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Provider perceptions of limited health literacy in community health centers

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Abstract

Objective—To examine techniques used by community health center (HC) providers to care for patients with limited health literacy (LHL).

Methods—Survey mailed to 803 HC providers in 10 Midwestern states. Response rate was 47.5%. Associations between variables were examined using generalized estimating equations (GEE) models to account for clustering of respondents within health centers.

Results—The average provider estimates of LHL prevalence among English-speaking and Spanish-speaking patients were 41% $\pm$ 24% (mean $\pm$ SD) and 48% $\pm$ 30%, respectively. Those with training in health literacy were more likely to have patients repeat instructions back to check understanding (OR=2.05, $p=0.04$) and were more likely to give out health education materials designed for patients with LHL (OR=2.80, $p=0.0002$). Providers differed by type in encouraging patients to bring friends or family members to appointments ($p=0.02$).

Conclusions—Providers estimate LHL to be highly prevalent in their HCs, and use various techniques to assist patients.

Practice Implications—Training in health literacy is associated with increased usage of evidence-based techniques to assist patients with LHL. Providers at all levels would likely benefit from LHL training. Most providers believe providing health education materials designed specifically for patients with LHL would be very helpful.

Keywords

health literacy; community health centers; providers

1. Introduction

Community Health Centers (HCs), as the nation's major safety net health care providers for over 15 million people, face significant challenges treating patients with limited health literacy (LHL) [1]. The majority of HC patients are low income (91%), uninsured (40%) or publicly

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insured through Medicaid (36%), and racial and ethnic minorities (63%) [1]. Furthermore, nearly one-third of all HC patients are best served in a language other than English [1].

The 2003 National Assessment of Adult Literacy (NAAL), a large, nationally representative survey, found that 22% of United States adults had no better than basic health literacy, while 14 % had below basic health literacy, corresponding to being non-literate in English or having no more than the most simple and concrete literacy skills. This survey found that Black and Hispanic adults, non-native English speakers, older adults, those with less than a high school education, and adults living below the poverty level had lower average health literacy [2]. LHL has been linked with health outcomes such as self-reported poor health, increased risk of hospital admission, diagnosis of disease at later stages, poor adherence to medication regimens, and poorer disease knowledge and outcomes [3–12]. Schillinger et al. found that among patients with type 2 diabetes attending a public hospital's primary care clinics in San Francisco, California, inadequate health literacy was associated with worse glycemic control and higher rates of retinopathy [11]. Furthermore, LHL has been shown to be associated with higher health care costs among adult Medicaid patients [13].

While there is much anecdotal evidence of LHL affecting patient care in HCs, we are aware of only one health literacy study conducted in this setting, in a single rural community health center. This study had a small sample size (N=70), and examined patients' functional health literacy. Fifteen percent of participants in this study scored in the Inadequate and Marginal Functional Health Literacy ranges on the Test of Functional Health Literacy in Adults (TOFHLA) [14]. We were unable to identify any studies which specifically examined HC providers' perceptions of how LHL affected their patients and what methods they used to identify and help patients with LHL. Therefore, our objectives were to determine provider estimates of LHL prevalence in HCs, how HC providers are screening and assisting patients with LHL, what programs they believe would be effective, and what barriers they foresee to implementing interventions.

2. Methods

The MidWest Clinicians' Network (MWCN) is a nonprofit corporation consisting of approximately 100 community health centers, primary care associations, individual providers, and other partners within 10 Midwestern states [15]. MWCN's mission is to enhance professional and personal growth of clinicians so they can become effective leaders in their health centers and promoters of quality, community-based primary health care [15]. MWCN organizational members may be federally qualified community health centers, non-Bureau of Primary Health Care supported National Health Service Corps sites, and primary care clinics [15]. Our sample was composed almost entirely of federally qualified HCs; one center was not a federally qualified HC but had a patient population similar to that generally seen in federally qualified HCs.

The MWCN Research Committee is composed of clinicians, administrators, and clinician-researchers from health centers, as well as researchers from the University of Chicago. The Committee includes several general internists and nurse practitioners who have extensive experience conducting research in HCs and providing primary care to vulnerable populations, including migrant farm workers and inner-city, racial/ethnic minority populations. Other MWCN Research Committee members have experience in project management, health behavior, statistics, and community-based participatory research. Based on previous research and clinical experience caring for vulnerable HC populations, the MWCN Research Committee identified LHL as a major priority for research.

The provider survey was developed by the MWCN Research Committee members, and was based on their own experiences and a review of the literature. The survey and study design were approved by The University of Chicago's Institutional Review Board. The survey contained 22 items, and domains included: 1) the perceived scope of LHL issues at the provider's HC, 2) strategies the provider currently uses when assessing and assisting patients with LHL, 3) formal programs their HC has initiated at the organizational level, and whether or not these programs were successful, 4) barriers to implementing a formal health literacy program at their HC, 5) the provider's perception of what would be a useful program to implement at their health center to address LHL, and 6) basic demographic information. All question response scale formats were either on a Likert-type scale, a "check all that apply" response format, or a simple "yes/no" response format, with the exception of one open-ended question at the end asking providers to add any additional comments or suggestions they had regarding LHL in HCs. The survey was pilot tested in a separate sample of 10 HC clinicians and revised for clarity and content and face validity based on their feedback.

The survey sample consisted of 803 providers from 49 different HCs. The mailing list used for this survey was generated from provider lists at each MWCN member organization that utilizes the MWCN Patient Satisfaction Survey. This Patient Satisfaction survey was optional for health centers and its purpose was to provide the organization with information and insight from the patient's viewpoint about the services provided. At the time the mailing list was compiled, there were approximately 97 MWCN organizational members and affiliated clinics. Of those 97 members, 57 participated in the 2005 patient satisfaction surveys, and of those, 49 provided useable mailing information for their providers. Because it included both health center addresses and provider names, we used this sample of 49 MWCN member agencies to identify our pool of 803 providers for the initial mailing of the survey. The HCs surveyed were located in 10 Midwestern states: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, Ohio, and Wisconsin. There was no difference in the distribution by state between MWCN HCs who participated or did not participate in the patient satisfaction survey. However, a higher percentage of rural HCs chose to participate in the survey, with 21 (72%) of 29 rural HCs using the patient satisfaction survey as compared to 28 (41%) of 68 urban HCs ($p=0.005$).

The survey sample included physicians, mid-level health care providers (e.g., nurse practitioners and physician assistants), dentists, dental hygienists, and registered nurses. We sent 803 surveys in the first of three mailings. Providers were informed in the cover letter that the survey was confidential and that their individual responses or names would not be shared with anyone including the HC where they were employed. We subsequently learned that 102 subjects were ineligible due to no longer being employed at the HC, being an employee of the HC but not a health care provider, or being a HC provider who treated only children. These 102 providers were removed, leaving 701 providers in the sample. If the survey was not returned after the initial mailing, we mailed up to two reminder letters with the survey and return envelope to non-responders, with a \$2 bill enclosed as a small incentive for the third mailing.

This study was designed to generate primarily descriptive data. We ran descriptive statistics for each survey variable including mean and standard deviation for continuous variables, and frequency counts for categorical variables. Continuous variables were categorized according to the distribution of values for the variable in the dataset. We also examined associations between the binary outcomes of whether or not a specific technique, such as using a validated questionnaire to assess LHL or having patients repeat instructions back to assist patients with LHL, was used with the following independent variables: whether or not a provider had received LHL training, and provider type. For this purpose, we used generalized estimating equations (GEE) logistic regression [16,17], which incorporates correlation due to nesting of respondents within HCs and provides standard errors that include this source of variation.

Variables considered for model adjustment were the provider-level variables of age and gender, as well as the center-level variable of location (rural vs. urban). These covariates were included in models if they modified the odds ratios (OR) of interest by more than 10%. Data analysis was performed with SAS v.9 (SAS Institute Inc., Cary, NC).

3. Results

3.1 Respondent and health center characteristics

Three hundred thirty-three out of 701 eligible respondents completed and returned surveys for an overall response rate of 47.5%. The response rates for the first, second, and third survey mailings were 24.0%, 16.1%, and 17.7%, respectively. Forty-seven (96%) of the 49 participating centers returned data. The majority of respondents were either physicians (43%) or nurse practitioners (20%). Fifty-eight percent of the respondents were female, 74% were white, and the mean $\pm$ SD age was 45 ± 11 years. The average number of years of being a practicing health care provider was 13 ± 11 years. Fifty-five percent of the respondents reported working in urban HCs. The average reported percent of non-English speaking patients the respondents treated was $25\% \pm 30\%$, with a median of 10% and a range from 0%–99%. Many providers reported their HC had professional interpreters (45%) and/or bilingual staff (63%) available for patients who spoke only Spanish. Twenty-two percent of respondents reported receiving formal training specific to patients with LHL.

3.2 Limited health literacy prevalence

Provider estimates of LHL prevalence among English-speaking and Spanish-speaking patients averaged $41\% \pm 24\%$ and $48\% \pm 30\%$, respectively. However, the provider estimated LHL prevalence range was quite wide across respondents for both English and Spanish speaking patients (0–100% for both), with the median provider-estimated prevalence being 40% and 50%, respectively. Among providers who responded to the questions regarding how health literacy affected their patients, the majority reported that LHL interfered at least a moderate amount with both their English and Spanish speaking patients' ability to understand basic health information (84% and 89%, respectively), obtain appropriate health services (79% and 85%, respectively), and follow through on recommended treatments (91% and 91%, respectively).

3.3 Health literacy assessment techniques

The most common method providers reported using to assess health literacy was asking patients if they understood instructions or had any questions, with 96% of providers reporting that they did this often or always (Table 1). Although very few providers surveyed assessed health literacy with a validated questionnaire, those with formal training in health literacy were more likely to report using this method at least sometimes (OR=2.63, 95% CI=1.13–6.09, $p=0.02$, unadjusted). Providers who received formal training in health literacy were also more likely to ask a patient for the last grade they completed in order to assess literacy level (OR=2.05, 95% CI=1.21–3.48, $p=0.008$, unadjusted).

3.4 Limited health literacy assistance techniques

Regardless of provider type, almost every respondent reported using at least one special method or technique to assist patients with LHL. The most often used techniques included: describing medical conditions, treatments, and instructions in layman's terms (95%), reviewing instructions carefully with the patient (95%), providing patients with health education materials (86%), encouraging patients to bring a friend or family member to their appointment (68%), and having patients repeat instructions to check their understanding (66%), a "Teach Back" method which has been shown to be effective [18,19]. The least used method was providing

patients with health education materials designed specifically for patients with LHL (35%). Only a small percentage of providers reported either not using or not being aware of any specific methods or techniques to assist patients with LHL (4% and 5%, respectively, Table 2), despite 78% of respondents reporting no formal training in LHL.

Table 2 presents the distribution of techniques used to assist patients with LHL across provider types. Methods for assisting patients with LHL for the most part were not significantly different over provider types. Encouraging patients to bring a friend or family member to appointments was the single exception ($p = 0.02$, adjusted for provider age and rural vs. urban location). Specifically, physicians ($OR=2.12$, 95% $CI = 1.37-3.29$, $p=0.001$) and physicians assistants ($OR=4.65$, 95% $CI = 1.80-12.0$, $p=0.002$) were more likely to report using this technique than other types of providers. Unadjusted results were similar.

Providers who received formal training in health literacy were more likely to have patients repeat instructions back to check understanding ($OR=2.05$, 95% $CI=1.03-4.10$, $p=0.04$, adjusted for provider age and gender). They were also more likely to provide patients with health education materials designed specifically for patients with LHL ($OR=2.80$, 95% $CI=1.62-4.85$, $p=0.0002$, unadjusted).

3.5 Formal Health Center Programs

Among all respondents, the most commonly reported HC-level programs were encouraging patients to bring a friend or family member to appointments (68%) and referring patients to a social worker or other clinic personnel (62%); these interventions were reported to be effective or very/extremely effective by 62% and 74% of those participating in them, respectively (Table 3). Meanwhile, although only 20 providers reported their HC had a dedicated LHL specialist, 42% of those who did reported the LHL specialist was effective, and 37% reported the LHL specialist was very or extremely effective (Table 3).

The program that most providers believed would be very or extremely helpful at their HC was providing health education materials designed especially for patients with LHL, although the majority of respondents believed any of the programs listed would be at least somewhat helpful (Table 4). The two most frequently cited barriers to implementing a formal health literacy program were providers not having enough time to screen patients for LHL (65%), and health literacy being considered a low priority as compared to other problems (62%) (Table 5).

4. Discussion and Conclusion

4.1 Discussion

Providers at HCs estimated the prevalence of LHL to be quite high among their patients, with the average percent reported for English and Spanish speaking patients being 41% and 48%, respectively. These estimates are similar to the results found on the 2003 National Assessment of Adult Literacy, where 36% of all adults were found to have basic or below basic health literacy, with the percent being higher among patients receiving Medicaid (60%), those with no insurance (53%), and among Black (58%) and Hispanic patients (66%), groups which make up a large percentage of many HCs' patient populations [1–2]. This indicates that HC personnel are generally aware of and have a fairly good idea of the prevalence of LHL within their patient population. These results also suggest that LHL provider training is helpful, in that providers who received formal LHL training were more likely to report having patients repeat instructions back to check understanding, a technique shown to be effective in previous studies. [18,19]. Moreover, a majority of providers (78%) felt provider training in techniques to assist patients with LHL would be beneficial at their HC.

LHL is also recognized as a concern at the organizational level, with many providers reporting their HC has instituted programs to address LHL, and a small proportion of providers (6%) indicating their HC actually had a dedicated LHL specialist. HC leadership and provider attitudes do not seem to be a barrier to implementing LHL programs, as very few providers reported lack of leadership support or the belief that LHL programs would not improve patient care or outcomes as barriers. Most providers believed lack of time and monetary resources and LHL being considered a low priority were barriers to addressing LHL in their HCs. Despite these barriers, many providers have personally implemented various techniques to assess and assist their patients with LHL, while others have participated in more formal health literacy programs or interventions implemented in their HCs. Many providers believed simple, low or no cost interventions would be the most helpful at their HC, such as providing health education materials designed especially for patients with LHL and encouraging patients to bring a friend or family member to appointments, while many also thought formal provider training in LHL would be helpful.

We are unaware of any studies that demonstrate the effectiveness of techniques that some providers report they are currently using, such as asking patients if they understand or have any questions and using their “gut feeling” as a clinician. Furthermore, while 59% of providers believed providing LHL health education materials would be a very helpful future intervention (Table 4), of the providers who had actually used LHL health education materials in a formal program at their center, 43 % found them to be only somewhat effective (Table 3). Several other studies have shown that simplified reading materials do not necessarily increase understanding [20–22]. A recent systematic review of interventions to improve health outcomes in patients with LHL found videotapes, computer programs, and group education sessions to be effective. However, methodological limitations of the current literature make definitive conclusions difficult [23].

Our study has several limitations. This sample was composed of HC providers in the Midwest, limiting generalizability. Nonetheless, HCs are vital providers of health care for vulnerable populations at risk for limited health literacy, and are thus an important group to study in their own right. In addition, compared to the general organizational membership of the MWCN, urban HCs are relatively underrepresented in our sample. However, our study has a relatively large sample of HCs, with 57% being in urban areas, which is a slightly higher distribution of urban HCs than that found in the United States overall (48%) [24]. Our sample also contained different provider types, including physicians (44%), mid-level providers (e.g., physician assistants, 11%, and nurse practitioners, 20%), and dental providers (15%), which includes dentists and dental hygienists, along with other providers (11%). Our percentages of physicians, mid-level providers, and dental providers were distributed roughly the same as that found in HCs across the United States, as determined by the National Association of Community Health Centers, with the distribution of Full-Time Equivalents across provider types nationally as follows: primary care physicians (52%), nurse practitioners and physician assistants (30%), and dental providers (18%) [24]. Moreover, providers across the HCs reported a broad range (0% to 99%) of non-English speaking patient populations.

Selection bias is possible given our response rate was 47.5%. However, this response rate is comparable to other mailed provider surveys [25,26]. Furthermore, the providers who returned the survey were likely those most sensitive to the issues surrounding health literacy, and therefore, our results may overestimate the actual use of screening and techniques to assist patients with LHL in HCs. We also do not know how much time each type of provider spends with patients. If nurse practitioners have more time than physicians to counsel patients, this might explain why they are less likely to encourage patients to bring a friend or family member to their appointments.

4.2 Conclusion

This study is the first to our knowledge that examines HC providers' perceptions of LHL's effect on their patients, and to gather their opinions and experiences regarding methods they use or would like to use to help their patients overcome LHL. We also identified several barriers providers foresaw that could be addressed if their center tried to implement a health literacy program. This study serves as a first step in determining future health literacy interventions in HCs, which will ultimately lead to better care and improved health outcomes for medically vulnerable patients.

4.3 Practice Implications

The Council on Scientific Affairs for the American Medical Association has called for increased professional and public awareness of health literacy issues and improved patient-physician communication skills [27]. Seventy-eight percent of the providers in our sample of HCs reported receiving no formal training in health literacy. Future research studies need to focus on efficient methods to screen and identify patients with LHL, effective health education techniques for LHL patients, outcomes and costs associated with poor health literacy, and the causal pathway linking poor health literacy to health outcomes [27]. Furthermore, research should examine the effectiveness of LHL assessment and treatment techniques providers are already using, and address the barriers they have identified, such as limited time and monetary resources. The three programs deemed to be most effective by providers at HCs where they were being implemented were referring patients to social workers or other clinic personnel, intensive health education sessions, and having a LHL specialist in their center. This suggests that devoting more personnel time to helping patients with LHL, or even better, having personnel specifically dedicated to working with patients with LHL is effective. Case studies of HCs that are implementing multiple HC-wide LHL interventions may prove informative and aid in developing effective practice approaches to LHL other HCs can follow. Innovative community and health system-based programs which have been shown to be effective, such as culturally appropriate education programs taught by lay health educators or indigenous community leaders should also be considered for implementation in HCs [28,29].

On a national level, many HCs have been participating in the Health Disparities Collaboratives (HDC), which are overseen by the Health Resources and Services Administration's Bureau of Primary Health Care. This major quality improvement initiative is designed to reduce health disparities and improve the quality of care in health centers [30]. Since LHL has been shown to affect patient understanding and health outcomes, health literacy training and interventions should be incorporated more intensively into the HDC, either within existing disease focused HDC programs or else as a separate collaborative. Finally, best practice guidelines need to be developed and disseminated for the assessment and treatment of LHL.

Statement

I confirm all patient/personal identifiers have been removed or disguised so the patient/person (s) described are not identifiable and cannot be identified through the details of the story.

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Table 1

Techniques providers reported using to assess health literacy (%) * †

Technique	N	Never	Rarely	Sometimes	Often	Always
Ask a patient if they understand instructions or have any questions.	323	-	0.6	3	38	58
Use your "gut feeling" as a clinician to assess health literacy.	327	2	9	27	45	18
Have patient repeat instructions back to you.	327	6	14	42	35	3
Ask a patient for the last grade completed.	327	24	27	24	16	9
Formally assess health literacy with a validated questionnaire.	325	70	20	6	2	2

* Percentages in table may not add up to 100% due to rounding.

† Response to survey item: "Please indicate how often you do each of the following to assess health literacy when you are personally caring for patients."

Table 2

Techniques used to assist patient with limited health literacy by provider type (%)[†]

Technique	Overall (N=330) [§]	Physicians (N=144)	Physician Assistants (N=35)	Nurse Practitioners (N=67)	Dentists and Dental Hygienists (N=48)	Other (N=36)
Review instructions carefully with patient	95 ⁺	98	97	96	96	81
Have patient repeat instructions back to you to check understanding	66	67	86	70	46	64
Describe medical conditions, treatments, and instructions in layman's terms	95	97	97	94	100	83
Provide patient with health education materials	86	85	86	88	94	72
Provide patient with health education materials designed specifically for patients with limited health literacy	35	36	31	45	31	22
Refer patient to other services available	54	54	60	58	35	64
Encourage patients to bring a friend or family member to appointments	68 [*]	74	83	55	65	61
Do not use any special methods or techniques	4	3	6	6	6	3
Am not aware of any specific methods or techniques	5	7	0	3	4	11

[†]Response to survey item: "Please select the special methods or techniques you use to assist your patients who have low health literacy."

[§]Significance level from GEE logistic regression, adjusted for provider age, gender and/or urban vs. rural site:

* p < 0.05,

+ p < 0.10.

Table 3

Perceived effectiveness of existing formal health literacy programs in community health centers (N = 333) * †

Program or Intervention	Instituted Program N (%)	Not at all effective (% of those who instituted program)	Somewhat effective (% of those who instituted program)	Effective (% of those who instituted program)	Very/Extremely Effective (% of those who instituted program)
Bring friend or family member	225 (68)	0.5	37	42	20
Refer patients to social worker or other clinic personnel	207 (62)	0.5	25	49	25
Provided limited health literacy health education materials	163 (49)	0	43	43	15
Intensive, individualized health education session(s)	103 (31)	0	25	48	27
Refer to adult education center for help with language or reading	60 (18)	2	40	50	8
Formal training in techniques to better assist patients with limited health literacy	54 (16)	4	45	43	9
Dedicated limited health literacy specialist to the center [‡]	20 (6)	0	21	42	37

* Percentages in columns 3–6 may not add up to 100% due to rounding.

† Refers to survey item: “Please indicate in the table below which type of low health literacy program(s) or intervention(s) your health center has instituted (if any), and how effective you believe the intervention has been.”

[‡] The definition of a “limited health literacy specialist” was left to the interpretation of the respondent due to the various types of personnel that might fill this role, such as a nurse, social worker, or patient educator.

Table 4

Providers' beliefs about helpfulness of possible health literacy programs[†]

Program or Intervention	N	Not at All Helpful (%)	Somewhat Helpful (%)	Helpful (%)	Very or Extremely Helpful (%)
Formal provider training in health literacy	324	2	21	40	38
Providing limited health literacy health education materials	327	2	10	29	59
Intensive, individualized health education session(s)	321	7	19	33	41
Encouraging patients to bring a friend or family member to appointments	325	3	23	30	44
Patient reminder cards for key processes of care	320	11	21	34	34
Referring patients to social worker or other clinic personnel	323	5	21	39	36
Referring patients to adult education center for help with language or reading	323	6	30	35	29
Formal limited health literacy screening, and providing appropriate services based on that screening	321	7	22	34	37

[†]Response to survey item: "Please indicate in the table below how helpful you believe each of these low health literacy programs or interventions would be at your health center."

Table 5Perceived barriers to implementing formal health literacy programs [†]

Barrier	Percentage of Respondents
Lack of time to screen patients	65
Health literacy is lower priority	62
Lack of money	58
Lack time to implement a health literacy program	57
Lack of knowledge about limited health literacy	53
Good limited health literacy programs are not readily available	46
Belief that program would not improve outcomes or quality of patient care	21
Belief that health literacy is not a major problem at health center	16
Too difficult to implement a culturally competent health literacy program	14
Patients use many different languages	12
Senior leadership not supportive	7

[†] Response to survey item: “What barriers to implementing formal health literacy programs at your health center do you foresee occurring? (fill in all that apply)”