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Health literacy and medication administration performance by caregivers of adults with developmental disabilities

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Abstract

Objectives—To measure health literacy (HL) of caregivers of adults with intellectual/ developmental disabilities (IDDs); to determine the association between HL and a medication administration task (MAT) assessment; and to identify caregiver characteristics associated with higher HL and MAT scores.

Design—Cross-sectional study.

Setting—Southeastern Michigan.

Participants—Caregivers, aged 18 years or older, who provided supportive care of adults with IDDs.

Interventions—Survey and demonstration.

Main Outcome Measures—Short Test of Functional Health Literacy in Adults (STOFHLA); a MAT assessment consisting of interpretation of five sets of medication instructions followed by demonstration of understanding using a pill box; and a survey of caregivers' demographics, medication-related experiences, education, characteristics of persons for whom they provide care, and care-related activities performed.

Results—A total of 47 caregivers provided data. Caregivers had a mean age of 45.7 ± 14.6 years; 41 (87.2%) were women and 38 (80.9%) had education beyond high school. Caregivers were involved in obtaining medication from pharmacies, reminded the person with IDD to take medications and/or administered them to the person, documented medication and health information, and accompanied persons with IDD to physician offices. Most did not conduct monitoring procedures. The STOFHLA mean score was 34.5 ± 2.5 (median, 35; range, 22-36), while the MAT mean score was 12.0 ± 2.2 (median, 12; range, 6-15). Compared with family caregivers, direct support staff more frequently had undergone some medication training and had other people with whom they could discuss medication questions, but they had worked with the person with IDD a significantly shorter amount of time. No significant differences in STOFHLA and MAT scores between the family caregivers and direct support staff were observed. Caregiver

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education was significantly correlated with the STOFHLA score. MAT scores were not significantly correlated with caregiver characteristics.

Conclusion—Caregivers are involved in the medication use process for people who have IDD. Ensuring caregiver understanding of medication regimens and/or improving medication-related HL may be an important step to ensure safe and effective use of medications by people with IDD.

Health literacy (HL) is generally 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.^{1–3} HL is directly associated with abilities to perform health-related tasks such as medication administration correctly.

In a systematic review of the HL literature, Berkman et al. noted a number of studies linking lower HL with poorer skills in medication administration and in interpretation of directions on prescription drug labels or nutrition product labels.⁴ Low HL also is associated with other negative outcomes, such as poor use of preventive care, worsened self-management of chronic diseases, and increased hospitalizations, all-cause mortality, and cardiovascular death.^{5–16}

Pharmacists may not fully use proven techniques to assist in communication with people with lower HL. In a study of 14 techniques for communicating with people with low HL, pharmacists performed 10 techniques less than 40% of the time. Nurses and physicians use these techniques much more often.¹⁷

Pharmacists provide information to patients via written patient education pamphlets frequently. The question is whether patients understand this information and can use it to increase their use of appropriate health behaviors. A study examining the association between literacy and understanding of the directions on prescription drug labels demonstrated that patients with low-to-marginal literacy frequently misunderstood prescription label instructions.¹³

Caregivers are people who provide assistance to others unable to perform various activities associated with daily living. Caregivers provide support to aging parents, children, and people with disabilities. In the United States, an estimated 42 million Americans assume caregiver roles, and on average, spend 20 hours per week providing care.¹⁸

Most people with intellectual and developmental disabilities (IDD) live in the community and have a lifelong need for support. Caregivers of adults with IDD often perform medication administration procedures daily. Caregivers should have adequate HL to perform the required tasks to assist with medication use and provision of medical care pursuant to physician instruction. If caregivers do not have adequate HL, adherence to medical plans of care may be compromised. For example, a recent study of HL of paid caregivers for people with dementia found that more than 33% of participants had inadequate HL and had difficulties following medication-related instructions.¹⁹ One limitation of this study was that for most participants, English was their second language, a known risk factor for poor HL.

Many caregivers of people with IDD are family or direct support staff. Direct support staff is defined as caregivers employed by agencies providing support to people with IDD. Little is

known about the HL of the caregivers, either family or direct support staff, of people with IDD.

Objectives

The purpose of this study was to measure the HL of caregivers of adults with IDD who are involved in some aspect of assisting in medication administration and determine whether an association existed between HL level and performance on a standardized assessment of medication administration. The medication administration task (MAT) test was used as the standardized assessment measure.

Additionally, the study sought to identify characteristics of caregivers associated with HL and performance on the MAT. Most direct support staff undergo some form of medication administration training. Therefore, we sought to determine whether the type of caregiver (family versus direct care staff) had any association with the caregiver's level of HL and score on the MAT. We hypothesized that, because most direct support staff undergo medication administration training and recertification, these individuals would score higher on the HL and MAT compared with caregivers who are family or friends.

Methods

Recruitment

Caregivers were recruited from multiple sources. Family caregivers and direct support staff were recruited through a local chapter of The Arc and from one service and support provider agency. The Arc is a national community-based organization that advocates and provides support services for people with IDD and their families throughout the United States.

The local Arc chapter in Wayne County, MI, participated in the study. A recruitment announcement was placed in the monthly newsletter asking chapter members to recruit both family caregivers and direct support staff.

Additionally, direct support staff were recruited from a community-based agency that provided support staff for group homes (adult foster care) or to individuals with IDD who live semi-independently in their own homes. A study recruitment letter was attached to direct support staff persons' paychecks, and recruitment letters were sent to the agency's supervisors requesting they verbally announce the study to direct support staff.

Inclusion criteria consisted of caregivers aged 18 years or older who cared for at least one person with IDD who took one or more prescription medications.

The study was approved by the University of Michigan Medical School Institutional Review Board. All participants provided signed informed consent and received a \$40 gift card.

Data collection and methods

Participants began the survey portion of the study with completion of the Short Test of Functional Health Literacy in Adults (STOFHLA), used to assess HL of care-givers.²⁰ STOFHLA is a shortened version of the Test of Functional Health Literacy in Adults

(TOFHLA), an instrument designed to measure a person's ability to read and understand the things commonly encountered in the health care setting. STOFHLA has good internal consistency (Cronbach's alpha) ranging from 0.68 to 0.97 and demonstrated correlation (r = 0.8) to the Rapid Estimate of Adult Literacy in Medicine (REALM) test.

STOFHLA asked participants to read and complete health-related passages by inserting missing words at selected intervals throughout text. Participants were prompted to choose the correct word from a list of four possibilities at each place where words had been removed. The first passage described the preparation a patient must undergo for an upper gastrointestinal (GI) series and had 16 words missing. The second passage came from the patient rights and responsibilities section of a Medicaid application form and had 20 words missing. The final score was a count of the correct word choices made by the participant. A STOFHLA score of 16 or less was classified as having inadequate HL; scores from 17 to 22 were considered marginal HL, and scores from 23 to 36 were considered adequate HL.

Following this, caregivers completed a written survey (see the online Appendix for interview questions, available on JAPhA.org in the Supplemental Content section). It obtained demographic information of the caregiver (age, gender, education) and determined the primary person for whom the individual had provided care (age and gender). Caregivers who provided care for more than one individual were instructed to answer specific to the person who required the most assistance with medication use.

The survey included questions to determine the average number of hours per day the person with IDD required personal assistance. Caregivers also were asked about their prior experience as a caregiver, how they gained initial charge over the person for whom care was provided, and the length of time they worked with the individual.

The frequency of performing health-related tasks that were medication centered was assessed. This included frequency of obtaining medications from the pharmacy, reminding the person to take medication, administering doses of medication, and reviewing and documenting health-related tasks of the individual. Additionally, physician-centered tasks were assessed (scheduling appointments, transporting to appointments, seeing the physician with the person with IDD). To determine personal experience with medication-related issues, caregivers were asked if they had taken or currently take prescription medication on a long-term or regular basis.

Caregivers were asked if they had another person with whom they could consult when they had questions related to medications or medication administration. Caregivers also were asked whether they had received formal medication administration training in the past.

Caregiver understanding of the medication administration process was assessed using mock prescription vials for a medication label reading and sorting test, developed by Lindquist et al.¹⁹ For this study, the test was called the medication administration task (MAT). The MAT used is similar to a number of validated instruments that use simulated medication regimens to assess medication-taking instructions.²¹

Five medication vials with labels were assessed by each caregiver. Directions for use were printed on each prescription vial label and varied from a standard once-a-day regimen to more complicated instructions such as taking with meals, length of time to take the full regimen, and taking multiple tablets at one time of the day. Medication names listed on the prescription vial label were drugs that were not found in the United States, were prescribed at a very low rate, or were generic. Medication names were chosen to help ensure drug names would be unfamiliar to minimize the likelihood that caregivers had previous experience taking or administering the product.

Caregivers were given the bottles and asked how to give the medication in verbal prose form: "Tell me how you would give this medicine." Caregivers were then asked to demonstrate proper medication assisted use by placing the tablets and capsules correctly in a 7-day pillbox with four time slots for each day. Errors in dispensing were determined if verbal and/or practical demonstrations were incorrect. Each prescription vial task was graded on three criteria (number of tablets administered, time of day administered, and length of time the medication was to be taken, for a total score of 15 for the MAT. A research assistant was trained in the administration of the STOFHLA and MAT.

Data analysis

Means with standard deviation and median or percent frequencies were used to describe the overall sample characteristics, patients with IDDs, caregiver involvement in the medication use process, and STOFHLA and MAT scores.

Frequencies of correct responses for each assessment step used to score the MAT were determined for each of the five prescription instructions. Correlation between the STOFHLA and MAT score was determined using Spearman's rho. Further correlation analysis was conducted to assess the association between caregiver characteristics and the MAT test score and the STOFH-LA using either Spearman's rho or Pearson's correlation coefficient.

Participants were then categorized as direct support staff or family caregivers to test whether caregiver type was associated with STOFHLA or MAT test scores. Comparisons were made between subject demographics, history of formal medication administration training, personal experience with medications, and STOFH-LA and MAT test scores using Mann–Whitney U or chi-square tests, in which case median values or frequency with percentages are presented.

Results

Description of overall sample

Characteristics of the 47 caregivers who completed the study are provided in Table 1. Most caregivers were middle-aged, women, and moderately well educated (some college or more).

More than one-half of the caregivers had personal experience taking medication, and almost two-thirds had some formal medication administration training. Almost three-quarters of caregivers indicated having an opportunity to talk with others to ask questions about

medications. Almost one-half of caregivers had prior experience as a caregiver of people with IDD. Overall, caregivers had been working with the person for whom they provide care for less than 1 year.

Caregivers indicated that the person with IDD for whom they provided care required support a mean (\pm SD) of 13.5 \pm 8.6 hours per day. The majority of people with IDD who received care were middle-aged, with a mean of 50.5 \pm 14.1 years, while 66% were women. People with IDD were reported to take, on average, 7.6 \pm 5.1 medications daily, with an average of 2.9 \pm 1.2 medication administration times per day.

Overall, the HL of caregivers, as measured by the STOFHLA score, was in the adequate category (STOFH-LA score between 23 and 36). The overall average MAT score was 12 out of a total score of 15 (no errors), indicating a relatively good ability to interpret medication label directions and demonstrated ability to interpret that information into an appropriate medication administration task.

Medication use process tasks

Table 2 provides information about the number and percentage of caregivers who performed various tasks supporting the medication use process.

Most caregivers were involved in obtaining medication from a pharmacy, reminding the person with IDD to take medication, handing medication to the person with IDD to take, documenting information about the medication administration or monitoring, and to a lesser extent, accompanying the person to physician appointments, including seeing the physician with the patient. Few caregivers performed medication outcome monitoring tests.

Medication administration task test

Analysis of individual steps scored correctly on the MAT is provided in Table 3.

Two sets of prescription label instructions were problematic for participants. Instruction was for zopiclone 7.5 mg to be taken as a single tablet nightly as needed. Just over one-half of the caregivers performed the steps correctly. Caregivers did not typically provide as-needed medication to the IDD person for whom they provided care, leading to the poor performance on this task.

The prescription label for pyrantel 125 mg to be taken as six tablets daily for 3 days was also problematic. The primary problem faced was correctly placing tablets in multiple wells on each of the 3 days the medication was to be taken.

Correlations among caregiver characteristics and scores

Table 4 provides data on the correlation analysis among caregiver characteristics and the STOFHLA and MAT scores.

STOFHLA scores were significantly correlated with only one caregiver characteristic: caregiver education. Caregivers with more education had higher STOFHLA scores and thus

Characteristics of family caregivers and direct support staff

Table 1 provides the data for the comparison between the two groups of caregivers.

Significant differences between the two groups were found for caregiver age, gender of caregiver, training for medication administration, and having someone else to talk with regarding medication questions. Although not significantly different between groups, more family caregivers had a college education and more took medication themselves.

STOFHLA and MAT test scores were similar between groups (Table 1) and differences were not statistically significant, although the family caregivers scored higher on both assessments. STOFHLA scores ranged from 22 to 36. Only one participant in the direct support staff group scored below the threshold of 23, indicating marginal HL. All other caregivers scored in the adequate HL range.

MAT scores ranged from 6 to 15, with a score of 15 indicating no errors. A total of 8 (22.2%) direct support staff scored 10 or less on the MAT (5 or more errors), while only 1 (9.0%) of the family caregivers had a MAT score of 10 or less.

Discussion

Caregivers undertake responsibility and oversight of medication use by adults who have IDD. In this study, more than 70% of caregivers conducted three important steps of medication use process either all the time or most of the time, and more than 50% of the time for two others. More than one-half of caregivers accompanied persons with IDD to the physician's office. Understanding instructions for safe, appropriate use of medication and being an advocate for the person with IDD at the physician's office requires the caregiver to possess adequate HL to safely administer medication to the person with IDD. HL was adequate for family caregivers and almost all of the direct support staff in this study. In the state where this study was conducted, direct support staff must undergo training on topics related to medication administration. Informal or family caregivers are not required to take such training.

In the present study, the only caregiver characteristic significantly associated with HL was the level of education attained; higher education was associated with greater HL.

MAT scores were similar between caregiver types, and the mean scores were high. Family caregivers scored higher on the MAT, and greater variation was seen in MAT scores for direct support staff. Direct support staff generally reported undergoing medication administration training, while no family caregivers underwent this type of education. However, MAT scores of these caregivers were no different between the groups. Family caregivers provided care for a significantly longer period of time compared with direct support staff, and a greater proportion also took medications themselves. These data may demonstrate that experience providing care for a longer time period, coupled with taking medication themselves, may be valuable assets to family caregivers. Previous studies of

informal caregiving found that 18% never received any type of instruction or training related to medications²² and need medication management training.²³

The presence of a person with whom to discuss questions regarding medications, or having a reliable source of information to refer to when questions arise, is important for the caregiver. Informal caregivers of people with disabilities or older people seek health information from a variety of sources, including physicians, nurses, family or friends, other health professionals, or the Internet.²⁴ In the present study, significantly more of the direct support staff reported an ability to ask others questions regarding medication therapy compared with family caregivers. Direct support staff often work for agencies with administrative support to assist with questions about medication therapy.

Pharmacists who provide medication distribution to the homes of people with IDD may consider partnering with service provider agencies to provide comprehensive education to direct support staff on the medication use process and drug therapies to meet this need for support. Alternatively, the pharmacy may work with the service provider agency to ensure medication pass training for new direct support staff is comprehensive to all aspects of the medication use process. The pharmacy may work with the agency to develop quality metrics to monitor the medication use process within the home environment to identify situations where additional education would be useful.

Pharmacists should recognize that caregivers, whether family members or direct support staff, need to receive counseling and education as if they were the patient. To provide support for medication-related questions, pharmacists must be accessible when caregivers have specific questions or concerns about therapies. Pharmacists have the skills and knowledge to counsel all people who pick up medications. Pharmacists may be able to make a special effort to counsel caregivers of persons with IDD.

More complex medication interpretations or instructions were problematic for many providers. Correct answers for all three MAT concepts were seen most for the "take one tablet daily" instructions, a common and straightforward set of instructions for medications. The lowest number of correct responses on all three concepts was associated with instructions to take medications as needed for both types of caregivers, both family and professional. Only one-half to two-thirds of caregivers provided correct responses for these steps. The concept of "as needed" may have been interpreted in any number of ways, and caregivers may have been familiar with a different procedure for administering as-needed medications that do not coincide with the process chosen as correct for this study. This demonstrates that health professionals should ensure that caregivers understand complicated dosing instructions, including medications given on an as-needed basis.

This study fills the gap of previous studies assessing medication error rates of caregivers by assessing HL as a potential predictor of performing a medication administration error.^{25,26} In the correlation analysis of this study, the correlation between the MAT and the STOFLHA was modest but statistically significant. The modest correlation may result from the small sample size or the possibility that other caregiver characteristics or characteristics of relationships between caregivers and persons who they provide care for may have an

intervening effect. Caregiver education and HL were significantly associated in this study. Those who were educated past high school scored higher on the STOFHLA. One report shows that people hired into direct support staff roles have a wide range of educational attainment, with more than 50% having the highest level achieved being a high school degree or less.²⁷

It is important to implement and improve screening for understanding of appropriate use of medications for individuals with IDD and caregivers for HL at the health professionals' offices or pharmacies. Health professionals must ensure that caregivers and persons with IDD have an understanding of the intended directions for use of medications. The management of direct support staff should include education on the importance of communication of directions for use of medications. This may require more frequent assessment of medication-pass processes of home managers to determine whether further training is needed. Family caregivers also should receive education at primary points of interaction with health professionals such as prescriber's offices and pharmacies.

Pharmacists should become more knowledgeable about resources available to assist with assessment of individuals' HL. Ngoh and colleagues previously provided an excellent overview of HL and recommendations for the identification of people with lower HL.²⁸ Steps and actions pharmacists can use in counseling to enhance understanding of medication information provided to a person with lower HL are provided.²⁸ Pharmacists may use the Agency for Research and Quality (AHRQ) guide: "Is our pharmacy meeting patients' needs? A pharmacy HL assessment tool user's guide."²⁹ This tool can be used to raise pharmacy staff awareness of HL issues, can help detect barriers that may prevent people with lower HL skills from adequately using medications, and may help the pharmacy identify areas in which processes can be improved.

Limitations

Several limitations to this study exist

The STOFHLA instrument used may not have been sensitive enough to determine HL concepts more strongly associated with tasks necessary to safely interpret medication instructions. The full TOFHLA may have been more sensitive. However, the numeracy portion of the full TOFHLA includes a medication label interpretation section, which was an outcome measure and therefore not appropriate to use for the present study. STOFHLA and other measures of HL (the Newest Vital Sign [NVS]³⁰ and the Rapid Estimate of Adult Literacy in Medicine [REALM]³¹) have previously been used successfully to determine associations between HL of caregivers of children and medication administration problems.^{32–34}

Another limitation was the sampling method used to recruit participants. Sampling bias may have occurred, as all participants were recruited using announcements in newsletters and mailings. The sample may overrepresent people who have higher HL and more experience and confidence in administering medications.

The sample was small, with 47 participants completing the study. A larger sample size would be required to enable use of multivariate regression techniques to provide a clearer interpretation of associations between caregiver characteristics, STOFHLA scores, and MAT scores. The results of the present study may be used to calculate the appropriate sample size needed for future studies to be able to conduct a more thorough assessment.

Overall lifetime experiences of caregivers were not directly assessed. Question wording focused on the current person for whom caregivers were providing care. In the case of family caregivers, this was a longer period of time than for direct support staff. What is unknown is whether direct support staff provided care for other people either at the same time or for other people in the past. That assessment of their medication management experience was not measured.

The MAT test used a format of prescription vials with instructions printed on vial labels as well as filling a pill box. This format may be different from what some caregivers are familiar with, particularly direct support staff.

Conclusion

Caregivers of adults with IDD often oversee medication management of these individuals. Pharmacists undoubtedly encounter patients who have IDD and their caregivers in a variety of pharmacy practice settings. To attempt to ensure safe and effective medication use by people with IDD, pharmacists should work with care-givers to ensure understanding of medication regimens and be available to provide guidance when caregivers have questions or concerns about the therapies.

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Appendix: Study Instrument

Participant Name_____

_____ Study Number _____

Start with administration of the STOFHLA, followed by the Medication Label Reading and Sorting Test.

Read the following list of medical-related activities and indicate how often you do these activities for or with your client: (Do not perform; some of the time; most of the time; all of the time)

- 1. Obtaining medicines from the pharmacy
- 2. Reminding the client to take medications
- 3. Handing the client medications when it's time to take them

- 4. Scheduling doctor appointments for the client
- 5. Transporting the client to doctor appointments
- **6.** Seeing the doctor with the client, including providing health information to the physician
- 7. Perform testing such as poking the client's finger for blood sugar or taking a blood pressure
- **8.** Writing down in a diary any health related information to share with the client's physician or nurse.

Participant Age_____ Participant Gender_____

Client's Age _____ Client's Gender _____

Which of the following best describes your relationship to your client?

Family member/parent

Family member/spouse

Family member/brother, sister, aunt, uncle

Friend – not for pay

Employed by agency

Employed for client's family or designated guardian

Employed directly by client

How long have you provided care for your current client?

____months

Amount of time per day, on average, that the client you work with require caregiver time?

____hours

How many different medications does your client take per day on average?

How many different times of the day does your client take medicine?

Which of the following best describes your general education?

Didn't graduate high school

High school graduate/GED

Some college

College graduate

Did you receive a college degree in a health care area?

If yes, what area of health care____

Please list other jobs that you have had over the past 10 years

| Have you | ever had a job similar to the caregiving role you are in now? |
|-------------|---|
| Do you tal | e medication regularly? |
| Have you | participated in a medication administration training program of any type? |
| | |
| If yes | how long ago? |
| - | |
| List differ | ent ways you find information about medication |
| | ent ways you find information about medication |
| 1 | |
| 1 2 | |

| If yes, 1 | please describe | who they an | e |
|-----------|-----------------|-------------|----|
| n yes, | picase describe | who they a | .0 |

Medication Label Reading and Sorting Test

The following medication names and directions for use was be on labels on prescription vials. The respondent was read each one separately. They was then be asked: Tell me how you would give this medicine. They was then be asked to demonstrate by placing the pills in each vial into a 7-day pillbox with four time slots (morning, noon, dinner, evening). Errors in dispensing was be determined if either/or both verbal and practical demonstrations are incorrect.

1. Miglitol 25 mg

Take one table three times daily with meals

2. Pyrantel 125 mg

Take six tablets daily for 3 days.

3. Paliperidone 3 mg

Take one tablet daily

4. Zopiclone 7.5 mg

Take one tablet nightly as needed.

5. Cephalothin 500 mg

Take one capsule 3 times daily for 10 days.

Results:

References

- 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.
- 2. U.S. Department of Health and Human Services. Healthy People 2010: understanding and improving health. 2nd. Vol. Chapter 11. Washington, DC: U.S. Government Printing Office; 2000.
- 3. Institute of Medicine. Health literacy: a prescription to end confusion. Washington, DC: National Academies Press; 2004.
- 4. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011; 155:97–107. [PubMed: 21768583]
- 5. Gazmararian J, Baker D, Wasiams M, et al. Health literacy among Medicare enrollees in a managed care organization. JAMA. 1999; 281:545–551. [PubMed: 10022111]
- Baker DW, Gazmararian JA, Wasiam M, et al. Health literacy and use of outpatient physician services by Medicare managed care enrollees. J Gen Intern Med. 2004; 19:215–220. [PubMed: 15009775]
- Scott TL, Gazmararian JA, Wasiams MV, Baker DW. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. Med Care. 2002; 40:395–404. [PubMed: 11961474]
- Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. Chest. 1998; 114:1008–1015. [PubMed: 9792569]
- Gazmararian JA, Wasiams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. Patient Educ Couns. 2003; 51:267–275. [PubMed: 14630383]
- 10. Juzych MS, Randhawa S, Shukairy A, et al. Functional health literacy in patients with glaucoma in urban settings. Arch Ophthalmol. 2008; 126:718–724. [PubMed: 18474786]
- Wasiams 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; 158:166–172. [PubMed: 9448555]
- 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; 21:1215– 1221. [PubMed: 17105519]
- Davis TC, Wolf MS, Bass PF 3rd, et al. Literacy and misunderstanding prescription drug labels. Ann Intern Med. 2006; 145:887–894. [PubMed: 17135578]
- 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; 22:1523–1526. [PubMed: 17786521]
- Baker DW, Parker RM, Wasiams MV, Clark WS. Health literacy and the risk of hospital admission. J Gen Intern Med. 1998; 13:791–798. [PubMed: 9844076]
- Baker DW, Wolf MS, Feinglass J, et al. Health literacy and mortality among elderly persons. Arch Intern Med. 2007; 167:1503–1509. [PubMed: 17646604]
- Schwartzberg JG, Cowett A, VanGeest J, Wolf MS. Communication techniques for patients with low health literacy: a survey of physicians, nurses, and pharmacists. Am J Health Behav. 2007; 31(suppl 1):S96–S104. [PubMed: 17931143]
- Gillick MR. The critical role of caregivers in achieving patient-centered care. JAMA. 2013; 310:575–576. [PubMed: 23867885]
- Lindquist LA, Jain N, Tam K, et al. Inadequate health literacy among paid caregivers of seniors. J Gen Intern Med. 2010; 26:474–479. [PubMed: 21161420]
- Parker RM, Baker DW, Wasiams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med. 1995; 10:537–541. [PubMed: 8576769]

- Elliott RA, Marriott JL. Standardised assessment of patients' capacity to manage medications: a systematic review of published instruments. BMC Geriatrics. 2009; 9:27.10.1186/1471-2318-9-27 [PubMed: 19594913]
- 22. Donelan K, Hill CA, Hoffman C, et al. Challenged to care: informal caregivers in a changing health system. Health Aff. 2002; 21:222–231.
- Mastel-Smith B, Stanley-Hermanns M. "It's like we're grasping at anything": caregivers' education needs and preferred learning methods. Qual Health Res. 2012; 22:1007–1015. [PubMed: 22645226]
- 24. National Alliance for Caregiving and American Association of Retired Persons. [Accessed May 15, 2014] Caregiving in the U S. 2009. http://www.care-giving.org/data/ Caregiving_in_the_US_2009_full_report.pdf
- 25. Stupalski KA, Russell GE. Reported medication errors in community residences for individuals with mental retardation: a quality review. Ment Retard. 1999; 37:139–146. [PubMed: 10337130]
- van den Bemt PMLA, Robertz R, de Jong AL, et al. Drug administration errors in an institution for individuals with intellectual disability: an observational study. J Intellect Disabil Res. 2007; 51:528–536. [PubMed: 17537166]
- 27. The Lewin Group. A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities and behavioral health. Washington, DC: The Lewin Group; 2008.
- 28. Ngoh LN. Health literacy: a barrier to pharmacist-patient communication and medication adherence. J Am Pharm Assoc. 2009; 49:e132–e149.10.1331/JAPhA.2009.07075
- 29. Jacobson, KL.; Gazmararian, JA.; Kripalani, S., et al. Is our pharmacy meeting patient's needs? A pharmacy health literacy assessment tool user's guide. Rockville, MD: Agency for Healthcare Research and Quality; 2007 Oct. Prepared under contract No. 290-00-0011 T07. AHRQ publication number 07-0051
- 30. Weiss BD, Mays MZ, Martz W, et al. Quick assessment of literacy in primary care: the newest vital sign. Ann Fam Med. 2005; 3:514–522. [PubMed: 16338915]
- Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. Fam Med. 1993; 25:391–395. [PubMed: 8349060]
- Hironaka LK, Paasche-Orlow MK, Young RL, et al. Caregiver health literacy and adherence to a daily multi-vitamin with iron regimen in infants. Patient Educ Couns. 2009; 75:376–380. [PubMed: 19395227]
- 33. Cooper Bailey S, Pandit AU, Yin S, et al. Predictors of misunderstanding pediatric liquid medication instructions. Fam Med. 2009; 41:715–721. [PubMed: 19882395]
- Yin HS, Mendelsohn AL, Wolf MS, et al. Parents' medication administration errors. Arch Pediatr Adolesc Med. 2010; 164:181–186. [PubMed: 20124148]

Key Points

Background

- Safe and effective use of medication is associated with health literacy.
- Caregivers of people with intellectual/developmental disabilities (IDD) assist their clients with medication management.
- Knowing the association between health literacy and medication management tasks for caregivers of people with IDD will provide researchers and policy makers information of where to target training resources for caregivers.

Findings

- Caregiver education is associated with health literacy.
- Health literacy is associated with performance on a medication administration task test.
- Family caregivers and employed direct support staff have similar levels of health literacy and performance on the medication administration task test.
- This study provides information that could be used to conduct a larger, more comprehensive assessment of health literacy and medication management of caregivers of people with IDD.

| | Overall N (%) or mean (SD) and median | Direct support staff N (%) median | Family/friend caregiver N (%) or median | Groups significantly different? |
|---|--|---|---|---------------------------------------|
| Caregiver characteristics | (n = 47) | (n = 36) | (n = 11) | P values |
| Age (years) | 45.7 (14.6) 49.0 | 40.5 | 60.0 | 0.003 |
| Gender-female | 41 (87.2) | 34 (94.4) | 7 (63.6) | 0.02 |
| Caregiver education | | | | 0.60 |
| Less than high school graduate | 1 (2.1) | 1 (2.8) | 0 (0) | |
| High school graduate or equivalent | 8 (17.0) | 7 (19.4) | 1 (9.1) | |
| College courses or graduate | 38 (80.9) | 28 (77.8) | 10 (90.9) | |
| Takes medication personally | 28 (59.6) | 20 (55.6) | 8 (72.7) | 0.49 |
| Training in medication pass | 30 (63.8) | 30 (83.3) | 0 | < 0.001 |
| Has opportunity to discuss questions about medication with others | 32 (74.4) | 27 (84.4) | 5 (45.5) | 0.02 |
| Experience as caregiver of a person with IDD before current situation | 23 (48.9) | 20 (55.6) | 3 (27.3) | 0.17 |
| Length of time working with the person with IDD (months) | 8.0 (10.7) 3.0 | 3.0 | 29.0 | 0.11 |
| STOFHLA score | 34.5 (2.5) 35.0 | 35.0 | 36.0 | 0.13 |
| MAT score | 12.0 (2.2) 12.0 | 11.0 | 13.0 | 0.12 |

Table 1 Characteristics of participating caregivers

Abbreviations used: SD, standard deviation; IDD, intellectual and developmental disabilities; STOFHLA, Short Test of Functional Health Literacy in Adults; MAT, medication administration task.

P values in bold indicate significant differences at alpha < 0.05.

| Table 2 |
|--|
| Medication use process activities that caregivers performed (n = 47) |

| Medication use process step | All of the time N (%) | Most of the time N (%) | Some of the time N (%) | Do not perform N (%) |
|---|--------------------------|---------------------------|---------------------------|-------------------------|
| Obtain medication from pharmacy | 17 (37.0) | 16 (34.8) | 0 (0) | 13 (28.3) |
| Remind person with IDD to take medication | 30 (65.2) | 5 (10.9) | 6 (13.0) | 5 (10.9) |
| Hand medication to person with IDD | 32 (69.6) | 2 (4.3) | 8 (17.4) | 4 (8.7) |
| Perform monitoring procedures | 9 (19.6) | 1 (2.2) | 4 (8.7) | 32 (69.6) |
| Accompany person with IDD to physician appointments | 21 (45.7) | 4 (8.7) | 13 (28.3) | 8 (17.4) |
| Document medication and health information | 22 (47.8) | 6 (13.0) | 9 (19.6) | 9 (19.6) |

Abbreviation used: IDD, intellectual and developmental disabilities

| Table 3 |
|--|
| Participants' performance in individual steps in medication administration task test |

| Medication and administration steps | Frequency and percent correct for 47 participants N (%) |
|--|--|
| Miglitol 25 mg: Take one tablet three times daily with meals. | |
| Place 1 tablet per well | 47 (100) |
| Place in morning, noon, and evening wells | 37 (78.7) |
| All 7 days are filled | 42 (89.4) |
| Pyrantel 125 mg: Take six tablets daily for 3 days. | |
| Place 6 tablets | 32 (68.1) |
| Per one well | 32 (68.1) |
| For 3 consecutive wells | 44 (93.6) |
| Paliperidone 3 mg: Take one tablet daily. | |
| Place 1 tablet per well | 47 (100) |
| Per one well consistently per day | 47 (100) |
| All 7 days are filled | 42 (89.4) |
| Zopiclone 7.5 mg: Take one tablet nightly as needed. | |
| Place 1 tablet | 31 (66.0) |
| Per well consistently at bedtime well | 25 (53.2) |
| All 7 wells filled | 24 (51.5) |
| Cephalothin 500 mg: Take one tablet four times daily for 10 days. | |
| Place 1 tablet | 43 (91.5) |
| Per well consistently morning, noon, evening, and bedtime | 38 (80.9) |
| For 7 days (one pack) and for 3 more consecutive days on second pack prove | ided 37 (78.7) |

| Table 4 |
|--|
| Correlations between the STOFHLA, medication administration task test, and caregiver |
| characteristics |

| Caregiver characteristics | Correlation with STOFHLA scores (P value) | Correlation with MAT scores (P value) |
|---|--|---|
| STOFHLA score | | 0.29 ^{<i>a</i>} (0.045) |
| Age | $0.02^a (0.91)$ | $0.17^a (0.25)$ |
| Gender | $-0.03^{b}(0.85)$ | $0.06^{b}(0.71)$ |
| Education | 0.33 ^{<i>a</i>} (0.03) | $0.06^{a} (0.67)$ |
| Takes medication regularly | $-0.09^{b}(0.53)$ | -0.21^{b} (0.15) |
| Training on medication administration | $0.07^b (0.66)$ | 0.15 ^b (0.31) |
| Has opportunity to discuss questions about medication with others | -0.1^{b} (0.52) | -0.04^{b} (0.42) |
| Experience as caregiver of a person with IDD before current situation | -0.17 ^b (0.26) | -0.11^{b} (0.47) |
| Length of time working with the person with IDD | 0.28 ^{<i>a</i>} (0.06) | 0.19 ^a (0.21) |

Abbreviations used: IDD, intellectual and developmental disabilities; STOFHLA, Short Test of Functional Health Literacy in Adults; MAT, medication administration task.

P values in bold indicate significant differences at alpha < 0.05.

^aSpearman's rho correlation

 b Pearson's *r* correlation