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Requesting Help to Understand Medical Information Among People Living with HIV and Poor Health Literacy

Seth Kalichman, PhD, Jennifer Pellowski, MA, and Yiyun Chen, MPH

Abstract

Health literacy is known to influence medication adherence among people living with HIV/AIDS. People who experience difficulty reading health information may benefit from asking others to assist them with reading, interpreting, and understanding medical information. We examined medical chart-abstracted HIV viral load, medication adherence assessed by unannounced pill counts, and adherence improvement strategies among 245 individuals with lower-health literacy who do not request assistance, and 229 who do request assistance with reading and understanding health information. Participants were people living with HIV who were taking antiretroviral therapy and scored below 90% correct on a standardized test of functional health literacy. After controlling for health literacy scores, requesting informational assistance was associated with strategies used to improve adherence; individuals who asked for assistance were significantly more likely to use multiple adherence strategies. However, despite requesting informational assistance and using more adherence strategies, participants who requested informational assistance evidenced poorer treatment adherence and poorer suppression of HIV replication. Requesting assistance was more common among those with the poorest health literacy and therefore greatest challenges to adherence. People living with HIV who have poor health literacy skills may benefit from medication adherence programs and requests for assistance afford opportunities for social interventions.

Introduction

HIV infection has emerged as a chronic illness that is often controllable with antiretroviral therapy (ART). However, high levels of adherence remain necessary to achieve optimal clinical benefits of ART and to avoid developing drug-resistant strains of HIV. Among the most well-established barriers to health care in general,[1] and ART adherence in particular,[2–5] are poor reading ability and low literacy skills. Because HIV is concentrated in the poor and underserved, low literacy is prevalent among people living with HIV/AIDS. Studies show that low literacy predicts medication adherence over and above other well-established barriers to adherence, including substance use and depression.[6–8] Information resources that are associated with adherence, such as seeking health information on the Internet,[9] are less available to people with poor reading skills. In addition to not maintaining medication adherence, patients with poor literacy skills often fail to fully understand diagnostic information, health care directions, and instructions.[10–12]

Although limited literacy skills are known to predict poor treatment adherence, less is known about the strategies used by patients with low-literacy skills to compensate for their challenges in understanding health information and medical instructions. Patients may inform health care providers of their difficulties reading, ask family or friends to help them understand medical information, or request family or friends to accompany them to health care visits. The majority of medical patients with poor health literacy skills state that it would be helpful for their doctor or nurse to know that they do not understand some medical language.[13] However, patients often do not disclose their reading difficulties. Half of patients reading at or below third grade level experience shame or embarrassment about their difficulties reading, as do 19% of those who read between fourth and sixth grade levels.[13] More than two-thirds of patients with lower-health literacy admit that they have trouble reading, and 40% of those who do admit the problem report feeling ashamed of their reading ability.[14] In addition, two out of three patients who report feeling ashamed do not tell their spouse about their reading problems, half do not tell their children, and one in five never tell anyone that they have difficulty reading.[14,15]

The current study focused on individuals living with HIV and low-literacy skills who request reading assistance to

Department of Psychology, University of Connecticut, Storrs, Connecticut.

ameliorate the adverse impacts of poor health literacy and improve health related outcomes. Patients who request assistance with medical information may more effectively access and utilize adherence improvement strategies such as pillboxes, alarms, and reminders. We therefore examined the antiretroviral medication adherence of people living with HIV who have poor health literacy skills and who request information-related assistance in relation to their health care visits. We hypothesized that patients who request assistance interpreting and understanding medical information would demonstrate greater treatment adherence, greater suppression of HIV viral load, and more use of adherence improvement strategies.

Methods

Participants

People living with HIV/AIDS who were currently receiving antiretroviral therapy and scored below 90% correct on a health literacy test ($N = 474$) were reached through community recruitment strategies. Interested persons contacted our research program to schedule an intake assessment appointment.

Measures

Five sources of data were collected in the current study: literacy assessments, information-related assistance interviews, health behavior assessments, unannounced medication adherence pill counts, and chart abstracted viral load and CD4 counts. Each measure is described below.

Health literacy assessments. Reading literacy was assessed at screening with the reading comprehension scale of the Test of Functional Health Literacy in Adults (TOFHLA).[16,17] The scale is timed and includes 50 multiple-choice items, in which selecting the correct word among four options completes sentences from standard medical instructions. Scores ranged from 0 to 50 with the percent correct computed for the total score. Participants who scored below 90% correct were enrolled in the study.

We also administered the TOFHLA Numeracy Scale to assess numerical reasoning for medical instructions. This scale is administered in an interactive interview where participants are provided with medical instructions that require mental computation to arrive at answers such as the times of upcoming medical appointments, medication dosing instructions, and interpreting lab test results.

Reading assistance interviews. Participants were asked whether they acknowledge difficulty reading or trouble understanding what they read. We also asked participants if they have told their doctor or pharmacist that they experience difficulty reading. Participants also indicated if they experience vision problems or wear corrective lenses. To assess requests for medical information assistance, we asked participants the following three questions: "Do you ever bring someone to a medical appointment to help you understand and remember what your doctor tells you?" "Do you ever ask someone to help you fill out forms for getting benefits or services?" and "Do you ever ask someone to help you with reading instructions about your health and medications?" Responses were made on a Yes/No format and were used to place participants into two groups: (a) those who do not request informational assistance, and (b) those who do request informational assistance.

Computerized health behavior interviews. Assessments were administered using audio-computerized self-interviewing (ACASI) to reduce demand characteristics and limit socially evoked response biases.[18,19] The interview required approximately 30 min. Participants reported basic demographic information including age, gender, education, income, employment, and disability status. We also assessed 14 HIV-related symptoms of 2-weeks duration using a measure reported in previous research;[15] symptoms included shortness of breath; dry cough; oral or throat sores; thrush, Candida, or oral white patches; fatigue; unintentional weight loss; recurring fever; and night sweats. Participants reported the last time they had seen their doctor and whether they had missed a doctor's appointment in the previous month.

To assess global alcohol use we administered the Alcohol Use Disorders Identification Test (AUDIT), a 10-item scale designed to measure alcohol consumption and identify risks for alcohol abuse and dependence.[20] The first three items of the AUDIT represent quantity and frequency of alcohol use and the remaining seven items concern problems incurred from drinking alcohol. Scores of greater than 8 indicate high-risk for alcohol use disorders and problem drinking, with demonstrated specificities between 0.80 and 0.90.[21] In the current sample, the AUDIT was internally consistent, alpha = 0.90. Participants also completed the Centers for Epidemiological Studies Depression Scale (CESD), which asks how often they had specific thoughts, feelings, and behaviors in the past 7 days, responding *0 = no days, 1 = 1–2 days, 2 = 3–4 days, 3 = 5–7* days. We used the CESD cognitive and affective subscale to avoid confounding somatic symptoms of depression with the physical symptoms of HIV and other chronic health conditions.

The computerized interview also assessed use of medication adherence strategies. Participants were asked whether they use seven common memory-based strategies for improving medication adherence.[22,23] The strategies included using a pillbox, keeping medications in a visible place, alarms, and reminders. Responses included whether the participant never uses the strategy, sometimes (intermittent use), or always (consistent use).

Medication adherence. Participants consented to three monthly-unannounced telephone-based pill counts for the duration of the study, constituting a prospective measure of adherence. Unannounced pill counts are reliable and valid in assessing medication adherence when conducted in homes[24] and on the telephone with people living with HIV and low-literacy skills.[8,25] In this study, we conducted unannounced cell-phone based pill counts. Participants were provided with a free cell phone that restricted service for project contacts and emergency use. Following office-based training in the pill counting procedure, participants were called every 21–35 days at unscheduled times by a phone assessor over the course of 3 months. Adherence data represents the average percentage of pills taken as prescribed over three consecutive months. We defined suboptimal adherence as $< 85\%$ of pills taken.[26]

Chart-abstracted viral load and CD4 counts. We used a participant assisted method for collecting baseline chart abstracted viral load and CD4 cell counts from participants' medical records. Participants were given a form that requested their doctor's office to provide results and dates of their most recent viral load and CD4 cell counts. The form included a place for the provider's office stamp or signature to assure authenticity.

Procedures

Men and women living with HIV were recruited from AIDS services and community outreach to participate in a medication adherence intervention study. The data used in this study represent the run-in assessments that were collected prior to any intervention activities in that trial. The study was conducted in Atlanta, GA, a city with among the fastest growing HIV epidemics in the United States, between November 2008 and April 2011. Health literacy assessments were conducted prior to study entry to determine eligibility. Information assistance groups were formed on the basis of responses to the three health-related information assistance questions described above. Participants who indicated that they request help from others to understand or read health or medical information or complete health-related forms were defined as the group that requests informational assistance and were compared to their counterparts who do not request assistance.

Data analyses

Participants who requested reading assistance were compared to those who did not request assistance using bivariate logistic regression analyses. We report odds ratios and 95% confidence intervals (CI) adjusted for health literacy scores. Multivariable logistic regressions were subsequently conducted for adherence, viral load, and adherence strategies controlling for health literacy scores. All analyses tested a priori hypothesized relationships and used $p < 0.05$ to define statistical significance.

Results

Nearly half of lower-literacy participants acknowledged experiencing difficulty reading. However, only one in three participants indicated that their doctor was aware of their reading problems, and only 15% of participants stated that their pharmacist was aware that they have trouble reading (Table 1). Results showed that 48% ($n = 229$) of participants reported requesting reading assistance in health-related settings, with 37% requesting help filling out forms, 36% requesting help reading medical instructions, and 14% bringing someone to the doctor to help them understand medical instructions.

Table 1. Behaviors Associated with Requesting Health-Related Information Assistance

Requests for reading assistance	N	%
Do you ever ask someone to help you fill out forms for getting benefits or services?	174	37
Do you ever ask someone to help you with reading instructions about your health and medications?	169	36
Do you ever bring someone to a medical appointment to help you understand and remember what your doctor tells you?	67	14
Any one source of reading assistance	229	48
Literacy disclosure		
Acknowledges difficulty reading	234	49
Doctor is aware of reading problems	162	34
Pharmacist is aware of reading problems	59	15

Requesting information assistance, demographics, and health outcomes

Participants who requested informational assistance had fewer years of education, poorer reading literacy (TOFHLA) scores, poorer numeracy literacy, and were more likely to miss doctor appointments than those who did not request assistance. Requesting informational assistance was associated with HIV viral load in the direction opposite of that predicted; participants who requested informational assistance were less likely to have an undetectable viral load (Table 2). There were no other differences between informational assistance groups for demographic and health characteristics.

Requesting information assistance and medication adherence

Counter to our hypothesized direction of association, participants who requested information assistance had significantly poorer medication adherence assessed by unannounced prospective pill counts after adjusting for health literacy. This finding was observed for both the average medication adherence as well as adherence that was categorically defined by 85% of pills taken (Table 2). In contrast to medication adherence, results showed that participants who requested informational assistance were significantly more likely to have used all seven adherence improvement strategies, including use of pillboxes, leaving medications in visible places, use of alarm clocks, asking friends or family to remind them, using mealtimes as reminders, and use of reminder notes (Table 3).

Multivariable models

We tested a multivariable logistic regression model with information assistance groups entered and as the dependent variable and viral load and categorically defined adherence entered as independent variables, controlling for health literacy scores. Results indicated that individuals who requested informational assistance demonstrated poorer adherence, OR = 0.59, $p < 0.05$, 95%CI (0.39–0.91) and poorer HIV suppression, OR = 0.63, $p < 0.01$, 95%CI (0.42–0.96). In addition, multivariable analysis of associations between information assistance groups and all adherence strategies, controlling for literacy scores showed that greater use of all seven ART adherence strategies remained associated with requesting assistance (Table 3).

Discussion

Health literacy is a robust predictor of HIV treatment adherence.[8,11] In this sample of people living with HIV who scored low on a health literacy test and were taking antiretroviral medications, the average ART adherence was 84%

Table 2. Demographic and Health Characteristics of Persons with HIV Who Request Health-Related Information Assistance and Those Who Do Not Request Assistance

	Does not request assistance		*Requests assistance*			
	N = *245*		N = *229*			
Characteristic	*M*	*SD*	*M*	*SD*	*OR*	*95%CI*
Age	46.09	7.51	45.97	8.35	0.97	0.95–1.00
Education	12.37	1.78	11.21	1.85	0.77**	0.69–0.87
CD4 count	423.03	286.46	408.98	282.09	1.00	0.99–1.00
HIV symptoms	6.51	2.80	6.73	2.71	1.06	0.97–1.11
Adherence—% pills taken	86.61	16.92	82.09	19.91	0.22**	0.07–0.68
TOFHLA Score	80.78	12.15	64.20	25.96	0.01**	0.01–0.03
Numeracy Scale	4.95	1.63	4.11	2.06	0.78**	0.70–0.86
AUDIT score	5.82	3.66	5.89	3.75	1.00	0.95–1.05
CES-Depression	15.28	10.51	17.37	9.78	1.01	0.99–1.03
	N	%	*N*	%		
Men	178	73	150	66		
Women	67	27	79	34	1.50	0.92–2.29
African-American	231	94	211	93		
White	9	4	9	4		
Other ethnicity					1.20	0.61–1.65
Income < $10,000	177	73	172	75	0.93	0.69–1.25
Unemployed	82	34	74	32	0.94	0.64–1.3
Receives disability benefits	148	60	136	59	0.85	0.57–1.29
Wears corrective lenses	156	64	152	66	1.10	0.72–1.66
TOFHLA score < 85%	107	44	166	73	0.29**	0.20–0.43
CD4 < 200	53	23	55	26	0.69	0.43–1.22
Undetectable VL	100	42	68	32	0.63*	0.41–0.96
Adherence < 85%	95	41	109	54	0.64*	0.42–0.97
Doctor visit in past month	136	55	118	52	1.19	0.80–1.77
Missed doctor appointment in past month	24	10	33	15	0.54*	0.29–0.99

Analyses of nonliteracy measures adjusted for health literacy scores; *$p < 0.05$, **$p < 0.01$.

of pills taken as prescribed, and less than half of participants achieved the clinically meaningful cut-off of 85% adherent.[26] These levels of adherence indicate risks for treatment failure and the potential to develop HIV treatment resistant viral strains. Individuals who experience the most difficulty reading and understanding medical information were the most likely to request assistance to understand health-related information. Not surprisingly, requesting help to interpret and understand medical information was also associated with fewer years of education, poorer numerical literacy skills, and more likely to miss doctor appointments.

Also consistent with previous research, we found that few participants had disclosed their reading difficulties. Although nearly half of participants openly acknowledged their difficulty reading, only 34% had informed their doctor, and 15% made their pharmacist aware of their reading challenges. People may experience multiple barriers to disclosing their reading difficulties, including a sense of shame and literacy-related stigmas.[7,14] For people living with HIV infection, the challenges to disclosure are further complicated by AIDS-related stigmas.[27,28] The opportunities one has to request assistance understanding health information will therefore also depend on the degree to which people living with HIV disclose their HIV status. Addressing both AIDS and literacy-related stigma will therefore play key roles in developing strategies to assist HIV-positive patients with poor literacy skills. Other factors that were not assessed in the current study that may have also impacted the results are personality characteristics such as conscientiousness, locus of control, general self-efficacy, and social orientations such as introversion and extroversion.[29]

Although we predicted that requesting assistance with reading and interpreting health information would compensate for the challenges experienced by those with the lowest literacy skills, our results found the opposite; people who requested assistance remained the least adherent and had the poorest health outcomes. Poorer adherence among those who requested informational assistance occurred despite their reporting greater use of every adherence improvement strategy we assessed. This pattern of findings suggests that the people with the most difficulty understanding medical information do request help and obtain access to adherence assistance strategies. However, their efforts and the assistance they receive appear insufficient to achieve levels of adherence necessary to reap optimal benefits of antiretroviral therapies. These results therefore may inform interventions targeted to improve ART adherence for lower-literacy patients.

The results of the current study should be interpreted in light of its methodological limitations. The sample of people with HIV and poor literacy skills was one of convenience and cannot be considered representative of people living with HIV. The study was conducted in the southeastern United States, again restricting the generalizability of our findings. We also relied on an interpersonal interview to assess disclosure of reading difficulties and requests for informational assistance. The same social inhibitions of shame and stigma that interfere with

Table 3. Medication Adherence Strategies Used by Persons with HIV Who Do Not Request Health-Related Information Assistance and Those Who Do Request Assistance

	Does not request assistance N = *245*		*Requests assistance* N = *229*			
Adherence strategy	N	%	N	%	*OR 95%CI*	*Adjusted*[a] *OR 95%CI*
Pill box						
Never	134	55	35	42		
Intermittent	41	16	60	26		
Consistent	70	29	73	32	1.17* 1.03–1.35	1.21** 1.05–1.39
Leaves pills in visible place						
Never	102	41	69	30		
Intermittent	66	26	72	32		
Consistent	77	31	87	38	1.19* 1.03–1.37	1.24** 1.06–1.43
Uses an alarm clock						
Never	203	82	160	70		
Intermittent	22	9	43	19		
Consistent	20	8	25	11	1.29** 1.08–1.55	1.32** 1.09–1.59
Uses an alarm watch						
Never	211	86	171	75		
Intermittent	16	7	41	18		
Consistent	18	7	16	7	1.27* 1.05–1.54	1.29* 1.05–1.57
Asks a friend or family to remind						
Never	199	81	126	55		
Intermittent	42	17	85	37		
Consistent	4	2	18	8	1.81** 1.50–2.20	1.84** 1.50–2.25
Uses mealtime as reminder						
Never	110	45	69	31		
Intermittent	98	40	106	46		
Consistent	37	15	54	23	1.32** 1.13–1.54	1.34** 1.14–1.58
Calendar						
Never	178	73	126	55		
Intermittent	48	19	73	32		
Consistent	19	8	30	13	1.38** 1.17–1.62	1.41**, 1.19–1.68

*$p < 0.05$, **$p < 0.01$; [a]adjusted for health literacy score.

openly acknowledging reading challenges may have impeded their openness in our interview. Therefore, we should assume that more participants experience difficulty acknowledging their reading difficulties and other socially sensitive behaviors than were apparent in our results. Finally, we relied on self-reported measures to assess adherence improvement strategies that may have been influenced by recall and social desirability biases. With these limitations in mind, we believe that our findings have implications for interventions to assist people living with HIV and lower-literacy skills.

Few interventions have been tested for improving health behaviors and health outcomes for people with poor literacy skills, and even fewer have been directed at improving HIV treatment adherence for this population. Our findings suggest that individuals with moderate levels of reading literacy may benefit from adherence counseling and skills building interventions. For example, behavioral self-management counseling interventions often instruct patients to use several of the strategies we found rarely used among people who did not request informational assistance in our study.[30,31]

Our findings also suggest that more direct and intensive interventions may be needed for people who are the most challenged by poor reading skills. We did not see evidence that requesting assistance and using behavioral self-management strategies are helping these patients to achieve optimal treatment outcomes. However, requests for assistance offer clear opportunities for interventions. Health care providers, family, and friends may be enlisted to provide adherence support beyond merely reading and understanding medical information. Building supportive and skills-based adherence assistance networks may therefore capitalize on requests for help from those with the lowest literacy skills. Research is needed to test interventions such as direct observation therapy and daily medication reminders for this population.[32,33] In addition, intensive counseling approaches with long-term continuous adherence monitoring that have been useful in other significantly challenged populations such as those with substance abuse disorders and serious mental illness may prove beneficial to people with the poorest literacy skills.[34,35] Given the risks posed by HIV treatment resistance to individual and public health, interventions to improve the adherence of this vulnerable population are urgently needed.

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Address correspondence to:
Dr. Seth Kalichman
Department of Psychology
University of Connecticut
406 Babbidge Road, Unit 1020
Storrs 06269, CT

E-mail: seth.k@uconn.edu