Measuring Health Literacy among People Living with HIV who attend a Community-Based Ambulatory Clinic in Puerto Rico

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Objective: Health literacy is an important area for interventions aimed at reducing or eliminating the health disparities of people living with HIV (PLWH). We sought to determine the level of functional health literacy (FHL) and its association with medication adherence, symptoms, and their attendant management strategies in PLWH.

Methods: This was a cross-sectional study conducted with 200 adults from a community-based ambulatory clinic in San Juan, Puerto Rico.

Results: The mean age of the participants was 46.61. Almost half of all participants (47%) had marginal or inadequate levels of health literacy (21.5%, n = 23; 25.50%, n = 51, respectively). Educational level, being employed, annual income, having children, incorrect self-reported CD4+T cell counts, were they actually reported their viral loads, adherence to antiretroviral treatment (ART) , and use of self-care strategies for depression were significantly related to a given individual's level of health literacy ($p<0.05$). Significant interactions were found between adherence and FHL ($p = 0.0069$). People with marginal health literacy had a higher mean score (1.77 ± 937) on the adherence scale than did those with inadequate literacy levels. After adjusting for age, education, and the number of people per room at the participant's home, data showed that for those who were 45 years of age or younger, there were significant differences ($p = 0.002$) in the mean scores of the adherence scale between those with marginal levels of health literacy and those who had inadequate levels of same (5.66 ± 1.84).

Conclusion: Findings from this study fill an existing gap in the important area of health literacy among PLWH in Puerto Rico and highlight the importance of conducting future research geared towards incorporating FHL as an essential component in the management of adherence as well as in both symptoms and the management of same in PLWH. [*P R Health Sci J 2015;34:31-37*]

Key words: Health literacy, HIV, Ambulatory clinic, Puerto Rico

HIV infection is still expanding on a global scale. When prevalence is examined at this scale, it can be seen that the Caribbean accounts for the second highest area of prevalence of the epidemic (1) after Sub-Saharan Africa. Of the states and territories of the United States of America, Puerto Rico proportionately has the highest number of AIDS cases (2). Puerto Rico has reported 45,665 cases of HIV/AIDS since the beginning of the epidemic (3), and the rate of infection continues to rise.

People living with HIV (PLWH) are an important priority population in Puerto Rico because they are confronted with physical and psychological challenges related to the disease, medication modalities, and co-morbidities which challenges require accurate and focused interventions and ongoing management. Health literacy is a growing area of interest and is important for interventions aimed at reducing or eliminating health disparities in PLWH. Functional health literacy is an issue of utmost importance with regards to the management of the care of PLWH (4). It is defined as the capabilities that any person has for obtaining, processing, and communicating about health-related information, which information is necessary if that individual is going to be able to make informed health decisions (5, 6). Health-literacy levels are very frequently found to be low in PLWH as well as in minority groups, which

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low levels of literacy could result in difficulties accessing care services or understanding and maintaining self-care behaviors which could potentially improve the health and quality of life of the healthcare seeker (7). Thus there is agreement that a low level of health literacy makes people vulnerable to problems with accessing services, managing their symptoms, communicating with healthcare providers, understanding and following treatment options, and making informed decisions on health information for self-management of their illnesses (8–9). In the area of HIV, a relationship has been found between poor viral control and antiretroviral treatment (ART) adherence and low functional health literacy. Studies have found that a poor understanding of CD4+ T cell count, viral load, and medicine regimen can be predicted in persons with limited literacy (10, 11). In a prior qualitative study, a group of Puerto Rican providers working with women living with HIV mentioned low health literacy as one of the contributing factors to their patients' difficulties with adhering to ART regimens (12).

In Puerto Rico, there has been limited research in the area of functional health literacy in PLWH, thus this research represents an initial exploration of health literacy, medication adherence, symptoms, and their attendant management. This study attempted to address this identified gap in knowledge in Puerto Rico so as to provide healthcare providers with insights about this population.

Materials and Methods

Design and Study participants

This cross-sectional study was conducted with 200 adults recruited from a community-based ambulatory clinic in the metropolitan area of San Juan, Puerto Rico, which clinic provides HIV care to approximately 2,000 people encompassing a broad socio-demographic range. Participants were informed of the study by a staff member or by flyers posted in the ambulatory clinic. Graduate and undergraduate students were trained regarding the protection of human subjects, recruitment, data collection, data entry, and data management. In addition, the PI and research assistants conducted a meeting to orient the clinic staff on the purpose and procedures of the study and to explain the inclusion/exclusion criteria. The nurse case manager of the clinic referred participants to the trained undergraduate and graduate research assistants. Per inclusion criteria, all participants had to read the questionnaires by themselves in order to complete the study instruments. A participant was eligible if he or she had been diagnosed with HIV (confirmed by self-report), was over the age of 21 (age of majority in Puerto Rico), and was self-reporting symptoms, and being on ART; being pregnant did not rule out the participation of an interested subject. Exclusion criteria included a participant's having a documented diagnosis of dementia, being unable to understand the consent procedure (as judged by the person obtaining consent), self-reporting no symptoms, self-reporting not being on ART, and being blind or too ill to participate. Data collection was completed in a private area of the clinic and lasted no more than 2 hours; participants received a monetary incentive to cover food and transportation costs.

Ethical considerations

Institutional Review Board (IRB) approval was obtained from the Human Subjects Committee of the University of Puerto Rico, Medical Sciences Campus. All participants gave written informed consent prior to the initiation of the study procedures. A certificate of confidentiality was also obtained. Codes and identification numbers were created for each participant, and all information was kept confidential and secure at all times during data collection, entry, and management.

Measures

As part of the study, participants completed the following measures (which were presented in Spanish):

Demographic characteristics

Data were obtained from the participants regarding their personal and environmental characteristics including age, gender, ethnicity, years of education, annual income, whether they had children, whether they had an AIDS diagnosis, health status indicators (CD4+ T cell and viral load), and (when present) co-morbidities.

Test of Functional Health Literacy in Adults-Spanish – Puerto Rico version, 2010 (TOFHLA-SPR)

The Spanish-language version of the TOFHLA (13) was adapted to the Puerto Rico context in a sample of PLWH, after which its internal consistency was assessed. The scale reliability coefficient obtained for this scale was strong (estimated alpha = 0.95) for numeracy (estimated alpha = 0.919) and reading comprehension (estimated alpha= 0.953) (14). The original instrument consists of a 17-item test for numeracy and a 50-item test for reading comprehension. The numeracy section provides participants with prompts and questions related to healthcare instructions, diagnostic procedures, and prescription labels. Their understanding of this information is then evaluated. The reading comprehension section of the TOFHLA-SPR is based on the cloze method. The cloze method was developed in 1953 by Wilson Taylor as a method determining the readability of a given text; the method has subsequently been used for evaluating reading comprehension (15). In this section, participants read passages of text about medical topics in which every fifth to seventh word is omitted and must identify the replacement words that would be most appropriate given the context of the passage. Completing the TOFHLA-SPR takes participants approximately 10 to 20 minutes; it is scored on a scale of 0 to 100; the higher the score, the more adequate the functional

health literacy is. Results are divided into 3 categories: A person receiving a score of 0 to 59 is considered to have an inadequate level of health literacy; 60 to 74 is considered a marginal level; and 75 to 100 is considered adequate (13).

The Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev) (Symptoms)

This scale is composed of 64 items that capture the taker's symptoms (on the day of data collection) as well as the intensity with which those symptoms are being experienced. Items are rated on a 3-point Likert scale, with 1 being equal to mild, 2 being equal to moderate, and 3 being equal to severe. Calculations include the total number of symptoms (range = 0–64) and the mean severity of symptoms (range = 1–3). The reliability and validity of the instrument have been previously confirmed using a Puerto Rico sample. Cronbach's alpha reliability for the Puerto Rico Spanish version ranged from 0.943 to 0.956 for the overall 64-item instrument (16).

Revised ACTG – Reasons for Non-Adherence to Medication Regimen (ACTGrev)

The ACTGrev (17) surveys (by self-report) the various reasons for not taking medication. After a randomized clinical control study on adherence (18), it was later revised. Factor analysis was conducted on the original 14-item instrument (17), producing 2 factors with a total of 9 items: pill-taking problems (5 items) and forgetfulness (4 items). These 9 items constitute the revised scale. Each factor or subscale can be summed separately and then collectively to create the total score. In this study, the score of the adherence scale was computed by adding the scores assigned to each question related to medication consumption (that is, the frequency with which the participant missed taking his or her medication); the following scores were used: 1 was used to indicate "never," 2 indicated "rarely," 3, "sometimes," and 4, "often." Cronbach's alpha reliability was determined in a study conducted with 98 Puerto Rican participants for the 2 subscales, and the total score ranged from 0.84 to 0.80 (16).

The Revised Sign and Symptom Check-List for HIV (SSC-HIVrev)

This scale was developed through 2 studies (19). The top 6 symptoms and the strategies used to manage them were determined for 1217 participants across 4 countries and Puerto Rico. The Cronbach's alpha factor reliability scores for the Puerto Rico sample (n = 44) ranged from 0.67 to 0.90 for each of the factors (16). The frequency of depressive symptoms was measured on a scale of 1 to 7, indicating how many days in the week prior to taking the survey that the participant experienced a given symptom. The intensity, bothersomeness, and impact of depressive symptoms were all measured with 10-point visual analog scales. Response choices ranged from 1 (very low) to 10 (very high).

Data analysis

Statistical analysis was performed using the statistical software STATA version 10 (20). A participant's functional health literacy was classified as adequate if his or her score ranged from 75 to 100, marginal with a score ranging from 60 to 74, or inadequate with a score of 59 or lower. To develop an epidemiological profile of the study group by the level of functional health literacy, initially a descriptive analysis was performed. Descriptive statistics (i.e., means, standard deviations, frequencies, and percentages) were used to examine functional health literacy and the demographic characteristics of the sample, as well as each participant's adherence to his or her medication regimen and his or her symptoms and the management of those symptoms. Mean differences were assessed for continuous outcomes using one-way analysis of variance; previously, an evaluation of the variance homogeneity was performed. To determine significant differences, frequency distribution by health-literacy level was assessed with the chi-square distribution test. Lineal regression models were used to examine potential predictors of the adherence scale, including health literacy, age, education, and the number of people per room in a given participant's home.

Results

Characteristics of the sample

Two hundred adults consented to participate in this study. All participants reported that Spanish was their primary language, and all ranged in age from 21 to 78 years of age at the time of their participation.

Almost half of all participants (47%) showed marginal or inadequate levels of FHL (21.5%, n = 23; 25.50%, n = 51, respectively). In the members of our sample group, the mean number of years living with HIV was 12.9; 23% (n = 46) had been diagnosed with AIDS. Sixty-eight percent of the sample indicated that they had a high school education or higher. Table 1 shows additional demographic characteristics of the sample. Participants reported an average symptom intensity score (total possible score = 192) of 20.99 (±26.17), which score was arrived at by rating 64 common signs and symptoms for people living with HIV. On a 1 to 10 scale (1 = poor, and 10 = excellent), participants rated their physical conditions, psychological conditions, and available social support as quite high, averaging from 7.84 to 8.28. Data related to the CD4 variable will be further discussed in the Health Literacy and Related Factors section.

HIV symptoms and Symptom self-care strategies

Participants were asked to check yes if they had experienced any 1 or more of 6 symptoms within the past week and, if so, to identify the frequency, intensity, and impact of and level of distress caused by that or those symptoms. Additionally,

Table 1. Description of the participants' characteristics (n = 200)

Characteristics	%	SD	Range
Age	46.6	9.54	21–78
Gender			
Female	51 (n = 102)		
Male	49 (n = 98)		
Education			
Less than high school	34 (n = 68)		
High school	35.5 (n = 67)		
More than high school	32.5 (n = 65)		
Employment	21.5 (n = 43)		
Percent Working			
Full-time	13 (n = 26)		
Annual Income			
Less than $9,570	71.5 (n = 143)		
Insurance	95 Yes (n = 189)		
Have Children	66 Yes (n = 131)		
CD4 Count (n = 116)	1350	841	8–91,825*
Scale of Health Status			
Physical condition	8.2	2.16	1–10
Psychological condition	7.8	2.57	1–10
Social support	8.3	2.76	1–10
Scale of symptom intensity	21	26.17	0–141

*Participants appear to have confused CD4 with viral load in this self-report

participants were asked to check off which self-care strategies they used to manage the symptom or symptoms. Self-care strategies included engaging in physical activities, self-reflection, changing one's diet, making use of complementary therapies, taking one's medication, and using substances such as marihuana, cigarette, alcohol, or drugs from the street. We counted the number of self-care strategies reportedly used by the participants for each identified symptom. The symptoms for which participants implemented the greatest number of self-care strategies were diarrhea (M = 54.97), nausea (M = 38.43), and fatigue (M = 31). Ninety-five percent (n = 190) of the participants completed a 9-item scale on the reasons for not taking their medication in the past, and the mean score was 2.42 (SD = 4.37; range, 0–27).

Health literacy and Related factors

Table 3 shows the variables most significantly associated with health literacy. There were no significant associations between health literacy and gender, insurance status, physical condition, psychological condition, level of social support, symptom intensity, or most self-care strategies for managing symptoms (except in terms of depressive symptoms), resulting in their not being included on the above mentioned scale.

Table 2. Symptom self-care strategies

Variable	N	%	Mean intensity	SD	Range
Anxiety	81	41.55	2.42	4.37	0–27
Depression	72	36	17.34	44.75	2–273
Nausea	21	10.5	38.43	91.84	4–354
Fatigue	30	15	31.00	79.04	1–355
Neuropathy	54	27	12.48	32.64	1–181
Diarrhea	33	16.5	54.97	214.23	1–1149

A given individual's health-literacy level was highly correlated with his or her years of education, suggesting that the completion of high school was significantly related to having a greater level of health literacy. A discernible trend was that younger participants tended to have higher levels of health literacy than their older counterparts did ($p = 0.08$). The participants were also asked to self-report their CD4+ T cell counts, if known. The mean of the reported CD4 T cell count was 1,350 cells/mm^{3}Viral loads ranged from 8 to 91,825 copies/mL. Additionally, our data did not show there to be a significant association between depression and education ($p>0.10$). Interestingly, research has shown that individuals with adequate health literacy tend to miss taking their medication with less frequency (therefore adhering better to their ART treatment) than do their less knowledgeable counterparts. However, this study's finding that the participants with inadequate health literacy missed taking their medication with less frequency than did those whose health literacy level was marginal came as a surprise.

Linear regression models were used to examine potential predictors of the adherence scale, which predictors included the participant's health-literacy level, age, and level of education as well as the number of people per room at the participant's home (Table 4). Upon comparing adherence and health literacy, we discovered that there is significant interaction between the age group (≤ 45 vs. > 45) and health literacy ($p = 0.0069$). We found that for those participants who were 45 years of age or younger, significant differences were present ($p = 0.002$) in terms of the mean scores of the adherence scale between those with marginal health literacy and those who had inadequate levels of such literacy (μ_marginal-μ_inadecuate: 5.7, 95% CI= 2.1,9.3) after adjusting for education and the number of people per room at home ($p<0.05$). Among those older than 45 years, this difference was not significant ($p>0.10$) even when adjusting for education and the number of people per room at home ($p>0.05$).

Discussion

We sought to determine the level of functional health literacy and its association with medication adherence and symptoms and the strategies used to manage them in PLWH who attended a given community-based organization in San Juan, Puerto Rico. This study discovered that health literacy was highly associated with level of education. Sixty-six percent of the participants in this study had a high school–level education or beyond. Although health literacy varies by context and setting and cannot be considered a reasonable proxy for functional health literacy, there are some studies that suggest that people with limited literacy often have less than a high-school level of

Table 3. Selected demographic characteristics by health-literacy level

Variable	Inadequate	Marginal	Adequate	Test Statistic	*p*
Age	M = 48.12	M = 47.60	M = 45.47	F = 3.034	0.08
Education					
<12 years	37	15	16	X^2 = 72.96	<0.01
High school	11	23	33		
>12 years	3	5	56		
Employed					
Full-time	0	1	25	X^2 = 15.82	<0.01
Part-time	9	1	9		
Annual income					
<$9570	40	37	66	X^2 = 20.30	<0.01
>9570	5	2	23		
Have children					
Yes	40	33	58	X^2 = 11.11	0.004
No	11	10	47		
Mean CD4 count (self-reported)	M = 5,435 (n = 19)	M = 546 (n = 72)	M = 551 (n = 72)	F = 3.916	0.05
Reasons for not taking medication	1.72 (n = 47)	3.95 (n = 40)	2.15 (n = 103)	F = 3.34	0.038
Self-care strategies used for depression	46.86 (n = 7)	15.25 (n = 12)	7.79 (n = 19)	F = 3.585	0.04

education (21, 22). These results are important for our patients with marginal and inadequate FHLs and low educational levels since such patients may need targeted interventions, special assistance, more intensive instruction and follow-up assessments for addressing their illness and treatments.

The individuals in our sample who had inadequate health literacy also showed less knowledge about and understanding of their immunological and virological status than did their more health literate counterparts. The data showed that those with inadequate health literacy appeared to have poor knowledge of the concept of a CD4+ T cell count or were confused about reporting their CD4+ T cell counts and actually reported their viral loads. These findings align with those of previous studies (23, 11) that have shown that participants with inadequate health literacy have poor knowledge about CD4 count and viral load. This finding is clinically relevant, given that health-related knowledge is also an important factor in predicting a patient's ability to manage his or her HIV condition and adherence to ART (11). The quality of provider communication has been associated with patient understanding of HIV-related terms (7). Therefore, providers should take additional steps to improve the ways in which they communicate everyday health information to people with limited health literacy to ensure patient understanding of HIV-related processes and treatments.

Table 4. Multivariate linear model per age group to explain the difference in the scale for non-adherence to medication by literacy level adjusting for educational level and persons per room

	Age group (years)	
	≤45 (n = 72)	>45 (n = 94)
Predictors	**Adjusted β_i (95% CI)**	**Adjusted β_i (95% CI)**
Literacy level		
Inadequate	Reference	Reference
Marginal	5.7 (2.1, 9.3)*	0.1 (-1.8, 2.0)
Adequate	0.7 (-2.4, 3.7)	0.5 (-1.4, 2.4)
Educational level		
≤11	Reference	Reference
High school	0.6 (-2.0, 3.2)	-1.2 (-2.9, 0.5)
Associate/BA/MSc	2.3 (-.5, 5.1)	-1.6 (-3.6, 0.3)
Persons per room		
One	Reference	Reference
Two or more	0.7 (-1.6, 3.1)	-0.5 (-2.3, 1.3)

*P<0.05; β_i indicates the difference in the mean of the scale between the *i-th* category and the reference category of the predictor variable: $\beta_i = \mu_i - \mu_{reference}$.

In our study, adherence and literacy showed significant interaction effects. Participants with adequate or marginal health literacy demonstrated their relative higher levels of adherence by missing their ART medication less frequently. However, unlike what has been seen in other studies, the participants in our study with inadequate health literacy also less frequently reported having missed taking their medication. We believe this finding might be due to the fact that those participants in our study with inadequate health literacy did not understand the questions and were embarrassed or ashamed to admit that they didn't understand them and consequently did not answer them correctly. Another possible explanation for the lower frequency of missing medication could be the unique characteristics of the clinic. It is possible that participants with inadequate literacy may have been receiving more support and closer follow-up in managing their medication regimens than have been those whose levels of health literacy are marginal to adequate. Unfortunately we did not assess the types of services received by participants in the clinic and so are unable to either confirm or disprove this statement. Further research is needed to understand these disparate findings related to FHL and adherence.

No other significant associations were found between health literacy and age, gender, insurance status, physical condition, psychological condition, level of social support, symptom intensity, and self-care strategies (except for those pertaining to depression). Depression is highly prevalent in PLWH (24, 25). The presence of depressive symptoms is especially concerning because of the major risk for poor health outcomes and diminished quality of life. Studies have found that depressive symptoms are linked with low medication adherence (26), social stigmatization (27), risky behaviors (28), clinical progression to AIDS (29, 30), reduced physical and social function, poor quality of life (31), and suicide attempts (32). The risk of depression and suicide exists for persons living with HIV, and that is a major concern in this community. There have been

several studies showing depression to be significantly higher in Puerto Ricans than in other subgroups, although there are no studies that indicate that ethnic differences and symptoms are strongly related (33–35). Since, there are limited data regarding the link between health literacy and depression in PLWH, continued targeted research in those of our PLWH with inadequate levels of literacy who experience depression may provide additional guidance on how to best intervene with this particular vulnerable population to enhance mental wellbeing as well as physical and social support.

Based on the results, the following points should be noted. Although this study will add to the limited literature on health literacy among PLWH in Puerto Rico, this study should still be considered as being preliminary and, as such, having several limitations. First, the study results are not generalizable because of the design and the fact that we used convenience sampling. Second, the data collection for this study took place at a single point in time during a single assessment session. Third, the recruitment of participants was conducted at only one site, which site was located in the metropolitan area of San Juan. This may limit the generalizability of our results to other populations. Fourth, we relied only on a self-report method that is subject to memory errors and does not provide other tools to corroborate participant information. This may have affected our results. Had we been able to collect information from the medical records of the participants, we would have been able to verify the accuracy (or lack thereof) of the participant-supplied CD4+ T cell counts and HIV RNA viral loads.

In spite of these limitations, we believe that the findings from this study fill an existing gap in knowledge in the important area of health literacy among PLWH in Puerto Rico and highlight the importance of conducting future research geared towards incorporating FHL as an essential component in the management of medication adherence and those symptoms that may be present in PLWH. Health literacy is a developing area of interest on the island and is an important factor that should be considered when developing interventions directed at reducing health disparities in this population.

Resumen

Objetivo: La alfabetización funcional de la salud (AFS) es un área de importancia para intervenciones dirigidas a reducir o eliminar disparidades de la salud en personas que viven con VIH (PVCV). Se estudió el nivel de AFS y su relación con cumplimiento con medicamentos, síntomas y estrategias de manejo de síntomas en PVCV. Método: Estudio de corte transversal con 200 adultos de clínica ambulatoria de base comunitaria en San Juan, Puerto Rico. Resultados: La edad promedio fue 46.61. Casi la mitad de todos los participantes (47%) demostraron tener niveles marginales o inadecuados de AFS (21.5%, n=23; 25.50%, n=51, respectivamente). El nivel educativo, empleo, ingreso anual, tener hijos, auto-reporte incorrecto del contaje de CD4+T, ya que reportaron el contaje viral, cumplimiento con tratamiento antiretroviral y uso de estrategias de auto-cuidado para depresión, reflejaron estar significativamente relacionados con AFS ($p<0.05$). Se encontraron interacciones significativas entre cumplimiento y AFS ($p=0.0069$). Personas con AFS marginal demostraron un promedio más alto (1.77+937) en la escala de cumplimiento con respecto a personas con niveles inadecuados. Al ajustar por edad, educación, personas por cuarto en el hogar del participante, hubo diferencias significativas en personas con 45 años de edad o menos ($p=0.002$) en los promedios de la escala de cumplimiento entre aquellos con nivel de AFS marginal versus nivel inadecuado (5.66±1.84). Conclusión: Este estudio provee información que contribuye a disminuir la brecha existente en el área de alfabetización de PVCV en Puerto Rico, a la vez que enfatiza la importancia de conducir investigaciones futuras dirigidas a incorporar la alfabetización como componente esencial en el cumplimiento, síntomas y manejo de síntomas en PVCV.

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References

1. Joint United Nations Programme on HIV/AIDS (UNAIDS). The Status of HIV in the Caribbean. 2010. Available at: http://observatoriovihycarceles.org/es/caribe.raw?task=download&fid=195. Accessed October 30, 2013.
2. Henry J. Kaiser Family Foundation. The Global HIV/AIDS epidemic. October 2013. Available at: kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic. Accessed October 30, 2013.
3. Puerto Rico Health Department. People diagnosed and living with HIV/AIDS in Puerto Rico. San Juan, PR: HIV/AIDS Surveillance System. 2014.
4. Benotsch EG, Kalichman S, Weinhardt LS. HIV-AIDS Patients' evaluation of health information on the internet: The digital divide and vulnerability to fraudulent claims. J Consult Clin Psych 2004;72:1004–1011.
5. Berkman ND, Davis TC, McCormack L. Health Literacy: What is it? J Health Commun 2010;15 Suppl 2:9–19.

6. Nielsen-Bohlman L, Panzer AM, Kindig, DA, eds. Health Literacy: A Prescription to End Confusion. Committee on Health Literacy, Board on Neuroscience and Behavioral Health, Institute of Medicine. Washington, DC: The National Academies Press; 2004.
7. Van Servellen GV, Brown JS, Lombardi E, Herrera G. Health literacy in low-income Latino men and women receiving antiretroviral therapy in community-based treatment centers. AIDS Patient Care STDS 2003;17:283–298.
8. DeWalt DA, Pignone M, Malone R, Rawls C, Kosnar MC, George G, et al. Development and pilot testing of a disease management program for low literacy patients with heart failure. Patient Educ Couns 2004;55:78–86.
9. Wilson JF. The crucial link between literacy and health. Ann Intern Med 2003;139:875–878.
10. Wolf MS, Davis TC, Arozullah A, Penn R, Arnold C, Sugar M, Bennet CL. Relation between literacy and HIV treatment knowledge among patients on HAART regimens. AIDS Care 2005;17:863–873.
11. Wolf MS, Davis TC, Cross JT, Marin E, Green K, Bennett CL. Health literacy and patient knowledge in a Southern US HIV clinic. Int J STD AIDS 2004;15:747–752.
12. Rivero-Mendez M, Dawson Rose C, Solís-Baez S. A qualitative study of providers' perception of adherence of women living with HIV/AIDS in Puerto Rico. Qual Rep 2010;12:232–251.
13. Nurss JR, Parker RM, Baker DW. TOFHLA: Test of functional health literacy in adults. Hartford, MI: Peppercorn Books and Press, Inc.; 1995.
14. Rivero-Méndez M, Suárez E, Solís-Báez SS, Hernández G, Cordero W, Vázquez I, et al.. Internal consistency of the Spanish health literacy test (TOFHLA-SPR) for Puerto Rico. P R Health Sci J 2010;29:49–53.
15. Artola GT. El Procedimiento cloze: una revisión general. Rev Complut Educ 1991;2:69–81.
16. Rivero-Mendez M, Portillo C, Solís SS, Wantland D, Holzemer, LW. Symptoms and quality of life of people living with HIV infection in Puerto Rico. P R Health Sci J 2009;28:54–59.
17. Chesney MA, Ickovics JR, Chambers, DB, Gifford, AL, Neidig J, Zwickl B, Wu AW. Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). AIDS Care 2000;12:255–266.
18. Holzemer WL, Bakken S, Portillo CJ, Grimes R, Welch J, Wantland D, Mullan JT. Testing a nurse-tailored HIV medication adherence intervention. Nurs Res 2006;55:189–197.
19. Holzemer WL, Hudson A, Kersey KM, Hamilton MJ, Bakken S. The Revised Sign and Symptom Check-List for HIV (SSC-HIVrev). J Assoc Nurses AIDS Care 2001;12:60–70.
20. Stata [computer program]. Release 10. College Station, TX: Stata Corp LP; 2007.
21. Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR. The prevalence of limited health literacy. J Gen Intern Med 2004;20:175–184.
22. Shea JA, Beers BB, McDonald VJ, Quistberg DA, Ravenell KL, Asch DA. Assessing health literacy in African American and Caucasian adults: Disparities in rapid estimate of adult literacy in medicine (REALM) scores. Fam Med 2004;36:575–581.
23. Kalichman CS, Rompa D. Functional health literacy is associated with health status and health related knowledge in people living with HIV-AIDS. J Acquir Immune Defic Syndr, 2000 ;25:337–344.
24. Eller LS, Corless I, Bunch EH, Kemppainen J, Holzemer WL, Nokes K, et al. Self-care strategies for depressive symptoms in people with HIV disease. J Adv Nurs 2005;51: 119–130.
25. Bhatia R, Hartman C, Kallen MA, Graham J, Giordano TP. Persons newly diagnosed with HIV infection are at high risk for depression and poor linkage to care: Results from the Steps Study. AIDS Behav 2011;15: 1161–1170.
26. Horberg MA, Silverberg MJ, Hurley LB, Towner WJ, Klein DB, Bersoff-Matcha S, et al. Effects of depression and selective serotonin reuptake inhibitor use on adherence to highly active antiretroviral therapy and on clinical outcomes in HIV-infected patients. J Acquir Immune Defic Syndr 2008;47:384–390.
27. Roeloffs C, Sherbourne C, Unutzer J, Fink A, Tang L, Wells KB. Stigma and depression among primary care patients. Gen Hosp Psychiatry 2003;25:311–315.
28. Alegria M, Vera M, Freeman DH Jr, Robles R, Santos MC, Rivera CL. HIV infection, risk behaviors, and depressive symptoms among Puerto Rican sex workers. Am J Public Health 1994;84:2000–2002.
29. Leserman J. HIV disease progression: depression, stress, and possible mechanisms. Biol Psychiatry 2003;54:295–306.
30. Leserman J. Role of depression, stress, and trauma in HIV disease progression. Psychosom Med 2008;70:539–545.
31. Judd F, Komiti A, Chua P, Mijch A, Hoy J, Grech P, et al.. Nature of depression in patients with HIV/AIDS. Aust N Z J Psychiatry 2005;39: 826–832.
32. Jovet-Toledo GG, Clatts MC, Rodriguez-Diaz CE, Goldsamt L, Vargas-Molina RL. Risk factors for suicide attemps in a clinic-based sample of people living with HIV in Puerto Rico. AIDS Care [serial online]. 2014;26:1032–1035. Available at: http://dx.doi.org/10.1080/09540121.2014.894618. Accessed March 14, 2014.
33. Lewis-Fernandez R, Das AK, Alfonso, C, Weissman MM, Olfson M. Depression in US Hispanics: diagnostic and management considerations in family practice. J Am Board Fam Pract 2005;18:282–296.
34. Wantland D J, Holzemer WL, Moezzi S, Willard SS, Arudo J, Kirksey K, et al. A randomized controlled trial testing the efficacy of an HIV/AIDS symptom management manual. J Pain Symptom Manage 2008;36: 235–246.
35. Eller LS, Rivero-Mendez M, Voss L, Chen WT, Chaiphibalsarisdi P, Iipinge S, et al. Depressive symptoms, self-esteem, HIV symptom management self-efficacy and self-compassion in people living with HIV. AIDS Care 2014;26:795–803.