, and Williams (2015)	Australia The United States England Community members/general population Patients in general practices 9-94 34-2,000	Dementia AD	A person's knowledge regarding dementia Knowledge and beliefs regarding dementia that aid recognition, management, or prevention	Focus group Vignette(s) describing dementia symptoms and behaviors of a person Self-reported adequateness of dementia knowledge True or false statements assessing comprehension of dementia symptoms, cause, treatment and prognosis Open-ended questions about dementia risk factor and risk reduction Questions related to intervention program content—AD symptoms, causes	—
Dementia knowledge					
Lee et al. (2016) Millard et al. (2011) Zheng and Woo (2016)	Australia; England; South Korea; the United States Community members/general population AD/dementia/cognitive impairment patients Health care professionals 55+ / no age range 153-6,141	Dementia		Self-report "Do you consider your dementia knowledge adequate?" Questions regarding dementia causes, symptoms, treatment and prognosis	78%-85%
Health literacy					
Apolinario, Mansur, Carthery-Goulart, Brucki, and Nitirini (2015) Bennett, Boyle, James, and Bennett (2012) Bliss et al. (2013) Gupta et al. (2016) Han, Boyle, James, Yu, and Bennett (2015) Kobayashi, Wardle, Wolf, and Wagner (2015) Nguyen et al. (2013) Stewart et al. (2018) Wilson, Yu, James, Bennett, and Boyle (2017)	The United States; England; Brazil Community members/general population Older adults with diabetes Informal caregivers 18-100.8 48-5,256	Dementia AD Cognitive decline/ impairment/health	The ability to access, understand, and utilize health information and concepts in ways that promote good health outcomes. The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (Do not have trouble) accessing, understanding, and using information to make basic health decisions.	9 items including questions on Medicare, following doctors' prescription instructions, leading causes of death in older persons, and a question framing the same drug risk information in difference ways The Adult Literacy and Life Skills Survey Short Test of Functional Literacy in Adults (S-TOFFLA) Focus group interviews	27.7%-54.8%
Financial literacy					
Bennett et al. (2012) Han et al. (2015) Stewart et al. (2018) Wilson et al. (2017)	The United States Community members/general population 58-100.8 487-755	AD ⁴⁴ Cognitive decline/ impairment/health	The ability to access, understand, and utilize financial information and concepts in ways that promote good financial outcomes.	23 items, with simple arithmetic items to evaluate numeracy and question about financial concepts such as compound interest.	—
Baird, Ford, and Podell (2007)	The United States Community members/general population Mean age: 75 129	Cognitive decline/ impairment/health		The ILS Money Management Subscale	

(continued)

Table 1. (continued)

References	Study location Population Age range ^a Sample size	Disease focus	Definition of literacy	Instrument(s) used to assess literacy	% low/inadequate literacy
Literacy					
Baird et al. (2007)	Brazil; China;	AD	The ability to read and write; a dynamic, lifelong learning process that involves the acquisition and application of relevant knowledge to circumstances encountered in everyday life.	Total 32 items (9 for health literacy, 23 for financial literacy)	4.0%-88.4%
Barnes, Tager, Satariano, and Yaffe (2004)	Cuba; France; India; Mexico; Peru; South Korea; Spain; Thailand; the Dominican Republic; The United States; Venezuela	Dementia Cognitive decline/impairment/health	The ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts.	National Adult Reading Test	
Boyle et al. (2013)	Community members/general population		The ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts.	Reading Recognition Subtest of the Wide Range Achievement Test-Version 3 (WRAT-3)	
Brewster et al. (2014)	Community dwelling older adults who are APOE ε4 carriers		The ability to identify, understand, interpret, and use written materials to function effectively in varying context.	Rapid Estimate of Adult Literacy in Medicine (REALM)	
Chandra et al. (1998a)	Community members/general population who reside in socially deprived areas		Able to read and/or write	American version of the National Adult Reading Test for English speaking people	
Chandra et al. (1998b)	Medicare recipients		English reading level	Word Accentuation Test for Spanish speakers	
Contador et al. (2017)	AD/dementia/cognitive impairment patients		Oral word reading	Reading written information, assessed by the interviewer.	
Jitapunkul, Kumanusont, Phoolcharoen, and Suriyawongpaisal (2001)	Patients with varying degrees of medical illnesses and cognitive impairment, including AD		Single word reading	North American Adult Reading Test (NART)	
Kaup et al. (2015)	30-105			Self-assessed reading and/or writing ability	
Kuczmarski, Cotugna, Mason, Evans, and Zonderman (2015)	105-12,887				
Lee et al. (2016)					
Manly, Touradj, Tang, and Stern (2003)					
Manly, Schupf, Tang, and Stern (2005)					
Mayeux et al. (1995)					
Mehta et al. (2009)					
R. Pandav, Dodge, DeKosky, and Ganguli (2003)					
R. S. Pandav, Chandra, Dodge, DeKosky, and Ganguli (2004)					
Prince et al. (2012)					
Rovner, Casten, and Leiby (2016)					
Sachs-Ericsson and Blazer (2005)					
Sczufca et al. (2008)					
Sczufca, Almeida, and Menezes (2010)					
Stewart et al. (2018)					
Valle et al. (2006)					
Vivot et al. (2015)					
Yaffe et al. (2013)					
Health literacy about incontinence					
Mullins, Bliss, Rolnick, Henre, and Jackson (2016)	The United States Informal caregivers Mean age: 64 48	AD	—	Focus group and interviews	—
Mental health literacy					
Chong et al. (2016)	Singapore	Dementia	Knowledge and beliefs about mental disorders which aid their recognition, management or prevention	Vignette(s)	33.7%
Stansbury, Harley, and Brown-Hughes (2010)	The United States African American clergy Community members/general population 18-68 9-3,006	AD			
Digital health literacy					
Xavier et al. (2014)	England Community members/general population 50-89 6,442	Cognitive decline/impairment/health	The ability to engage, plan, execute, and evaluate digital actions such as web browsing and exchanging E-mails as aids for dealing with daily life task.	Self-reported use Internet or email	64.9% did not use Internet/email

^aAge range and mean age were reported at base line if the study was a cohort study.

Literacy Focus

Literacy was examined the most ($n = 28$), followed by health literacy ($n = 9$), dementia literacy ($n = 7$), financial literacy ($n = 4$), dementia knowledge ($n = 3$), AD knowledge ($n = 2$), mental health literacy ($n = 2$), and others (AD literacy, digital literacy, health literacy about incontinence, financial knowledge; each was examined in one study). Eight studies discussed multiple literacies or knowledge. Ten studies used the terms “literacy,” “knowledge,” or “skill” interchangeably.

Literacy Definition

Thirty studies did not define literacy. The definition of literacy varied among the remaining studies that defined the term ($n = 20$). Studies of literacy, health literacy, or digital literacy ($n = 7$) addressed people’s ability to access, understand, utilize information/materials to define the term. Studies of AD literacy, dementia literacy, or mental health literacy ($n = 4$) defined literacy as people’s knowledge and belief regarding AD/dementia/mental disorder. One study about dementia literacy (Low et al., 2010) only addressed knowledge when they defined the term dementia literacy while another study conducted by the same authors defined this term as people’s knowledge and beliefs (Low & Anstey, 2009). Eight studies of literacy defined the term as the ability to read and/or write. Four studies did not define the literacy terms they focused on.

Among the studies that defined literacy, 11 studies used definition from published research or reports (e.g., health literacy definition from Institute of Medicine (Nielsen-Bohman, Panzer, & Kindig, 2004), or Nutbeam, 1998; mental health literacy from Jorm et al., 1997). One study stated that the definition was from a local registry, but did not provide a citation. Eight studies did not include a source for the definition that they provided.

Literacy Measurement

Ten studies did not specify how literacy was measured. Among the remaining studies that discussed measurement, four used multiple methods. Quantitative surveys were used most often ($n = 30$), including the WRAT version 3 ($n = 6$; word recognition and pronunciation test), REALM ($n = 4$; medical terminology reading and pronunciation test), shortened version of the TOFHLA ($n = 3$; reading comprehension and numeracy test), North American Adult Reading Test ($n = 2$; word recognition test), and true/false statements or questions regarding AD/dementia causes, symptoms, prognosis, and treatment ($n = 2$). Five studies used the same 32-item questionnaire to assess health literacy (nine items) and financial literacy (23 items) and considered sum of health literacy and financial literacy as a total literacy. Among the five studies, Boyle et al. (2013) did not separate health and financial literacy and used total literacy

in the analysis. Six studies provided vignette(s) describing person(s) with ADRD and examined if study participants were able to recognize individuals’ symptoms. One study used open-ended questions for participants to describe dementia risk factors and risk reduction.

Qualitative studies did not use a specific instrument to assess literacy. Rather, literacy was the main focus of discussion groups or interviews or it emerged as a theme. Three qualitative studies examined participants’ perceived level of literacy and another study used interviewers’ perceived level of participants’ literacy.

Some studies measured a different type of literacy than the literacy they defined or used throughout the study. Sun, Gao, and Coon (2013) used the term “AD literacy,” but measured AD knowledge using 24 items about AD symptoms, course, risk factors, diagnosis and treatment, and caregiving. Noble, Hedmann, and Williams (2015) conducted an intervention program to increase AD knowledge among students. They used “dementia health literacy” in the title, used terms “AD health literacy,” “dementia literacy,” and “AD knowledge” in the main text, and assessed AD knowledge. In a multicountry study, literacy was only measured for participants in India (instrument not specified) and for participants in the United States, education level was used as an indicator for literacy level. Vivot et al. (2015) assessed literacy as a surrogate of cognitive reserve.

How Literacy Was Studied

Two fifths of the studies ($n = 20$) assessed literacy level and some ($n = 13$) also examined factors associated with literacy. APOE $\epsilon 4$ allele and decreased cognition, cognitive impairment, or dementia in old age were related to low levels of literacy (Boyle et al., 2013; Lee e016; Stewart et al., 2018); while duration in the United States among Chinese Americans was not related to dementia literacy (Diamond & Woo, 214). Higher literacy was associated with more participation in cognitive/social and physical activity among African Americans with mild cognitive impairment (Rovner, Casten, & Leiby, 2016). Higher level of AD knowledge was related to higher perceived threat of AD (Sun, Gao, & Coon, 2013). Lack of dementia knowledge was a barrier to change lifestyles and behaviors to reduce dementia risk (Kim, Sargent-Cox, & Anstey, 2015). Two studies implemented interventions aimed at increasing AD knowledge (Noble, Hedmann, & Williams, et al., 2015; Valle, Yamada, & Matiella, 2006).

Two fifths of the studies ($n = 20$) assessed literacy level and some ($n = 13$) also examined factors associated with literacy. APOE $\epsilon 4$ allele and decreased cognition, cognitive impairment, or dementia in old age were related to low levels of literacy, while duration in the United States among Chinese Americans was not related to dementia literacy. Higher literacy was associated with more participation in cognitive/social and physical

activity among African Americans with mild cognitive impairment. Higher level of AD knowledge was related to higher perceived threat of AD (Sun, Gao, & Coon, 2013). Lack of dementia knowledge was a barrier to change lifestyles and behaviors to reduce dementia risk. Two studies implemented interventions aimed at increasing AD knowledge.

In some studies, literacy was not the main foci. Literacy was used as an adjustment variable in studies that examining associations between AD and self-assessed school performance, AD and hemoglobin level, cognitive impairment and blood pressure, cognitive impairment and neurological factors, or cognitive function and caffeine intake. In a study examining the association between AD-related genotypes and cognitive decline, literacy was considered one domain of cognitive decline (Vivot et al., 2015).

In two qualitative studies, health literacy was used to describe a lack of health literacy related to incontinence care among informal caregivers of people with ADRD and their health literacy needs related to incontinence and skin care (Bliss et al., 2013; Mullins, Bliss, Rolnick, Henre, & Jackson, 2016).

Discussion

This scoping review aimed to examine how literacy is being defined and used in ADRD studies. Our review revealed that multiple literacy types were examined in ADRD studies and that these literacies were measured by various tools and methods. Although terms were different, the purpose of examining literacy was similar: that is, literacy may have a role in people's cognitive health and ADRD. Most studies in this review showed that higher literacy is associated with better cognitive health and lower prevalence of ADRD.

There was inconsistency in how the terms were defined as all studies that defined a term(s) addressed reading or writing skills. Reading/writing level alone, however, may not reflect a person's literacy. Some studies that defined literacy actually addressed multiple literacies, for example, scientific literacy (AD knowledge), cultural literacy (people's belief regarding AD), and ability to access, understand, and utilize information.

These varied literacies in studies reviewed, however, were not consistent in each study. In addition, more than half of studies did not define the literacy term used in the research. Inconsistency in definitions and using undefined terms may make study findings incomparable across studies. For example, literacy as an ability to read or write and literacy as ability to access, understand, and utilize information are different. Interestingly, all studies that used the term "knowledge" did not define that term. Given that we reviewed studies having "literacy" in the title or abstract, the studies using the term "knowledge" without a definition used either another type of literacy in the study (Baird, Ford, & Podell, 2007; Lee et al., 2016; Millard, Kennedy, & Baune, 2011; Valle, Yamada,

& Matiella, 2006) or "knowledge" and "literacy" interchangeably (Stansbury, Marshall, Harley, & Nelson, 2010; Zheng & Woo, 2016).

Studies used various measurements even if they examined the same type of literacy. Furthermore, some studies measured different literacies compared with the literacy term actually defined in the study. This may be due in part to a lack of consistency in definition of the terms. Studies might have discussed the same type of literacy but present different definitions and different strategies for assessing literacy. We found studies used inappropriate tools to assess literacies such as a pronunciation test or self-perceived or interviewer-perceived level of literacy instead of a validated tool. These assessments, while useful, may not accurately reflect the person's literacy.

Some types of literacy and populations that are potentially important were less studied. Due to the increased burden of disease in people's later stages of life, older people as well as their caregivers often face financial issues resulting from health care costs (Riffin, Van Ness, Wolff, & Fried, 2017; Wolff, Spillman, Freedman, & Kasper, 2016). In addition, health and financial decisions for elders are often made with or only by their informal caregivers such as family members or friends (National Alliance for Caregiving & AARP Public Policy Institute, 2015; Riffin et al., 2017; Wolff et al., 2016). Thus, attention is being paid to improving financial literacy ("the ability to access, understand, and utilize financial information") (James, Boyle, Bennett, & Bennett, 2012) among older adults and caregivers. Only five studies reviewed measured financial literacy/knowledge and two studies included caregivers of individuals with ADRD. Individuals living with ADRD spend about 4 times more out-of-pocket expenses for health care and long-term care services than others of the similar age (Alzheimer's Association, 2016). In addition, their informal caregivers often spend significant amount of money to take care of ADRD patients and even cut back their own spending, saving, retirement saving, or work hours (Alzheimer's Association, 2016). Given that individuals living with ADRD and their caregivers are at a risk of financial insecurity, financial literacy would be important to prepare them for care planning. Health literacy of caregivers of individuals with ADRD is also important because they perform numerous tasks that include managing medical situations, health information seeking, communication with health care providers, and making health decisions for their care recipients (National Alliance for Caregiving, & AARP Public Policy Institute, 2015; Spillman, Wolff, Freedman, & Kasper, 2014). The two studies that included caregivers highlighted lack of health literacy among caregivers and their need for improved caregiving-related health literacy (Bliss et al., 2013; Mullins, Bliss, Rolnick, Henre, & Jackson, 2016). Further research is needed to understand the importance of literacy among caregivers and to develop interventions to improve their literacy.

This study has two limitations. First, only studies written in English were included in the review. Second, we reviewed studies having search terms in the title or abstract; thus, we might have missed relevant literature.

Conclusion

This study presents and describes literacy terms and instruments that have been used in ADRD research. We did not intend to recommend a single definition of literacy or a gold standard for measuring literacy. We acknowledge that various aspects of literacies each may have unique roles in ADRD; thus, it is important to consider examining multiple literacies in ADRD research. Still, defining the literacy term and use of a valid instrument are critical to better understand which aspects of literacy are associated with ADRD. Future ADRD research needs to define literacy terms and use appropriate tools that can more accurately reflect individuals' literacy. Understanding how people's level of literacy is associated with ADRD would provide insights into how we can better reach high-risk populations (e.g., individuals with lower literacy levels) for early detection of ADRD and relevant prevention efforts.

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