



Caregiver health literacy and health task performance: Findings from the LitCog caregiver cohort study

Rachel O'Connor^{a,b,*}, Morgan Bonham^{a,b}, Grace Magnuson^{a,b}, Lauren Opsasnick^{a,b},
 Jimmy Hurtado^{a,b}, Julia Yoshino Benavente^{a,b}, Laura M. Curtis^{a,b}, Michael S. Wolf^{a,b}

^a Center for Applied Health Research on Aging, Institute for Public Health and Medicine, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

^b Division of General Internal Medicine and Geriatrics, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA

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ABSTRACT

Objective: Many older adults receive assistance in managing their chronic conditions. Yet complicating the utility of caregiver support is whether caregivers have sufficient skills to aid in older adults' health management at home. We examined associations between caregiver health literacy and performance on health tasks.

Methods: Caregivers to older adults enrolled in a cognitive aging cohort were recruited to participate in a supplemental interview ($n = 97$). Caregivers completed one structured interview that included assessments of health literacy and health task performance.

Results: Caregivers demonstrated a range of health literacy skills (44% adequate, 36% marginal, 20% low health literacy). In adjusted analyses, caregivers with marginal and low health literacy demonstrated worse overall performance on the health tasks, and poorer interpretation of health information presented on print documents and recall of spoken communication (p 's < 0.05).

Conclusion: Caregivers with marginal or low health literacy demonstrated poorer performance on everyday health tasks that they commonly assist older adults with. The application of health literacy best-practices to support better training and capacity-building for caregivers is warranted.

Innovation: Few studies have considered the health literacy skills of caregivers and its application to caregivers' abilities to carry out common supportive tasks.

1. Introduction

Estimates suggest that between 62 and 80% of older adults are managing multiple (≥ 2) chronic conditions (MCC) [1,2], resulting in significant healthcare and self-management responsibilities. Studies have consistently documented the challenges older adults disproportionately face when navigating health systems, engaging healthcare providers, managing and adhering to prescribed regimens, and self-monitoring conditions [3-5]. As individuals age, there is a co-occurrence of increasing comorbidity and self-management responsibilities, with decreasing cognitive abilities, and as a result older adults commonly work with a family member or caregiver to manage their health at home. This support can range from assistance with healthy diet and physical activity, organizing and reminding to take medications, accompany to medical appointments, communicate with clinicians, coordinate medical care, and monitor symptoms [6]. Despite

the complexity of self-management of MCC, less attention is directed toward whether caregivers are equipped with sufficient skills to support patients with related health tasks.

Health literacy, "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions [7]," is an important determinant of individuals' abilities to engage in routine self-management behaviors. Health literacy skills are commonly categorized as adequate, marginal and limited health literacy. Individuals with marginal or limited health literacy have difficulty reading, understanding and interpreting most health materials. [8] Despite a substantial body of evidence supporting health literacy's influence on older adults' health behaviors [9,10], comparatively fewer studies have examined caregiver health literacy and its impact on caregivers' abilities to accurately carry out health-related tasks to support older adult health. Caregivers rarely receive formal training on patient's home health

* Corresponding author at: Center for Applied Health Research on Aging (CAHRA), Division of General Internal Medicine & Geriatrics, Feinberg School of Medicine, Northwestern University, 750 N Lake Shore Dr. 10th Floor, Chicago, IL 60611, USA.

E-mail address: r-conor@northwestern.edu (R. O'Connor).

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management activities [11], and therefore must rely on their existing health literacy skills to support patients in managing their health at home. Poorer caregiver health literacy is associated with greater caregiver healthcare communication difficulty [12] and poorer interpretation of medication information [13], but research has not been extended to other common health management tasks that caregivers may assist older adults with. Given the complex nature of self-management of MCC, we sought to investigate caregiver health literacy and its association with performance on everyday health tasks. We hypothesized that similar to patient health literacy associations with health behaviors, the same would extend to caregivers' abilities to carry out activities they may support patients with. We hypothesized that caregivers with adequate health literacy would demonstrate greater proficiency in these tasks, including reviewing and interpreting print documents, dosing a multi-drug regimen, recall of spoken counseling instructions, and recall of health information presented in multimedia format.

2. Methods

2.1. Sample and procedure

We used data from caregivers to patients enrolled in the Health Literacy and Cognitive Function among Older Adults Study (LitCog). LitCog is a cognitive aging cohort examining changes in cognition, health literacy, and self-care skills and their relation to health outcomes [14]. Beginning in 2008, 900 adults were recruited from one academic general internal medicine practice and six federally qualified health centers in Chicago, Illinois. English speaking adults who sought regular care (defined as two clinic visits within the past 2 years) from study sites were identified through practice records, and research coordinators contacted patients by telephone to screen for eligibility. Patients were eligible if they (1) were between the ages 55 and 74, (2) spoke English, and (3) had adequate cognitive capacity, as defined by ≤ 2 errors on the 6-item screener [15]. Enrolled participants are invited to complete follow-up interviews every three years.

Beginning at the fourth timepoint (T4), we invited LitCog participants' caregivers to complete a separate caregiver-focused structured interview. Caregivers are eligible if they (1) are ≥ 18 years of age, (2) provided care for ≥ 6 months, and (3) assisted with at least one activity of daily living, instrumental activity of daily living, or health management task. A total of 407 LitCog participants completed the T4 interview, of which 177 identified a caregiver. A total of 132 LitCog participants consented for research staff to contact their caregiver, of which 97 caregivers provided written consent and completed the interview (cooperation rate: 73%). Interviews were administered in-person by trained research coordinators; research coordinators recorded participant responses using REDCap survey software. The study was approved by the Northwestern University Institutional Review Board.

2.2. Measures

2.2.1. Health literacy

Health literacy was assessed using the Newest Vital Sign (NVS). The NVS is a screening tool used to determine the risk of limited health literacy. Patients are given a copy of a nutrition label and research coordinators asked six questions about how they would interpret and act on the information contained on the label [16]. The number of correct responses is summed to produce a health literacy score ranging from 0 to 6. Scores are classified in terms of likelihood of limited literacy (0–1: likely limited; 2–3: possibly limited; 4–6: adequate) [16]. For simplicity, these groups are referred to as low, marginal and adequate health literacy, respectively.

2.2.2. Health task performance

Health task performance was assessed using the Short Comprehensive Health Activities Scale (CHAS). Participants are presented 5

scenarios depicting common health-related tasks in a variety of formats, including print documents, prescription medication bottles, spoken health communication, and multimedia video [17]. Research coordinators asked participants to review the corresponding materials, and then asked participants a series of questions assessing comprehension. Questions range from retrieval of print information, recall of verbal and multimedia information, demonstration of understanding information for pill bottles, and more complicated tasks requiring calculation, multistep commands, and reasoning. All scenarios were potentially relevant tasks caregivers may carry out when assisting patients, and a description of each of the scenarios, questions, and materials used are presented in Table 1. The Short CHAS consists of 30 items and includes the following subscales, Print (10 items), Medication Dosing (9 items), Spoken Counseling (4 items), and Multimedia (7 items). Total and subscale scores are standardized to range from 0 to 100, with higher scores indicating better performance.

The CHAS was initially developed for the patient interviews of the LitCog study and contained 9 scenarios and a total of 45 items. For the caregiver interviews, the CHAS was shortened to 30 items to reduce the administration time (Short CHAS). The 9 original scenarios were first reduced to 5, chosen based on length and ease of administration maintaining the distribution across the domains (print, spoken instruction, medication regimen, multimedia video). We further considered the remaining 33 items using a 2-parameter IRT model. Items that were either too easy ($\beta < -2$) or too difficult ($\beta > 2$) or had low discrimination ($\alpha < 0.64$) based on guidelines proposed by Baker (2001) were either removed or combined with others [18], resulting in 30 items.

2.2.3. Covariates

We collected self-reported sociodemographic and health information including, age, gender, race and ethnicity, and number of chronic conditions.

2.3. Analysis plan

Descriptive statistics were calculated for all participant characteristics. Chi-square statistics, specifying Fisher's Exact Test, and analysis of variance (ANOVA) tests were first used to examine differences in demographic factors by health literacy, as appropriate. Next, we conducted ANOVA tests to examine differences in health task performance by health literacy. To examine predictors of performance on the CHAS and its subscales, a series of multivariable linear regression models were performed. Multivariable models contained health literacy, age, gender,

Table 1
Description of health scenarios.

Information presentation: Task	Description
Print documents: Monitor blood sugar	Calculate and interpret numeric information from a chart listing 7 days of recorded blood levels before and after meals for an individual with diabetes
Print documents: Choose a facility	Examine written text about pressure sore prevention, a chart comparing prevention at two nursing homes, and a map in order to select the best facility
Medication bottles: Manage prescription medications	Review prescription bottles from a hypothetical 7-drug medication regimen; make inferences on usage and dose both regimens over a 24-h period using a medication box
Spoken instructions: Understand new diagnosis	Receive oral instructions from a physician regarding a diagnosis and course of treatment for gastroesophageal reflux; answer questions to assess immediate and delayed recall about management at home
Multimedia video: Recall symptom prevention information	Watch a video clip on identifying, monitoring, and controlling asthma triggers; answer questions to assess immediate and delayed recall of information

race, and number of chronic conditions. Age, gender, race and number of chronic conditions were included as covariates, due to their associations with health task performance and following previous adjusted models from the LitCog study [19]. All analyses were performed using SAS, version 9.4.

3. Results

The demographic characteristics of caregivers are presented in Table 2; caregivers were on average 64 years old, half (52%) were female, and identified as White (45%) or Black (39%). More than half (57%) of caregivers were spouses, and more than a quarter (28%) were adult children. Caregivers demonstrated a range of health literacy skills; 44% were classified as adequate, 36% marginal, and 20% low health literacy. All caregivers were supporting an older adult with at least one chronic condition, and 88% of care recipients were managing at least 2 chronic conditions.

The mean CHAS total score was 56.9 out of a possible 100 points, and

Table 2
Caregiver Demographic Characteristics by Health Literacy.

Characteristic, n(%)	Overall N = 97	Adequate N = 43	Marginal N = 35	Low N = 19	p-value
Age, mean (SD)	63.5 (12.6)	65.0 (11.4)	63.4 (15.7)	60.2 (7.9)	0.39
Chronic Conditions, mean (SD)	2.6 (2.0)	2.5 (1.7)	2.8 (2.1)	2.8 (2.3)	0.75
Prescription Medicines, mean (SD)	3.2 (3.3)	2.5 (2.4)	4.5 (4.4)	2.2 (2.3)	0.02
Gender					0.30
Female	51 (52.6)	26 (60.5)	15 (42.9)	10 (52.6)	
Male	46 (47.4)	17 (39.5)	20 (57.1)	9 (47.4)	
Race/Ethnicity					<0.001
Black	38 (39.2)	10 (23.3)	13 (37.1)	15 (79.0)	
White	44 (45.4)	30 (69.8)	13 (37.1)	1 (5.3)	
Other	15 (15.5)	3 (7.0)	9 (25.7)	3 (15.8)	
Income					<0.001
\$24,999 or less	20 (21.3)	3 (7.1)	11 (31.4)	6 (35.3)	
\$25,000–\$49,999	21 (22.3)	7 (16.7)	7 (20.0)	7 (41.2)	
\$50,000 or greater	53 (56.4)	32 (76.2)	17 (48.6)	4 (23.5)	
Education					<0.001
High School Degree or less	23 (23.7)	4 (9.3)	12 (34.3)	7 (36.8)	
Some college or technical school	26 (26.8)	8 (18.6)	9 (25.7)	9 (47.4)	
College graduate	21 (21.7)	14 (32.6)	5 (14.3)	2 (10.5)	
Graduate degree	27 (27.8)	17 (39.5)	9 (25.7)	1 (5.3)	
Relationship to Participant					<0.001
Spouse/Partner	55 (56.7)	31 (72.1)	20 (57.1)	4 (21.1)	
Child	27 (27.8)	10 (23.3)	10 (28.6)	7 (36.8)	
Other (Family Member, Friend, Paid)	15 (15.5)	2 (4.7)	5 (14.3)	8 (42.1)	
Live with Care Recipient					<0.001
Yes	68 (70.1)	38 (88.4)	23 (65.7)	7 (36.8)	
No	29 (29.9)	5 (11.6)	12 (34.3)	12 (63.2)	

scores ranged from 10.0 to 96.6. There was a range of health task performance by health literacy in unadjusted analyses (Table 3). Participants with adequate health literacy had better overall CHAS scores in comparison with participants with marginal and low health literacy (M = 67.5 vs. M = 51.2 vs. M = 41.3, $p < 0.001$). We also observed differences by health literacy for each of the CHAS subscales: Print Documents (M = 85.5 vs. M = 63.1 vs. M = 56.1, $p < 0.001$), Spoken Communication (M = 66.5 vs. M = 47.3 vs. M = 31.6, $p < 0.001$), Multimedia (M = 45.7 vs. M = 32.3 vs. M = 29.7, $p = 0.02$), and Medication Dosing (M = 72.1 vs. M = 63.4 vs. M = 50.0, $p = 0.008$).

In adjusted analyses (Table 4), compared to caregivers with adequate health literacy, caregivers with marginal and low health literacy demonstrated worse overall health task performance (Marginal: $\beta -13.0$ (95% CI -20.6, -5.5); Low: $\beta -20.1$ (95% CI -30.1, -10.0)). Caregivers with marginal and low health literacy demonstrated poorer interpretation of health information presented on print documents (Marginal: $\beta -16.9$ (95% CI -28.8, -5.1); Low: $\beta -22.4$ (95% CI -39.0, -5.8)), and recall of spoken communication (Marginal: $\beta -15.7$ (95% CI -25.5, -5.8); Low: $\beta -26.8$ (95% CI -39.7, -13.9)). Caregivers with marginal health literacy demonstrated poorer recall of health information presented in multimedia format (Marginal: $\beta -12.6$ (95% CI -24.2, -1.1)). Lastly, a non-significant trend was observed for dosing a multi-drug regimen; caregivers with low health literacy making more errors in dosing a multidrug regimen (Low: $\beta -15.6$ (95% CI -31.2, 0.1), $p = 0.05$) compared with caregivers with adequate health literacy.

4. Discussion and conclusion

4.1. Discussion

In this sample of caregivers to older adults managing multiple chronic conditions, caregivers demonstrated a range of health literacy skills. Furthermore, caregiver health literacy was associated with performance on a variety of common health tasks including recall of spoken counseling instructions and interpretation of print health information. These findings underscore the need for greater consideration of caregiver health literacy, as we found less than half of our sample had adequate health literacy.

Overall, we observed the best performance on interpretation of print information, and the poorest performance on recall of spoken counseling and health information presented in multimedia format. These findings underscore the importance of including corresponding print information to aide patients and caregivers recall spoken counseling presented during clinical encounters. Patients often attend clinical encounters with caregivers, to enhance recall of instructions at home. Yet, the presence of a caregiver may not be sufficient in aiding later recall of health information, and providing supplemental tangible supports may support patients and their caregivers in managing their health at home. Furthermore, the adoption of the Health Literate Care Model by healthcare organizations is a systems level approach to enhance patient care. Within this model, clinicians approach patient care with an assumption that patients and caregivers are at risk of not understanding their health conditions and how to manage and adjust the delivery of healthcare accordingly [20].

Caregivers with low health literacy demonstrated more errors dosing a multi-drug regimen. These findings are consistent with a prior study among paid caregivers found high rates of limited health literacy (36%) and inadequate self-management skills; nearly two thirds made significant errors when dosing out multi-drug regimens [13]. These findings have important implications as greater dosing errors may result in adverse patient outcomes, and overtime increase caregiving responsibilities and burden. Medication counseling from pharmacists may be important for not only patients, but their caregivers who are involved in organizing and dosing multi-drug regimens.

Caregivers, like individuals in general, would benefit from the application of health-literacy best practices to promote comprehension

Table 3
Association of Caregiver Health Literacy with Performance on Health Tasks (Mean, Standard Deviation).

Variable	All participants (n = 97)	Adequate Health Literacy (n = 43)	Marginal Health Literacy (n = 35)	Low Health Literacy (n = 19)	p-value
CHAS Total score	56.9 (15.1)	67.5 (12.3)	51.2 (18.4)	41.3 (14.1)	<0.001
Print Documents	72.3 (26.0)	85.5 (14.8)	63.1 (29.8)	56.1 (24.5)	<0.001
Spoken Communication	53.0 (19.6)	66.5 (20.4)	47.3 (18.7)	31.6 (19.3)	<0.001
Multimedia	38.3 (22.6)	45.7 (19.2)	32.3 (26.3)	29.7 (22.9)	0.02
Medication Dosing	65.4 (22.8)	72.1 (21.2)	63.4 (23.8)	50.0 (24.9)	0.008

Table 4
Adjusted Association between Caregiver Health Literacy and Performance on Health Tasks.

Variable	Marginal Health Literacy β (95% CI)	p- value	Low Health Literacy β (95% CI)	p-value
CHAS Total score	-13.0 (-20.6, -5.5)	0.001	-20.1 (-30.1, -10.0)	<0.001
Print Documents	-16.9 (-28.8, -5.1)	0.005	-22.4 (-39.0, -5.8)	0.008
Spoken Communication	-15.7 (-25.5, -5.8)	0.002	-26.8 (-39.7, -13.9)	<0.001
Multimedia	-12.6 (-24.2, -1.1)	0.03	-13.0 (-29.2, 3.2)	0.12
Medication Dosing	-5.9 (-17.4, 5.7)	0.32	-15.6 (-31.2, 0.1)	0.05

*Adequate health literacy is the reference category.
*Adjusted for age, gender, race, # of chronic conditions.
*Sample size for each model: Total score: n = 87, Print Document: n = 86, Spoken Communication: n = 87, Multimedia: n = 82, Medication Dosing: n = 84.

and application of health information. One example of this application is an online training module to promote caregiver communication with healthcare clinicians among caregivers for individuals with cancer. The modules were developed to include plain language and cultural inclusion following health-literacy best-practices, and have demonstrated preliminary acceptability and feasibility [21]. Additionally, reducing the cognitive burden of health tasks is one way to promote comprehension. Promising examples include chunking information that is provided [22], including both spoken and print information [23], and using teach-to-goal to ensure comprehension [24,25]. Yet, a critical first step is to ensure caregivers receive adequate training and education about patient health management regimens. Few caregivers report ever receiving training related to supporting older adults self-management [11]. Caregivers must be provided with supporting information as a critical first step, and that information must be easy to comprehend.

Among our sample of caregivers, we observed differences in health literacy levels by socioeconomic position (including educational attainment and household income) and race; individuals of lower socioeconomic position and Black race were more likely to be classified as having marginal or low health literacy. These findings are consistent with national estimates of health literacy levels [26]. Individual health literacy skills are informed by a myriad of these same factors [27], which is the result of socioeconomic and political contexts which shape access to high quality resources that enable individuals to develop health literacy skills [28]. We have focused on individual health literacy skills, which contrasts with organizational health literacy; organizational health literacy is the degree to which organizations support individuals to find, understand and use information and services to inform health-related decisions and actions [29]. Furthermore, Coleman and colleagues have asserted that organizational health literacy are “preventable, structural features of US health care that contribute to systemic racism,” since health information is largely overly complicated and results in systemic disadvantage for patients and caregivers with lower health literacy who are disproportionately more likely to identify with

communities of color or lower socioeconomic position [30]. Greater investment in equitable high quality education and access to high quality health resources for all individuals are necessary as a long-term solution to bolster individual health literacy skills. In the nearer term, healthcare organizations can seek to enhance their organizational health literacy to mitigate further disparities that disproportionately affect these populations.

This study should be considered in the context of several limitations. First, caregivers were presented hypothetical scenarios, and their performance may not necessarily capture their true performance on actual health tasks. Additionally, the tasks were framed in a general manner, and not worded as an activity they were assisting the LitCog patient with. While these tasks were hypothetical, their appearance is similar to how they would appear if encountered in everyday life. Furthermore, caregivers may not necessarily assist patients with these specific-health related tasks, and these findings may not reflect their performance on tasks that they are assisting with. Additionally, we are limited in our moderate cooperation rate, and due to the two-step enrollment procedures, we had higher non-response bias; however, among individuals who identified having a caregiver, we did not observe demographic differences between those whose caregiver did and did not participate. Furthermore, our findings are limited to an English-speaking population in one urban city in the Midwest in the United States. Lastly, the cross-sectional nature of these analyses limits inferences regarding causality.

4.2. Innovation

This study extends existing research documenting associations between limited caregiver health literacy and poorer caregiver mental well-being and greater caregiver burden [31,32]. Research on caregiving has predominantly drawn on the stress process theory, and as a result has focused on predictors of caregiver burden and caregiver health outcomes [33,34]. This body of research has to a lesser degree considered the practical needs of caregivers and caregiver’s capacity to successfully carry out supportive caregiving tasks. The care provided by caregivers fulfills a vital need, making it difficult to raise the issue of assessing its quality [35]. Nonetheless, caregivers are often asked to take on substantial responsibilities, with limited opportunities for guidance. Few studies have considered the health literacy skills of caregivers and its application to caregivers’ abilities to carry out common supportive tasks. Our study is unique in that a broad expanse of health tasks included in the S-CHAS are reflective of scenarios that caregivers may encounter. Additionally, our study asks caregivers to demonstrate actual ability to carry out these tasks, rather than self-reporting difficulty, which may often be underestimated. This study provides unique insight into aspects that caregivers may support older patients with, but may be challenged in carrying out on their own. This information may be useful in the development of caregiving supportive services that enhance caregivers capacity to carry out caregiving tasks at home. Additionally, it may also illuminate areas for improvement in the delivery of health-care as clinicians partner with caregivers to promote patient well-being.

4.3. Conclusion

In conclusion, we observed a range of health literacy skills among

caregivers to older adults managing MCC, and caregiver health literacy was associated with performance on everyday health tasks. Caregivers with marginal or low health literacy demonstrated poorer performance on everyday health tasks that they commonly assist older adults with. The application of health literacy best-practices to support better training and capacity-building for caregivers is warranted.

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Contributors

RO and MW conceptualized the study. MB and JH administered the project and RO, MB, LC, JYB, MW supervised the project administration. GM, LO, LC cleaned and analyzed data. RO wrote the original draft and revised the paper. MB, GM, LO, JH, JYB, LC, MW reviewed and edited the draft paper. All authors approved the final version of the manuscript.

CRedit authorship contribution statement

Rachel O'Connor: Conceptualization, Methodology, Supervision, Writing – original draft, Writing – review & editing. **Morgan Bonham:** Project administration, Writing – review & editing. **Grace Magnuson:** Data curation, Formal analysis, Writing – review & editing. **Lauren Opsasnick:** Data curation, Formal analysis, Writing – review & editing. **Jeimmy Hurtado:** Project administration, Writing – review & editing. **Julia Yoshino Benavente:** Project administration, Supervision, Writing – review & editing. **Laura M. Curtis:** Data curation, Formal analysis, Methodology, Writing – review & editing. **Michael S. Wolf:** Conceptualization, Funding acquisition, Investigation, Methodology, Supervision, Writing – review & editing.

Declaration of Competing Interest

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References

- Gerteis J, Izrael D, Deitz D, LeRoy L, Ricciardi R, Miller T, et al. Multiple chronic conditions Chartbook, AHRQ publications no, Q14-0038. Rockville, MD: Agency for healthcare Research and Quality; 2014.
- Ward BW. Prevalence of multiple chronic conditions among US adults: estimates from the National Health Interview Survey, 2010. *Prev Chronic Dis* 2013;10.
- Gellad WF, Grenard JL, Marcum ZA. A systematic review of barriers to medication adherence in the elderly: looking beyond cost and regimen complexity. *Am J Geriatr Pharmacother* 2011;9(1):11–23.
- McCarthy DM, Waite KR, Curtis LM, Engel KG, Baker DW, Wolf MS. What did the doctor say? Health literacy and recall of medical instructions. *Med Care* 2012;50(4):277–82.
- Federman AD, Wolf MS, Sofianou A, Martynenko M, O'Connor R, Halm EA, et al. Self-management behaviors in older adults with asthma: associations with health literacy. *J Am Geriatr Soc* 2014;62(5):872–9.
- Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annu Rev Psychol* 2020;71(1):635–59.
- Institute of Medicine. Health literacy: A prescription to end confusion. Washington DC: National Academy Press; 2004.
- Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995;10(10):537–41.
- O'Connor R, Moore A, Wolf MS. Health literacy and its impact on health and healthcare outcomes. *Stud Health Technol Inform* 2020;269:3–21.
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011;155(2):97–107.
- Burgdorf J, Roth DL, Riffin C, Wolff JL. Factors associated with receipt of training among caregivers of older adults. *JAMA Intern Med* 2019;179(6):833–5.
- Fields B, Rodakowski J, James AE, Beach S. Caregiver health literacy predicting healthcare communication and system navigation difficulty. *Fam Syst Health* 2018;36(4):482–92.
- Lindquist LA, Jain N, Tam K, Martin GJ, Baker DW. Inadequate health literacy among paid caregivers of seniors. *J Gen Intern Med* 2011;26(5):474–9.
- Wolf MS, Curtis LM, Wilson EA, Revelle W, Waite KR, Smith SG, et al. Literacy, cognitive function, and health: results of the LitCog study. *J Gen Intern Med* 2012;27(10):1300–7.
- Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care* 2002;40(9):771–81.
- Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: the newest vital sign. *Ann Fam Med* 2005;3(6):514–22.
- Curtis LM, Revelle W, Waite K, Wilson EA, Condon DM, Bojarski E, et al. Development and validation of the comprehensive health activities scale: a new approach to health literacy measurement. *J Health Commun* 2015;20(2):157–64.
- Baker FB. The basics of item response theory. ERIC. 2001.
- Wolf MS, Curtis LM, Wilson EA, Revelle W, Waite KR, Smith SG, et al. Literacy, cognitive function, and health: results of the LitCog study. *J Gen Intern Med* 2012;27(10):1300–7.
- Koh HK, Brach C, Harris LM, Parchman ML. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health Aff* 2013;32(2):357–67.
- Wittenberg E, Goldsmith JV, Rios M. Improving cancer caregiver communication and health literacy with a brief online training module. *Psychooncology* 2022;31(9):1616–8.
- Doak CC, Doak LG, Root JH. Teaching patients with low literacy skills. Philadelphia, PA: JB Lippincott & Company; 1996.
- Wilson EA, Park DC, Curtis LM, Cameron KA, Clayman ML, Makoul G, et al. Media and memory: the efficacy of video and print materials for promoting patient education about asthma. *Patient Educ Couns* 2010;80(3):393–8.
- Baker DW, DeWalt DA, Schillinger D, Hawk V, Ruo B, Bibbins-Domingo K, et al. "Teach to goal": theory and design principles of an intervention to improve health failure self-management skills of patients with low health literacy. *J Health Commun* 2011;16(Suppl. 3):73–88.
- Press VG, Arora VM, Shah LM, Lewis SL, Charbeneau J, Naureckas ET, et al. Teaching the use of respiratory inhalers to hospitalized patients with asthma or COPD: a randomized trial. *J Gen Intern Med* 2012;27(10):1317–25.
- Kutner M, Greenburg E, Jin Y, Paulsen C. The health literacy of America's adults: results from the 2003 National Assessment of adult literacy. NCES 2006-483. National Center for education statistics; 2006.
- Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav* 2007;31(Supplement 1):S19–26.
- Solar O, Irwin A. A conceptual framework for action on the social determinants of health, social determinants of health discussion paper 2 (policy and practice). Geneva, Switzerland: World Health Organization; 2010.
- Brach C, Keller D, Hernandez LM, Baur C, Parker R, Dreyer B, et al. Ten attributes of health literate health care organizations. In: Discussion Paper. Washington, DC: National Academy of Medicine; 2012.
- Coleman C, Birk S, DeVoe J. Health literacy and systemic racism—using clear communication to reduce health care inequities. *JAMA Intern Med* 2023;83(8):753–4.
- Yuen EYN, Wilson C, Livingston PM, White V, McLeod V, Dufton PH, et al. Caregiver and care recipient health literacy, social support and connectedness on caregiver psychological morbidity: a cross-sectional dyad survey. *Psychooncology* 2023;32(8):1257–67.
- Demir Barutcu C. Relationship between caregiver health literacy and caregiver burden. *P R Health Sci J* 2019;38(3):163–9.
- Gitlin LN, Hodgson N. Caregivers as therapeutic agents in dementia care: The context of caregiving and the evidence base for interventions. In: Gaugler JE, Kane RL, editors. Family caregiving in the new Normal. San Diego: Academic Press; 2015. p. 305–53.
- E. National Academies of sciences, medicine, families caring for an aging America. Washington, DC: The National Academies Press; 2016.
- E. National Academies of Sciences, Medicine. Reducing the impact of dementia in America: A decadal survey of the behavioral and social sciences. 2021.