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Feature Article

Health literacy and its correlates in informal caregivers of adults with memory loss

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ABSTRACT

This secondary analysis examined health literacy among informal caregivers of community-dwelling older adults with memory loss and assessed correlates of caregiver health literacy using the Abilities, Skills and Knowledge Model. Caregiver health literacy ($n = 91$) was assessed by the Newest Vital Sign. Limited health literacy presented in 38.5% caregivers, with significantly low document literacy. Health literacy was associated bivariate with age, education, global cognitive function, executive function, and working memory (all $ps < 0.001$), as well as medication knowledge ($p = 0.015$). Hierarchical regression analyses revealed that older age ($p = 0.017$), and lower global cognitive function ($p < 0.001$), working memory ($p = 0.001$), and academic skills (years of education) ($p = 0.004$), independently predicted lower health literacy ($R^2 = 0.54$). Medication knowledge, however, was not found to be an independent predictor in the model. Findings suggest limited health literacy is a potential issue among informal caregivers of adults with memory loss. Appropriate assessment and personalized support are needed for informal caregivers who are at high risk for poor health literacy.

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Introduction

The number of community-dwelling older adults with some form of early cognitive decline resulting in dementia increases with age. Older adults with memory loss often have more care-related needs compared to those adults who are physically impaired but cognitively intact.¹ Informal caregivers who are often family members or kin-like friends, perform an important role in the daily care of these older adults with memory loss, including engaging in the management of their comorbid health conditions by supervising or assuming responsibility for medication taking.^{1–3} While it is widely acknowledged that older adults with memory loss are at risk for medication errors,⁴ there is an increasingly recognized possibility for informal caregivers to make medication errors due to factors such as incorrect knowledge about the medications or limited health literacy.^{5–7} The literature suggests that individuals with inadequate health literacy are less likely to understand basic

information about medications⁸ and are less able to recall correct medication name, dosage, and frequency of administration compared to those with adequate health literacy.⁹ As informal caregivers play a vital role in the care of older adults with memory loss, it is important to assess and improve caregivers' capability to understand, appraise and use health information, including information related to medication taking and safety, which potentially influences how effectively caregivers are able to undertake this caregiving responsibility.

Limited published research addresses caregiver health literacy and its assessment.⁵ Most of the literature on this topic focuses on parental caregivers of children rather than caregivers of older adults.^{6,10} Older adults are a unique population given the possibility for such individuals to have a number of chronic conditions requiring multiple medications. Successful medication management in this patient population is often complicated and challenging for both patients and their caregivers. Assessment of caregiver health literacy, especially key concepts-related health literacy needs of caregivers of older adults, are less developed.⁵ Yuen and colleagues recently developed a measure of health literacy of caregivers of cancer patients. However, this measure may not be applicable to caregivers of older adults with other chronic conditions.¹¹ A good understanding of the key components of caregiver

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health literacy may contribute to the development and evaluation of measurements and interventions to support informal caregivers in caring for older adults.

Health literacy is a complex social construct with multiple and conflicting definitions and measurements.¹² The most commonly cited definition is from the Institute of Medicine (IOM) indicating health literacy as the individual's capacity "to obtain, process, and understand basic health information and services needed to make appropriate health decisions".¹³ Within and beyond this definition, many conceptual models have been developed to identify components contributing to health literacy, for the purpose of facilitating measurement, and leading to practical interventions.^{14,15} Ownby and colleagues¹⁶ proposed the Abilities, Skills and Knowledge (ASK) Model that describes health literacy as a composite of general cognitive abilities, academic and other skills, and health-related knowledge. The ASK model focuses on factors underlying health literacy, specifically on the individual's "capacity" included in the IOM definition of health literacy. Using the ASK model as a guide, the current study was designed to examine correlates of caregiver health literacy in informal caregivers of older adults with memory loss.

Relationships between key elements of the ASK Model and the construct of patient health literacy have been reported in literature. For example, cognitive abilities like working memory, processing speed, reasoning, and verbal ability have shown strong associations with a person's health literacy.^{17,18} Health-related knowledge broadly refers to general health information or specifically to disease- or medication-related knowledge. A significant relationship was identified between medication knowledge and health literacy, after controlling for demographic characteristics.^{8,19} Devraj et al.²⁰ reported that patients with low health literacy had poor knowledge of pain medications. In addition, older age has repeatedly been reported as associated with limited health literacy,^{21,22} especially among older individuals with low levels of education.²³ Although cognitive abilities, academic skills and medication knowledge have each demonstrated an association with patient health literacy, the ASK Model as a whole has not been tested in informal caregivers who engage in medication management for adults with memory loss.

The ASK Model has been tested among Spanish- and English-speaking community-dwelling volunteers, by three common tests for patient health literacy, the Test of Functional Health Literacy in Adults (TOFHLA),²⁴ the Rapid Estimate of Adult Literacy in Medicine (REALM),²⁵ and a Spanish version of the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA).²⁶ The Newest Vital Sign (NVS), another recent commonly used brief assessment tool for health literacy,^{27,28} was not included in the original ASK model testing. The NVS is efficient to administer in primary care practices while maintaining work flow.²⁹ It has been used to measure medication health literacy,^{20,30} and has demonstrated high sensitivity across population.^{10,31} Particularly, the NVS has been recommended as a more sensitive measure of caregiver health literacy.⁵ The NVS was used in the current study to measure caregiver health literacy among informal caregivers who engage in medication management for adults with memory loss.

As there is limited research assessing informal caregivers' health literacy and its underlying components, the first purpose of this study was to characterize health literacy measured by the NVS among informal caregivers of community-dwelling adults with memory loss. Secondly, the study examined relationships between health literacy and caregivers' cognitive abilities, academic skills, and medication knowledge, after controlling for socio-demographic characteristics, based on the ASK Model. It was hypothesized that caregiver health literacy, as measured by the NVS,

would be significantly associated with measures of each element of the ASK model.

Material and methods

Participants and procedure

This study was a secondary analysis of baseline data from a randomized controlled trial (RCT) designed to increase problem-solving skills related to medication management in informal caregivers of adults with memory loss. In the parent trial, adults with memory loss and their informal caregivers (N = 91 dyads) were recruited from the community and an Alzheimer Disease Research Center. Community sources included the use of targeted mass mailings, caregiver support groups, brochures placed in pharmacies and clinics, posters and mailings to the community via libraries, adult day care centers, community centers, and the University setting and accounted for most of the contacts. A total of 173 contacts were made; 33 contacts did not meet inclusion criteria, and another 49 declined to participate. Following baseline data collection, eligible dyads were randomized to either intervention or usual care control groups. Inclusion criteria were self-reported memory loss, having an informal caregiver who was assisting with medication taking, and having at least two comorbidities that required prescribed medications. Exclusion criteria were having no caregiver or living in a residential care setting. Details of the inclusion/exclusion and the study procedure of this RCT have been reported elsewhere.² The Institutional Review Board at the University of Pittsburgh approved the RCT. The current study used a descriptive correlational design to examine the health literacy of the 91 informal caregivers at baseline and factors associated with their health literacy as identified in the ASK Model.

Measures

Socio-demographic characteristics of patients and caregivers, such as age (years), gender (male vs. female), race (white vs. non-white), and education (years), as well as the number of comorbidities were collected by two questionnaires developed for the University of Pittsburgh School of Nursing Center for Research in Chronic Disorders.³² Information regarding the relationship of caregivers to patients (spouse vs. non-spouse), living arrangement (same household vs. non-same household), caregiving years, and the number of medications managed was also collected.

Health literacy was measured using the Newest Vital Sign (NVS).²⁸ This tool includes 6 questions about an ice cream nutrition label to assess a patient's prose (words, questions 5 & 6), numeracy (numbers, questions 1 & 2), and document (forms, questions 3 & 4) health literacy. Each correct answer is given 1 point; an incorrect answer is recorded as 0. The total score can range from 0 to 6 with higher scores indicating higher literacy. The scores of 0–3 define limited literacy and scores of 4–6 indicate adequate literacy. The total score of each subscale can range from 0 to 2 with higher scores indicating higher subscale of literacy. The NVS has established internal consistency with a Cronbach's alpha of 0.76, and a moderate correlation of 0.54–0.59 with the TOFHLA in patient populations including older adults.^{28,31} For the present study, the internal consistency based of Cronbach's alpha was 0.73 (n = 91).

Cognitive abilities were assessed using four cognitive tests. First, the Blessed Orientation-Memory-Concentration Test (BOMCT) is a 6-item measure of global cognitive function with an established test-retest reliability and convergent validity.³³ Scores can range from 0 to 28 with higher scores indicating lower cognitive function. Second, the Letter-Number Sequencing Scale, a subtest of the Wechsler Memory Scale, 3rd Edition (WMS-3) was used to measure

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