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Primary Care Experiences of Emergency Department Patients With Limited Health Literacy

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Abstract

It is unclear why patients with limited health literacy have fewer visits with a personal doctor and more emergency department (ED) visits than patients with adequate health literacy. We identified significant differences in perceived access to a personal doctor and high-quality provider interactions among adults with limited compared to adequate health literacy presenting for emergency treatment. Practice and provider strategies to ensure that patients have timely access to care and high-quality provider interactions may address some of the reasons patients with limited health literacy use more emergency department–based and less preventive care than those with adequate health literacy.

Keywords

access to health care; ambulatory care; health literacy; patient-provider relationship

Emergency department (ed) visits have increased dramatically over the past 2 decades, often for conditions that could be treated more effectively in a lower-cost, primary care setting (Pitts et al., 2010; Tang et al., 2010). The overall cost of emergency visits, the adverse effects of ED crowding on quality of ED care, and predictions that the Patient Protection and Affordable Care Act could have the unintended consequence of increasing ED use have heightened interest in strategies to reduce ED visits (Agency for Healthcare Research and Quality, 2012; Johnson et al., 2012; Pitts et al., 2010; Taubman et al., 2014).

Health literacy represents an individual's capacity to obtain, communicate, process, and understand healthcare information and services necessary to make appropriate health

decisions (Berkman et al., 2011; Nielson-Bohlman et al., 2004). Patients with limited health literacy have more frequent and costly ED visits and use less preventive care services than patients with adequate health literacy (Baker et al., 1997, 2004; Berkman et al., 2011; Howard et al., 2005; Kellermann & Weinick, 2012; Nielson-Bohlman et al., 2004; Schumacher et al., 2013). Although the reasons are unclear, patients with limited health literacy are at risk of seeking emergency care even if they have access to a medical home or a usual source of care (Hunt et al., 2006; Weber et al., 2005). Suggested explanations include difficulty accessing their provider, poor-quality interactions with their physician, or difficulty handling an acute health problem (Baker et al., 2004; Institute of Medicine, 1993; Kangovi et al., 2013; Schumacher et al., 2013). A better understanding of the reasons patients with limited health literacy who have a personal doctor seek emergency treatment is needed to identify strategies to increase the use of preventive rather than ED-based care.

The objective of this study was to determine to what extent health literacy is associated with differences in perceived access to care with a personal doctor and quality of patient-provider interactions among adults seeking emergency care. The study was conducted at 3 diverse US academic medical centers experienced in health literacy assessment of their respective ED populations.

METHODS

Study design and setting

An observational, cross-sectional study design was conducted that included a structured interview and health literacy assessment of adults presenting to 1 of 3 diverse EDs located in Detroit, Michigan, Jacksonville, Florida, and Gainesville, Florida, between October 2011 and January 2012.

Selection of participants

Study participants were identified and approached in the ED waiting room by a trained research assistant who administered a structured interview by reading survey questions and response options aloud. Patients were eligible for study participation if they were English-speaking and were able to provide informed consent. Across all 3 sites, the study participation rate was 72%. Exclusion criteria included those with severely impaired vision; hearing problems; being in police custody or who required emergent treatment or intervention (eg, hemodynamic instability, respiratory compromise, nurse-assessed high-risk situation, altered mental status, severe pain, or distress). Sampling was designed to represent each site's general ED population, and included surveys during all days of the week, at all times of day. Time, day, and mode of arrival of the general ED populations for each of the 3 sites in the month preceding study initiation were mirrored in the sampled population at each site. To ensure random sampling, a systematic approach was followed whereby an initial patient was selected at random and every sixth patient was approached thereafter. Research assistants reviewed consent documents with patients and reasons for refusal were documented. Of the 330 patients who participated in the study, 62% reported having a usual provider ($n = 204$). Consistent with the validated survey used, only patients reporting a usual provider were asked follow-up questions about their experiences with that provider.

Participation was voluntary and data collection was approved by the institutional review boards associated with each site.

Measures

Measures were obtained from structured interview, health literacy assessment, and electronic medical record review.

Health literacy—Health literacy was assessed with the Rapid Estimate of Adult literacy in Medicine, which is highly correlated with standardized reading tests and the Test of Functional Health Literacy in Adults (Davis et al., 2005; Parker et al., 1995). The Rapid Estimate of Adult literacy in Medicine is a reading recognition test comprising 66 medically related words arranged in ascending order of difficulty (Davis et al., 1993; Schwartzberg et al., 2005). Patients are asked to read aloud to check for correct pronunciation and scores are categorized into literacy levels equivalent to grades 0 through 12 (Parker et al., 1995). Limited health literacy is defined as a score less than 61 (eighth-grade or lower reading level) and adequate health literacy defined as a score of 61 or greater (ninth-grade or above reading level) (Osborn et al., 2007).

Patient-level control variables—Confounding factors were identified using the Andersen Behavioral Model of Health Services Use (Andersen, 1995). Andersen's model suggests that health services access and use are dependent on *predisposing factors* or the propensity to use health care; *enabling factors* that facilitate or impede use; and *need factors* indicating perceived or indicated need for care (Andersen, 1995). In this study, *predisposing factors* included age in years, gender, and race (white/other). Non-white racial subgroups were combined as "other" because the sample size for each minority subgroup did not support reliable model estimation. *Enabling factors* included employment (yes/no), marital status (married or single/never married, separated/divorced, or widowed), and health insurance status (uninsured/insured). *Need factors* included patient self-rated health status (excellent/very good or good/fair/poor) (Keating et al., 2002) and the number of self-reported chronic conditions from the structured interview (Keating et al., 2002). To control for illness severity, nurse-recorded ED triage severity score on the day of interview was included. Triage severity at the time of patient presentation to the ED was assessed using the Emergency Severity Index (ESI) scores, which were categorized as high acuity (ESI = 1–2) and less urgent (ESI = 3–5) (McCarthy et al., 2009). Control variables were self-reported from the in-person survey except triage severity score and health insurance status, which were obtained from review of the electronic medical record.

Outcome variables—Self-reported assessments of access to care with a personal doctor and quality of patient-provider interactions in the 6 months prior to the ED visit were assessed using 9 items from the Ambulatory Care and Experiences Survey (ACES) (Safran et al., 2006). The ACES assesses patient experiences with care for patients with a usual provider in 2 areas: patient-provider interactions (communication, integration of care, knowledge of the patient, health promotion) and organizational/structural features of care (organizational access, visit-based continuity, integration, clinical team, and office staff). All ACES summary measures exceed established criteria for Likert scales and demonstrate high

internal consistency and reliability (the Cronbach alpha > 0.70). The ACES has been used in numerous studies to assess relationships between primary care and outcomes of care (Rodriguez et al., 2007, 2008; Safran et al., 2006). Patients responding “usually, almost always, or always” to survey measures were considered to have adequate primary care experiences. Responses of “never and almost never” were categorized as suboptimal primary care experiences (Keating et al., 2002). A response of “sometimes” was also considered a suboptimal experience because it reflects inconsistency of care (Keating et al., 2002).

Statistical analysis

Between-health literacy group differences in predisposing, enabling, and need factors were assessed using a chi-square test. Multivariable logistic regression models were used to examine the influence of health literacy on access to care with a personal doctor and quality of patient-provider interactions, controlling for patient-level predisposing, enabling, and need variables. Logistic regression models were first run with health literacy alone (unadjusted) and then in fully adjusted multivariable models that included predisposing, enabling, and need factors. Results are presented as unadjusted and adjusted odds ratios (ORs) with accompanying 95% confidence intervals (CIs). All analyses were conducted using Stata v10 and model estimation accounted for patient clustering by ED site.

RESULTS

The average participant age was 45.5 (range = 18–82) years (Table 1). Thirty-eight percent of participants were male and 36% white. The majority (88%) of the nonwhite group were African American. Forty-four percent of participants had limited health literacy. Patients with limited health literacy were older and significantly more likely to be nonwhite and unemployed and have public insurance. There were no statistically significant health literacy group differences by gender, marital status, triage severity score (ESI), the number of chronic conditions, or self-reported health status on the day of the interview ($P > .05$). Nearly one-third of patients (29%) reported never, almost never, or sometimes receiving an answer to a medical question the same day when calling their personal doctor’s office (Table 2). Furthermore, almost 40% of respondents reported not receiving the help or advice needed when calling their personal doctor’s office after regular office hours.

ED patient health literacy and access to a personal doctor

In the unadjusted analysis, patients with limited health literacy were significantly less likely than those with adequate health literacy to report getting a same-day answer to a medical question when calling their doctor’s office (OR = 0.50; 95% CI = 0.26–0.95) (Table 3). This finding remained consistent in the fully adjusted analysis that included predisposing, enabling, and need factors (OR = 0.44; 95% CI = 0.22–0.87). Although patients with limited health literacy were also less likely than those with adequate literacy in the unadjusted analysis to report their personal doctor’s office provided care for their illness or injury as soon as needed (OR = 0.59; 95% CI = 0.41–0.84) or got the help or advice they needed when calling after hours (OR = 0.54; 95% CI = 0.39–0.76), these findings were no longer statistically significant after adjustment ($P > .05$).

ED patient health literacy and quality of patient-provider interactions

In the unadjusted analysis, patients with limited health literacy were significantly less likely than those with adequate literacy to report their personal doctor listens carefully (OR = 0.42; 95% CI = 0.25–0.70), a finding that remained significant in the fully adjusted analysis (OR = 0.36; 95% CI = 0.17–0.74) (Table 3). In fully adjusted models, patients with limited health literacy were significantly less likely than those with adequate literacy to report their personal doctor gives clear instructions about what to do to take care of health problems or symptoms (OR = 0.49; 95% CI = 0.31–0.79), or spends enough time with them (OR = 0.42; 95% CI = 0.26–0.69). Patients with limited health literacy were also significantly less likely to report feeling able to tell their personal doctor anything, even things not told to anyone else (OR = 0.61; 95% CI = 0.38–0.99).

DISCUSSION

Our study demonstrates important differences in perceived access to care and high-quality interactions with a personal doctor among adults presenting to the ED with limited compared to adequate health literacy. To our knowledge, this is the first report outlining literacy-based differences in primary care experiences of adults with a personal doctor who present for emergency treatment. Patients with limited health literacy were more likely to experience barriers to getting a same-day response to a medical question, were less likely to feel their personal doctor listens carefully, gives clear instructions, and spends enough time with them or to feel they can tell their personal doctor anything. These findings remained consistent after adjustment for a comprehensive set of factors and accounting for clustering by ED site. The underlying reasons patients with limited health literacy perceive barriers to care and to high-quality interactions with their doctor are not entirely clear. Recent evidence does suggest that patients with limited health literacy are less likely to experience participatory decision making during primary care visits and have less understanding of the health care process than those with adequate literacy despite similar patient and physician communication behaviors (Aboumatar et al., 2013). Other reports indicate that primary care physicians rarely assess patient recall and comprehension of new concepts such as medication changes, a step that can significantly improve clinical outcomes (Schillinger et al., 2003). It is important to identify the perceived barriers to care with a personal doctor experienced by patients with limited health literacy seeking emergency treatment since poorer-quality primary care experiences may partially explain why these individuals have higher ED use and fewer preventive care visits than those with higher health literacy (Baker et al., 2004; Berkman et al., 2011; Nielson-Bohlman et al., 2004; Schumacher et al., 2013).

It is likely that factors other than literacy-based differences in primary care experiences contribute to more frequent ED use and less preventive care in individuals with low health literacy. Delays in care seeking for acute health problems or poorer self-management of chronic health problems are plausible reasons patients with limited health literacy may use the ED more than those with adequate health literacy (Baker et al., 2004). In addition, socioeconomic factors, including lack of health insurance, have been implicated as root causes of barriers to health care with a personal doctor and thus frequent ED use. In our study, we found no significant literacy-based differences in perceived health status, the

number of chronic medical conditions, or nurse-assessed triage severity at the time of the ED visit. Furthermore, the persistence of our findings in the fully adjusted models that include health insurance and employment status suggests that limited health literacy is an independent barrier to access to care and high-quality patient-provider interactions.

This study was conducted among ED participants who reported having a personal doctor or a usual source of care. Our findings are consistent with prior research that suggests a usual source of care or medical home is not necessarily associated with lower rates of ED use (Hunt et al., 2006; Weber et al., 2005). Indeed, prior work indicates that the benefits of having a personal doctor or usual source of care are diminished if barriers to timely answers to health questions or barriers to quality interactions with the provider exist (Schillinger et al., 2003, 2004). These results highlight the importance of identifying modifiable practice characteristics that could improve the primary care experience of patients with limited health literacy. However, limited health literacy may be difficult to detect and experts recommend assuming all patients may have difficulty understanding health information. To address these challenges, the Agency for Healthcare Research and Quality has established a health literacy universal precautions toolkit to help providers and practices ensure that patients succeed in the healthcare environment ("Health Literacy Universal Precautions Toolkit," April 2010). The toolkit includes strategies for clearly communicating with patients to ensure patient understanding of health information and includes methods to improve telephone communication with patients. Dissemination of these strategies is critical given recent work that indicates physicians rarely implement such strategies in their practice (Schwartzberg et al., 2007).

By identifying significant literacy-based differences in specific primary care experiences, our study adds to previous work, which suggests that difficulty attaining a timely primary care appointment and communicating with office-based staff are linked to patients' unmet health needs and nonurgent ED use (Berry et al., 2008; O'Malley, 2013; Sarver et al., 2002). Research is needed to determine if enhanced access to care with a personal doctor and quality of patient-provider interactions and communication increase preventive care and reduce ED-based care in patients with limited health literacy (Greene, 2009; Keene et al., 2011; Kemper & Mettler, 2002). Despite increasing access to primary care, Medicaid expansion has recently been shown to broadly increase ED visits in newly insured individuals (Taubman et al., 2014). The fact that the newly insured under Medicaid through the Affordable Care Act may be at high risk for both limited health literacy and frequent ED visits underscores the importance of our findings (Taubman et al., 2014).

This study has several limitations. First, this study was conducted only in adults presenting to the ED and did not control for education, income, place of residence, or source of primary care. We did not control for education since health literacy and education appear to operate in the same causal pathway for health outcomes (Wolf et al., 2005). Thus, including education in fully adjusted models may underestimate the association between literacy and outcomes. Second, given the limited sample, we may not have been able to detect small differences between health literacy groups in some access to care and quality of interaction measures. Despite the limited sample size, significant differences were detected and a consistent pattern of findings emerged. Third, although the study was conducted by design in

3 socioeconomically diverse geographic locations in the Midwest and Southeast, with findings that remained consistent after accounting for site in all models, future work should be expanded to include rural and community practice sites to increase generalizability. Also, we are unable to comment on whether patients with limited health literacy attempted to seek care with their personal physician or felt less able to handle their acute health problem than those with adequate literacy (Baker et al., 2004). However, our previous work suggests that patients with adequate and limited health literacy are equally likely to consider their condition an emergency on the day of an ED visit (Schumacher et al., 2013). Finally, the association between health literacy and access to a personal doctor and patient-provider interaction is based on patient self-report and thus subject to recall bias though findings persisted after controlling for a comprehensive set of patient factors.

In summary, the results of this study demonstrate that limited health literacy in the ED population is independently associated with perceived barriers to accessing care with a personal doctor and quality of patient-provider interactions. Further study is needed to determine whether the underlying reasons patients with limited health literacy perceive these barriers are due to differential treatment, sources of primary care, or other factors. Practice and physician strategies to assist patients in gaining timely access to usable health information and ensure the quality of patient-provider interactions may address some of the underlying reasons patients with limited health literacy use more ED-based and less preventive care than those with adequate health literacy.

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Table 1Characteristics of Emergency Department Participants Reporting a Personal Doctor (N = 204)^a

Patient Characteristics	Overall (N = 204)	Adequate Health Literacy (n = 115)	Limited Health Literacy (n = 89)
Predisposing			
Mean age (SD), y	45.5 (17.5)	43.0 (16.2)	48.8 (18.8)
Gender			
Male	38	38	39
Female	62	62	61
Race			
Non-Hispanic white	36	46	24
Other	64	54	76
Need			
Mean number of chronic conditions ^b (SD)	2.5 (1.7)	2.3 (1.7)	2.7 (1.8)
Emergency Severity Index ^c			
High acuity	27	23	33
Less urgent	73	77	67
Self-reported health status			
Excellent or very good	30	30	29
Good, fair, or poor	70	70	71
Enabling			
Married			
No	72	70	74
Yes	28	30	26
Insurance status			
Public	54	42	69
Private	27	33	19
None	19	24	11
Employment status			
Yes	36	44	26
No	64	56	74

^aValues in bold indicate significant differences between a given characteristic and health literacy level ($P < .05$). Percentages may not add to 100% due to rounding.

^bThe following 12 chronic conditions were self-reported: heart attack, cancer, angina, diabetes, congestive heart failure, arthritis, stroke, depression, high blood pressure, atrial fibrillation, chronic obstructive pulmonary disease, and any other.

^cCategorized as high acuity (ESI = 1, 2) or less urgent (ESI = 3, 4, 5).

Table 2

Ambulatory Care Experiences of Emergency Department Patients Who Report Having a Personal Doctor (N = 204)

Total Study Population (N = 204), % (n)	
Access to personal doctor	
Personal doctor's office provided care for illness or injury as soon as needed	
Never, almost never, sometimes	23 (41)
Usually, almost always, always	77 (138)
Received a routine appointment or check-up as soon as needed	
Never, almost never, sometimes	18 (32)
Usually, almost always, always	82 (141)
When calling, got answer to medical question on the same day	
Never, almost never, sometimes	29 (44)
Usually, almost always, always	71 (106)
When calling after hours, got the help or advice needed	
Never, almost never, sometimes	37 (22)
Usually, almost always, always	63 (37)
Quality of patient-provider interactions	
Personal doctor listens carefully	
Never, almost never, sometimes	14 (24)
Usually, almost always, always	86 (153)
Personal doctor gives clear instructions about what to do to take care of health problem or symptoms	
Never, almost never, sometimes	11 (20)
Usually, almost always, always	89 (156)
Personal doctor seems to know all important information about medical history	
Never, almost never, sometimes	15 (26)
Usually, almost always, always	85 (151)
Personal doctor spends enough time with you	
Never, almost never, sometimes	23 (41)
Usually, almost always, always	77 (135)
Feel you can tell your personal doctor anything even things not told to anyone else	
Never, almost never, sometimes	22 (39)
Usually, almost always, always	78 (138)

Table 3

Association Between Patient Health Literacy and Access to a Personal Doctor and Quality of Patient-Provider Interactions (N = 204)^a

	Limited Compared to Adequate Health Literacy ^b		
	Unadjusted	Adjusted for Predisposing, Need, and Enabling Factors	P
	Odds Ratio (95% CI)	Odds Ratio (95% CI)	
Access to personal doctor			
Personal doctor's office provided care for illness or injury as soon as needed	0.59 (0.41–0.84)	0.72 (0.47–1.12)	.15
Received a routine appointment or check-up as soon as needed	0.74 (0.48–1.15)	0.83 (0.28–2.47)	.74
When calling, got answer to medical question on the same day	0.50 (0.26–0.95)	0.44 (0.22–0.87)	.02
When calling after hours, got the help or advice needed	0.54 (0.39–0.76)	0.42 (0.12–1.42)	.16
Quality of patient-provider interactions			
Personal doctor listens carefully	0.42 (0.25–0.70)	0.36 (0.17–0.74)	<.01
Personal doctor gives clear instructions about what to do to take care of health problem or symptoms.	0.60 (0.31–1.17)	0.49 (0.31–0.79)	<.01
Personal doctor seems to know all important information about medical history	1.06 (0.74–1.51)	0.75 (0.41–1.36)	.34
Personal doctor spends enough time with you	0.46 (0.26–0.80)	0.42 (0.26–0.69)	<.01
Feel you can tell your personal doctor anything even things not told to anyone else	0.59 (0.24–1.44)	0.61 (0.38–0.99)	<.05

^aValues in bold indicate significance between adequate and limited health literacy, $P < .05$.

^bAnalyses adjusted for the following factors: Predisposing: age, gender, race; Need: self-reported health status, chronic conditions, triage severity; Enabling: insurance status, marriage status and employment status.