Inadequate Health Literacy Among Paid Caregivers of Seniors

Lee A. Lindquist, MD, MPH, MBA^{1,2}, Nelia Jain, BS, MD², Karen Tam, BS², Gary J. Martin, MD², and David W. Baker, MD, MPH²

¹Division of Geriatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; ²Division of General Internal Medicine, Northwestern University Feinberg School of Medicine, Chicago, IL, USA.

BACKGROUND: Many seniors rely on paid non-familial caregivers to maintain their independence at home. Caregivers often assist with medication reminding and activities of daily living. No prior studies have examined the health literacy levels among paid non-familial caregivers.

OBJECTIVES: To determine health literacy levels and the health-related responsibilities of paid non-familial caregivers of seniors.

DESIGN: One-on-one face-to-face surveys. The Test for Functional Health Literacy (TOFHLA) was administered to identify health literacy levels. Caregivers were asked to demonstrate their skill in medication use by following directions on pill bottles and sorting medications into pill boxes.

PARTICIPANTS: Ninety-eight paid unrelated caregivers of seniors recruited at physician offices, caregiver agencies, senior shopping areas, and independent living facilities.

RESULTS: Average age of caregivers was 49.5 years, and 86.7% were female. Inadequate health literacy was found in 35.7% of caregivers; 60.2% of all caregivers made errors with the pillbox test medications, showing difficulty in following label directions. Health-related tasks (i.e., medication reminding, sorting, dispensing, and accompanying seniors to physician appointments) were performed by 85.7% of caregivers. The mean age of their seniors was 83.9 years (range 65–99 years), and 82.1% were female.

CONCLUSION: Paid non-familial caregivers are essential for many seniors to remain independent and maintain their health. Many caregivers perform health-related duties, but over 1/3 have inadequate health literacy and have difficulties following medication-related instructions. Educating caregivers and ascertaining their health literacy levels prior to assigning health-related tasks may be an important process in providing optimal care to seniors.

KEY WORDS: caregivers; older patients; health literacy.

J Gen Intern Med 26(5):474–9

DOI: 10.1007/s11606-010-1596-2

© Society of General Internal Medicine 2010

INTRODUCTION

Seniors with cognitive and physical challenges frequently rely on caregivers to assist with their care. While family members often fill the role of caregiver, there is increasing usage of unrelated individuals being hired as caregivers.¹ These non-familial caregivers are hired from a wide range of sources, and often very little information is known by employers about their skill sets. There is also a paucity of published literature about their backgrounds, training, and skill sets. Considering that caregivers frequently are asked to assist with medications as well as follow physician instructions, caregivers should have adequate health literacy to perform the required tasks.

Inadequate health literacy is frequently an under-identified problem among patients. Health literacy refers to how well patients comprehend health care information, and is defined as an individual's ability to read, understand, and use health care information to make effective health care decisions and follow instructions for treatment.² Low health literacy is associated with multiple negative outcomes, such as poor use of preventative care,^{3–5} worse self-management of chronic disease,^{6–9} incorrect medication use,^{10–12} increased hospitalizations,¹³ and all-cause mortality and cardiovascular death.¹⁴

Seniors themselves often have low health literacy, which suggests an even greater need for caregivers to have adequate health literacy. In a study of health literacy among Medicare enrollees, Gazmararian et al. identified that functional health literacy decreases with age. Among seniors aged 65–69, 24.2% (15.6% low, 8.6% marginal) were found to have inadequate health literacy; however, among seniors aged 80–84, the number increased to 54.4% (39.0% low, 15.4% marginal).³ Seniors—who have the most medical problems, medications, and instructions—may have caregivers who lack the ability to follow medical directions correctly. Many caregivers accompany seniors to physician appointments, and instructions for medical care are frequently given directly to the caregiver. If the caregiver does not have adequate health literacy, compliance with the medical plan of care for the senior may be compromised, and the senior may be inadvertently harmed.

Currently there is no published information known about the health literacy levels of this group of caregivers. This study aims to explore the health literacy levels of paid non-familial caregivers of community-dwelling seniors, specifically identifying the frequency of inadequate health literacy in this group. We also will examine how often caregivers with

Received December 8, 2009

Revised April 7, 2010

Accepted November 22, 2010

Published online December 15, 2010

inadequate health literacy perform health-related duties for their seniors.

METHODS

Recruitment of Subjects

We obtained approval from the Institutional Review Board of Northwestern University. Research assistants recruited paid, non-familial caregivers who provided care for seniors (>65 years) over a 6-month period using multiple strategies such as physician and nurse referral, caregiver word of mouth, and flyers. Recruitment occurred at: senior centers, shopping malls, local parks, lobbies of senior apartment buildings, and caregiver agency meetings in the Chicago metropolitan and surrounding suburban areas. We conducted structured face-to-face surveys in private (i.e., closed door clinic rooms, unused offices) to maintain confidentiality with results withheld from their employers. Subjects received \$20 cash compensation upon completion of the interview.

Measures

After obtaining written informed consent, the interviewer collected demographic information from the subject. Research assistants asked how the caregiver gained initial employment with the senior (i.e., agency, church, friend of family, word of mouth), the length of time working for the senior, and prior work experience. The interviewer queried

the frequency of performing health-related tasks that were: (1) medication centered, such as obtaining medications from the pharmacy, reminding seniors to take medications, and handing medications to seniors, and (2) physician centered, such as scheduling appointments, transporting the senior to appointments, and seeing the physician with the senior. We also questioned caregivers on their salaries and their perceived fairness of pay.

To determine the level of health literacy of the caregiver, interviewers administered the Test of Functional Health Literacy in Adults (TOFHLA). Adequate Health Literacy was a score of 75 points or higher out of 100.^{15,16} The TOFHLA assesses the functional literacy of patients by sampling their ability to read and comprehend actual hospital and medical texts. It has been used throughout research as a marker of health literacy, and it has been validated and deemed reliable in the literature.¹⁵ It consists of two parts: a numeracy comprehension test of ten short hospital texts involving quantitative information as well as words (such as monitoring blood glucose, keeping clinic appointments, and taking medications) and a reading comprehension test of three hospital passages (including instructions on preparation for an upper gastrointestinal x-ray series, Medicaid patient rights, and hospital informed consent). Figure 1 shows two examples of questions asked as part of the TOFHLA. It takes between 10–20 min to complete.

We assessed medication-dispensing knowledge using mock-up pill bottles whose labels mimicked a nationwide chain pharmacy. To eliminate familiarity with prescription medications while still using real-world instructions, we used Canadian medications or obscure American medications (i.e., miglitol, paliperidone, zopiclone). Research staff also asked six internists if they had prescribed the selected

TOFHLA EXAMPLE #1
Subjects are shown the following card:

CLINIC APPOINTMENT		
CLINIC: Diabetic	DATE: April 2 nd	LOCATION: 3 rd floor
DAY: Thurs.	Issued by	HOUR: 10:20 am
YOU <u>MUST</u> BRING YOUR PLASTIC CARD WITH YOU		

Subjects are then asked:
When is your next appointment?
Where should you go?

TOFHLA EXAMPLE #2
Subjects are given a prose paragraph with basic instructions on preparation for an upper gastrointestinal x-ray series. Subjects are then handed the following questions:

For supper have only a _____ snack of fruit, _____ and jelly, with coffee or tea.

a. little	a. toes
b. broth	b. throat
c. attack	c. toast
d. nausea	d. thigh

After _____, you must not _____ or drink.

a. minute	a. easy
b. midnight	b. ate
c. during	c. drank
d. Before	d. eat

Figure 1. Examples of questions asked as part of the Test of Functional Health Literacy in Adults (TOFHLA).

Canadian or obscure American medications in the past 5 years. If any of the physicians had done so, the drug was removed from the study. Subjects were given the bottles and asked how they would give the medication in verbal prose form: "Tell me how you would give this medicine." They were then asked to demonstrate by placing the pills accordingly in a 7-day pillbox with four time slots (i.e., morning, noon, dinner, evening). Errors in dispensing were determined if both verbal and practical demonstrations were incorrect. The decision for this was to ensure that if the caregiver verbally understood how to give the medication but not how to use the pillbox, the caregiver would still receive credit.

Data Analysis

Statistical analyses were performed with SPSS version 17.0 (SPSS Inc., Chicago, IL). Frequencies of health literacy levels were calculated with specific health literacy levels being divided into the total number of subjects. Comparisons of (1) the health-related responsibilities and health literacy level, and (2) the proportion of each medication task performed

correctly by the health literacy level of the caregiver were done using chi-square tests.

RESULTS

Sample Characteristics

Over a 6-month period, 98 non-familial paid caregivers participated. The average age of caregivers was 49.5 years, and 86.7% were female. The majority were foreign born and had no family or support in the United States (54.1%) or locally (60.2%). Caregivers' prior work experience included health care-related [nursing (registered nurse, certified nursing assistant), dental assistant, pharmacy technician, alternative health worker; n=11], clerical (n=9), banking/finance (n=5), housekeeper/nanny (n=4), food service (n=4), retail (n=3), teaching (n=3), advertising/marketing (n=2), landscaping (n=2), security (n=1), artist (n=1), delivery services (n=1), welding (n=1), and stove repair (n=1). Of the 98 caregivers, 81.6% (n=80) stated that they had previous senior caregiving experience (Table 1). The mean age of their seniors was 83.9 years (range 65–99 years), and

Table 1. Characteristics of Paid Non-Familial Caregivers by Health Literacy Level (n=98)

	All caregivers (n=98)	Inadequate health literate caregivers* (n=35)	Adequate health literate caregivers* (n=63)
Mean age (range)	49.5 years (18–69 years)	50.16 years (18–69 years)	49.14 years (20–69 years)
Female	86.7% (85)	85.7% (30)	87.3% (55)
Country of origin			
USA	37.8% (37)	57.1% (20)	27.0% (17)
Philippines	33.6% (33)	28.6% (10)	36.5% (23)
Mexico	19.4% (19)	11.4% (4)	23.8% (15)
African continent	5.1% (5)	2.9% (1)	6.3% (4)
Poland/Ukraine	3.0% (3)	0	4.8% (3)
India	1.0% (1)	0	1.6% (1)
No family support locally	60.2% (59)	60.0% (21)	60.3% (38)
Education level			
Less than 12th grade	12.2% (12)	20.0% (7)	7.9% (5)
High school graduate	26.5% (26)	25.7% (9)	27.0% (17)
Some vocational or college	43.9% (43)	45.7% (16)	42.9% (27)
College graduate	17.3% (17)	8.6% (3)	22.2% (14)
Hired by			
Agency	63.3% (62)	68.6% (24)	60.3% (38)
Family member of senior	22.4% (22)	22.8% (8)	22.2% (14)
Senior	14.3% (14)	8.6% (3)	17.5% (11)
Salary decided on by			
Agency initially	63.3% (62)	68.6% (24)	60.3% (38)
Senior or relative of senior	18.3% (18)	20.0% (7)	17.5% (11)
"Standard rate" of caregivers	18.4% (18)	11.4% (4)	22.2% (14)
Average hourly pay	\$8.91	\$8.24	\$9.30
-Non 24-h caregiver	\$9.95 (\$6–17) (n=72)	\$9.48 (\$6–14) (n=24)	\$10.16 (\$6.25–17) (n=48)
-24-h caregiver	\$5.70 (\$1–9) (n=23)	\$5.62 (\$4–7.75) (n=11)	\$5.77 (\$1–9) (n=12)
Under minimum wage (\$7.75)	27.4% (26)	32.4% (11)	19.7% (15)
Fairness of salary for services			
Definitely fair	6.1% (6)	2.9% (1)	7.9% (5)
Probably fair	8.2% (8)	8.6% (3)	7.9% (5)
Fair	39.8% (39)	37.1% (13)	41.3% (26)
Unfair	45.9% (45)	51.4% (18)	42.9% (27)

*P-values for chi-square and t-tests were not significant between groups

82.1% were female. The mean length of time the senior was cared for by the caregivers was 30.7 months (range 1–192 months). Caregivers were hired through agencies (60.2%), family contacts (22.4%), and senior word of mouth (11.2%). Types of caregiving tasks and responsibilities expected of the caregivers are listed in Table 2. Average pay for caregivers was \$8.91 per hour, with 27.4% earning less than minimum wage. Caregivers who worked 24-h shifts on average earned much less (\$6.55 per hour) than non-24-h caregivers (\$10.21 per hour).

Health-Related Responsibilities and Health Literacy Levels

Inadequate health literacy was present in 35.7% of the caregivers. Health-related tasks (i.e., medication reminding, sorting, dispensing, and accompanying seniors to physician appointments) were performed more than half or all the time by 85.7% of caregivers. Those with inadequate health literacy performed health-related tasks as frequently as those with adequate health literacy levels. Both adequately and inadequately health literate caregivers performed medication dispensation for their seniors [82.5% (40) vs. 91.4% (32), $p=0.228$] and accompanied seniors to their physician appointments [74.6% (47) vs. 82.9% (29), $p=0.348$]. There was no significant difference between health-related tasks performed and level of health literacy. Inadequate health literacy was not significantly associated with source of hire ($p=0.417$), salary ($p=0.162$), or prior health care work experience ($p=0.23$). Caregivers with inadequate health literacy were not hired from

one particular source or work background, and were not paid significantly differently than caregivers with adequate health literacy.

Medication Label Reading and Sorting Test

On the Medication Label Reading and Sorting Test, a large number of caregivers were unable to follow the directions on pill bottles and place the medications accurately into pill boxes (Table 3). Specifically, caregivers with inadequate health literacy made significantly more errors on once daily dosing, three times a day dosing, and understanding when to stop short-term antibiotics. Regardless of health literacy, caregivers made errors with complex prescription directions. As an example, 42.9% of health literate and 34.3% of inadequately health literate caregivers had difficulty with the real-life prescription of pyrantel, a drug prescribed for treatment of gastrointestinal parasites, which is ‘take six tablets daily for 3 days.’ While this medication is not widely prescribed, these difficulties could translate into actual behaviors; caregivers may incorrectly complete a prednisone taper (with multiple tablets changing over several days) for a senior with an asthma exacerbation.

DISCUSSION

We sought to explore the frequency of inadequate health literacy among paid caregivers and the tasks they perform. Over one third of caregivers in our convenience sample had inadequate health literacy levels. Furthermore, we found that over 85% of caregivers were performing health-related tasks regardless of their health literacy levels. Inadequate health literacy is an under-recognized problem among paid non-familial caregivers of seniors. One concern is that many caregivers are asked to provide health-related activities for their seniors—including medication dispensing and following physician instructions—and may be making errors unknowingly. Caregivers who accompany seniors to physician appoint-

Table 2. Responsibilities Performed by Caregivers

Activity	More than half or all of the time
Medicine	
Obtaining medications from pharmacy	53.1% (52)
Reminding senior to take medications	73.5% (72)
Handing senior medications	53.1% (52)
Doctor appointments	
Scheduling doctor appointment	49.0% (48)
Transporting senior to appointment	66.3% (65)
Seeing doctor with senior	68.4% (67)
Food preparation	
Grocery shopping	70.4% (69)
Cooking/ meal preparation	76.5% (75)
Household	
Laundry	35.7% (35)
House cleaning	78.6% (77)
Garbage removal	87.8% (88)
Personal care	
Bathing	71.4% (70)
Combing hair/shaving/grooming	58.2% (57)
Dressing	72.4% (71)
Toilet use	56.2% (55)
Taking to hairdresser	44.9% (44)
Higher level responsibilities	
Using the telephone	68.4% (67)
Managing money	9.2% (9)

Table 3. Medication Dispensing Knowledge Correct Responses (n=98)

Medication	Adequate health literacy (n=63)	Inadequate health literacy (n=35)	P value
Miglitol 25 mg	87.3% (55)	62.9% (22)	0.005*
Three times daily with meals			
Pyrantel 125 mg	42.9% (27)	34.3% (12)	0.406
Take six tablets daily for 3 days			
Paliperidone 3 mg	98.4% (62)	82.9% (29)	0.004*
Take one daily			
Zopiclone 7.5 mg	68.3% (43)	62.9% (22)	0.609
Take one tablet nightly as needed			
Cephalothin 500 mg	87.3% (55)	65.7% (23)	0.011*
Three times daily × 10 days			

*Denotes significance ($p<0.05$)

ments may encounter physicians who assume their health literacy level is adequate and provide them with intricate instructions to follow. In the field of health literacy, some consider health literacy as the intersection of individual skills with the information provided by the health care system. Physicians may need to take into account that caregivers may not be forthcoming in their skill sets and that simpler instructions or enlisting family may be necessary to provide optimal care for seniors. It is also important that caregivers with low health literacy be identified through the use of appropriate instruments prior to assigning roles involving health care. Interventions and responsibilities can subsequently be tailored to those with inadequate health literacy.

The demographic data from our sample suggest that paid non-familial caregivers frequently have limited support systems, are underpaid, and experience challenging conditions. While 24-h caregivers are paid less (with the assumption that many hours will be spent sleeping), they can face multiple awakenings and limited sleep when caring for seniors with medical conditions such as dementia. Since many caregivers have limited job opportunities, they often face substandard work conditions with little recourse for below minimum wage pay.

The lack of national regulation and standardization of duties for paid non-familial caregivers allow for caregivers to be potentially taken advantage of by employers. As an example, agencies often charge premium prices to seniors for caregiving services and frequently take a large "cut" of the caregiver pay. Federal regulation among agencies supplying caregivers is also lacking, which enables this practice.

From a policy perspective, regulation is necessary in the caregiving industry among both caregivers and employers. First, for caregivers, educational programs may need to be developed to assist those with inadequate health literacy who wish to provide higher level care. These educational programs could be structured into workshops, with both didactic sessions and real-world trials. If a caregiver is to assist with health-related tasks, passing a simple test demonstrating competency may be reasonable to ensure appropriate care of their seniors. Secondly, agencies that supply paid caregivers should be held accountable for their employees. Like many businesses, agencies potentially could offer training or continuing education programs for their caregiver employees. Employers of caregivers may need to ensure licensure or testing is performed prior to assigning caregivers the responsibility of medical care of the senior. While licensure or testing may reduce the pool of caregivers available to give medications, it should not reduce the number of caregivers who are able to perform other tasks such as bathing, transferring, cooking, etc., that are equally integral to senior care.

While we recruited from multiple diverse sites, limitations of this study were the small study convenience sample and localization to an urban area. The degree to which the results from this sample can be generalized is unclear. Another limitation is that the Test of Functional Health Literacy and medication labels were both given in English. Since most pill bottles and physician directions are given in English, we felt that use of English would most closely replicate real-world situations. Nonetheless, many of the caregivers are non-native English speakers, and a language barrier may have been present, which could have affected the results. We did not have access to the home setting to confirm that the tasks were

being completed. Further studies involving first hand evaluation of the senior are necessary to understand the full impact of inadequate health literacy among caregivers.

From a practical standpoint, no easy strategies currently exist for lay people to ensure optimal care of seniors by caregivers. Initially, we would recommend background, education, and health literacy checks of caregivers who will be handling medications and following physician instructions. Physicians may also want to recommend that family members of seniors accompany the caregiver and senior to physician appointments to ensure accurate follow-up. On a day-to-day basis, observing caregivers performing tasks may be useful, but often working offspring do not justifiably have sufficient time.

Overall, paid non-familial caregivers provide valuable assistance to seniors that allows them to maintain their independence. Ultimately, we hope that this information on health literacy and characteristics of caregivers of seniors will shed light on a growing, unregulated industry. Caregivers are often held responsible for tasks outside of their skill set, while they are unfairly taken advantage of with low pay and difficult conditions. With more awareness of this issue by employers, health care professionals, and legislators, the quality of care that seniors receive can hopefully be improved.

ACKNOWLEDGEMENTS: We would like to thank the Barney Family Foundation for their support and funding of this study.

Conflict of Interest: None disclosed.

Corresponding Author: Lee A. Lindquist, MD, MPH, MBA; Division of General Internal Medicine, Northwestern University Feinberg School of Medicine, 750 North Lake Shore Drive, 10th floor, Chicago, IL 60611, USA (e-mail: LAL425@md.northwestern.edu).

REFERENCES

1. Hanyok LA, Finucane T, Carrese J, et al. Potential caregivers for homebound elderly: more numerous than supposed? *J Fam Pract.* 2009;58(7):E1-6.
2. Kirsch I, Jungeblut A, Jenkins L, Kolstad A. Adult Literacy in America: a First Look at the Results of the National Adult Literacy Survey. Washington, DC: National Center for Education Statistics, US Department of Education; 1993.
3. Gazmararian J, Baker D, Williams M, et al. Health literacy among Medicare enrollees in a managed care organization. *JAMA.* 1999;281(6):545-51.
4. Baker DW, Gazmararian JA, Williams MV, et al. Health literacy and use of outpatient physician services by Medicare managed care enrollees.[see comment]. *J Gen Intern Med.* 2004;19(3):215-20.
5. Scott TL, Gazmararian JA, Williams MV, Baker DW. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Med Care.* 2002;40(5):395-404.
6. BD WMV, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest.* 1998;114:1008-15.
7. Gazmararian JA, Williams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. *Patient Educ Couns.* 2003;51(3):267-75.
8. Juzych MS, Randhawa S, Shukaity A, et al. Functional health literacy in patients with glaucoma in urban settings. *Arch Ophthalmol.* 2008;126(5):718-24.
9. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med.* 1998;158(2):166-72.
10. Gazmararian JA, Kripalani S, Miller MJ, et al. Factors associated with medication refill adherence in cardiovascular-related diseases: a focus on health literacy. *J Gen Intern Med.* 2006;21(12):1215-21.

11. **Davis TC, Wolf MS, Bass PF 3rd, et al.** Literacy and misunderstanding prescription drug labels. *Ann Intern Med.* 2006;145(12):887–94.
12. **Persell SD, Osborn CY, Richard R, et al.** Limited health literacy is a barrier to medication reconciliation in ambulatory care. *J Gen Intern Med.* 2007;22(11):1523–6.
13. **Baker DW, Parker RM, Williams MV, Clark WS.** Health literacy and the risk of hospital admission.[see comment]. *J Gen Intern Med.* 1998;13(12):791–8.
14. **Baker DW, Wolf MS, Feinglass J, et al.** Health literacy and mortality among elderly persons. *Arch Intern Med.* 2007;167(14):1503–9.
15. **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.
16. **Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J.** Development of a brief test to measure functional health literacy. *Patient Educ Couns.* 1999;38(1):33–42.