Health Literacy as a Predictor of Follow-Up After an Abnormal Pap Smear
A Prospective Study

Stacy Tessler Lindau, MD, MAPP,1 Anirban Basu, PhD,2 Sara A. Leitsch, PhD3

1Departments of Obstetrics and Gynecology and Medicine, Pritzker School of Medicine, The University of Chicago, Chicago, IL, USA; 2Section of General Internal Medicine, Department of Medicine, The University of Chicago, Chicago, IL, USA; 3Department of Obstetrics and Gynecology, The University of Chicago, Chicago, IL, USA.

BACKGROUND: Low literacy influences cervical cancer screening knowledge, and is a possible contributor to racial disparities in cervical cancer.

OBJECTIVE: To examine the hypothesis that literacy predicts patient adherence to follow-up recommendations after an abnormal Pap smear.

DESIGN: A prospective, continuity clinic-based study.

PARTICIPANTS: From a sample of 538 women undergoing literacy testing at the time of Pap smear screening, we studied 68 women with abnormal Pap smear diagnoses.

MEASUREMENTS: Literacy was assessed using the Rapid Evaluation of Adult Literacy in Medicine (REALM). We also measured other proxies for literacy, including educational attainment and physician estimates of patients’ literacy level. Outcome measures included on-time and 1-year follow-up and duration of time to follow-up after an abnormal Pap smear.

RESULTS: Only one-third of the cohort adhered to follow-up recommendations. At 1 year, 25% of the women had not returned at all. Patients with inadequate literacy (as assessed by the REALM) were less likely to follow up within 1 year, although this result was not statistically significant (adjusted odds ratio [OR] = 3.8, 95% confidence interval [CI]: 0.8 to 17.4). Patients subjectively assessed by their physician to have low literacy were significantly more likely to fail to present for follow-up.

CONCLUSIONS: Among women with an abnormal Pap smear, those perceived by their physician to have low literacy were significantly more likely to fail to present for follow-up.

KEY WORDS: literacy; Pap smear; cervical cancer; adherence; stereotype; disparities.

METHODS

Sample

Between January and December 1999, all women who presented to the ambulatory primary care and HIV ob/gyn continuity of care clinics at a Chicago academic medical center were eligible for enrollment. Self-identified English-speaking patients were privately approached during registration at the clinic by 1 of 6 trained, nonphysician, female interviewers. In this large convenience sample, enrollment was sequential, according to patient presentation. Women younger than 18 years old were excluded. Of the 601 patients approached at the clinics, 538 agreed to participate, 30 refused, 17 were ineligible because of age, and 16 had missing data. Hence, the participation rate of those eligible was 90%. A detailed description of

ADDRESS CORRESPONDENCE AND REQUESTS FOR REPRINTS TO DR. LINDAU:
University of Chicago, 5841 S. Maryland, MC2007, Chicago, IL 60637
(e-mail: slindau@uchicago.edu).
the sample can be found in Lindau et al. Nine additional women are included here in the total participation rate as compared with the sample reported in 2002, due to resolution of missing data. The study consent form was affixed to the medical chart to prevent repeat enrollment. While comparable data about clinic attendees not approached for the study are unavailable, interviewer schedules rotated to maximize coverage at each clinic site and on each clinic day. The investigation protocol and consent procedures were approved by the Northwestern University Institutional Review Board.

**Patient Interview and Objective Health Literacy Assessment**

All interviews were conducted before the physician encounter. Women participated in a 10-minute interview ascertaining demographics, cervical cancer screening and health practice history, knowledge related to cervical cancer screening and prevention, and perception of previous patient-physician interaction about cervical cancer screening. The Rapid Estimate of Adult Literacy in Medicine (REALM) was used to determine an objective health literacy score. Recommended for use by the National Work Group on Literacy and Health, the REALM is a reading recognition test composed of 66 health-related words. Rapid Estimate of Adult Literacy in Medicine scores are typically used to estimate literacy level as follows: 0 to 18, ≤3rd grade; 19 to 44, 4th to 6th grade; 45 to 60, 7th to 8th grade; and 61 to 66, ≥9th grade.

The study did not dictate physician recommendations for follow-up, which vary by patient health status, age, and medical history. Common practice for these clinics was to recommend follow-up as soon as possible for cancer, carcinoma in situ (CIS), high-grade squamous intraepithelial lesions (HGSIL), and atypical glandular cells (AGUS). For most patients with low-grade squamous dysplasia, follow-up was recommended within 3 months. For those with atypical squamous cells of undetermined significance (ASCUS) or insufficient sample, follow-up recommendations typically allowed for return within 6 months (this study was conducted before widespread use of human papillomavirus testing, which is now used to triage follow-up for ASCUS). Patients with HIV or a history of abnormal Pap smear would have likely been instructed to return sooner than those without these diagnoses. The results were typically communicated to patient first via phone call and then via a variety of methods including repeat phone call, letter, and reminders at subsequent clinic visits scheduled for other reasons.

**Chart Abstraction**

Chart abstraction was used to clarify demographic and medical information obtained in the interview, and to determine Pap test results, physician recommendations for follow-up, method of patient contact, and follow-up adherence over 1 year following the index Pap test. A follow-up visit was defined as one where either a Pap smear was repeated, colposcopy was performed, or a procedure to treat a cervical lesion occurred. Research staff conducting chart abstraction were unaware of the participants’ literacy score.

**Analysis**

SPSS version 11.0 (SPSS, Chicago, IL) and STATA version 8.0 (Stata Corp., College Station, TX) were used for data analysis. The sociodemographic characteristics of patients who required follow-up visits were compared by literacy levels (REALM-based), using Fisher's exact tests.

Three sets of analyses were performed to determine the relationship between literacy and follow-up adherence. Within each set of analyses, separate models were run for each of the following predictor variables: (1) objective literacy level as measured by the REALM, (2) physician's subjective assessment of literacy level, (3) educational level (i.e., high school graduation status), and (4) physician's prediction of on-time follow-up. All models controlled for age, race, diagnosis of cancer or HIV, employment status, and private insurance status. Insurance status was not used as a covariate in models with physician assessment of literacy level due to substantial correlation between them.

In the first set of analyses, logistic regression was used to determine predictors of on-time patient follow-up, dichotomized as "on-time" (follow-up visit on or before the recommended date derived from the physician's recommendation in the medical record) and "not on-time."

Second, logistic regression was used to determine predictors of patient follow-up, dichotomized as ever (within 365 days of the index Pap) and never. The 365-day cutoff was used because standard practice in the clinical setting at that time was to recommend screening at a maximum of 1-year intervals. The 365-day cutoff, then, is analytically necessary, as a clinic visit occurring after 365 days may indicate either a follow-up or an annual screening visit.

The third set of analyses examined predictors of the duration of time to follow-up, using Cox proportional hazards regression. Time to follow-up was defined as the time between the abnormal Pap smear diagnosis and the actual follow-up date. A visit was defined as a follow-up visit if it occurred...