Poster Presentations – Monday October 19th, 2009

1. Lydia P. Buki

Cultural and conceptual knowledge: Conceptual and measurement advances in health literacy

In 2004, a groundbreaking report by the Institute of Medicine identified 4 components of health literacy: print literacy, oral literacy, numeracy, and cultural and conceptual knowledge. Since that time, conceptual advances have been made on several of these components. Our interest in this analysis is to advance conceptual clarity and measurement of cultural and conceptual knowledge, with the goal of effectively exploring the relationships between cultural processes and health literacy. In the IOM report, cultural and conceptual knowledge is defined as: "Cultural and conceptual knowledge represents the filter through which individuals obtain, process and understand health information and options for diagnosis and treatment (IOM, 2004)." Parting from this definition, we delved into the cultural literature to develop a clear conceptualization and operationalization of the construct. Based on our conceptual work, which was required for the development of the Cancer Literacy Measure (Buki & Yee, 2008), we propose that cultural and conceptual knowledge encompasses attitudes, beliefs, and knowledge, all of which arise in the context of cultural values. We provide examples from our own work and those of others suggesting effective ways to conceptualize, operationalize and measure these constructs.

To define attitudes, we draw from Fishbein and Ajzen's definition of attitude, wherein attitude is defined as "learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (Fishbein & Ajzen, 1975, p. 6). In their definition, the authors state that attitudes are *learned predispositions*, suggesting that attitudes are formed through experience and that they are relatively stable internal states that guide external expressions. Beliefs are the various attributes that an individual links to an object wherein an object can be any person, group of people, institution, organization, behavior, policy, and so on and attributes can be any object, trait, property, quality, characteristic, outcome or event (Eagly & Chaiken, 1993; Fishbein & Ajzen, 1975). We draw from what Hilpinen (1970) calls the "classic definition of knowledge" which suggests that knowledge is *justified true belief*. Central to this definition is the understanding that some beliefs are justified because they *verifiably true* (Klein, 1971). What differentiates knowledge from beliefs or attitudes, then, is that knowledge can be tested and validated. Beliefs are formed and influenced by various socializing forces like family, religious institutions, schools, and the mass media.

We noted that a lack of consistency in the way attitudes, beliefs, and knowledge are conceptualized and operationalized in the extant literature is hampering cultural advances in the study of health literacy. We hope that through providing greater clarity on these concepts, we will be more effective in our examinations of cultural processes and health outcomes.

2. Gillian Rowlands

Developing an empirically based conceptual model of how the determinants of health, including low Health Literacy, interact to influence health and well-being

Background

Health Literacy (HL) is a complex concept including both skills to understand health information and skills to act on health information to achieve and maintain health in a variety of health and

community settings. Experts in the fields of Health Literacy have developed conceptual models of HL and how it impacts on health outcomes; to date these are theoretical rather than based on empirical data. Our study aims to develop a conceptual framework, arising from empirical qualitative data, of how basic skills and social determinants (social inclusion, self-esteem, self efficacy and social networks) combine to influence health and well-being.

Methods

Participants over 18 were recruited from the Skilled for Health programme, a UK community-based project aiming to develop literacy, language, numeracy and life skills as applied to health. Semi structured interviews were conducted with 20 people across four sites in the UK. These interviews elicited participants' perceptions of how basic skills and social determinants have influenced their health and well-being. Participants then attended focus groups where the factors arising from the interviews were explored further, with a specific focus on how factors combine to influence health and well being. Analysis of the focus groups was in two stages. Firstly we undertook an inductive approach to develop a model of how basic skills and social determinants combined to influence health and well-being amongst this group of people. We then undertook a deductive approach to compare our model with current theoretical models of HL.

Results

We have developed a conceptual model from the data to show how basic skills and social determinants combine to influence health in a group of people that had self-identified as having low health literacy skills. Our participants gained knowledge through interactions with health professionals, family and social contacts, and media sources. They then used this knowledge to make lifestyle choices that could influence their health and well-being; personal finances, stress, ethnicity, culture and local communities were important factors in this process. Our framework shows how previous and current theoretical models fit with the experience of our participants.

Conclusions

We believe that this is the first study to use empirical data to develop a model of how basic skills. social determinants, social inclusion, self-esteem, self efficacy and social networks combine to influence health and well-being. This model can only reflect the views and experiences of our study participants, and needs further exploration and validation; approaches could include both qualitative studies in other population groups, and statistical modelling using data on population skills and health outcomes. Once validated in larger studies, our model could form the basis of a 'whole systems approach' to health which maximizes meaning for vulnerable participants and thus increases the probability of understanding, participation and compliance.

3. Pedah Touradji

Deconstructing Health Literacy: Toward Conceptual Specificity

BACKGROUND: Health literacy is associated both with education and with literacy. However, the implications of these associations, with regard to characterizing health literacy as a unique construct, and considering whether unique assessment and intervention approaches are needed, have not been well-examined. While health literacy has emerged in the field of medicine as a key factor associated with health outcomes and disparities, in public health and in the field of neuropsychology/cognitive neuroscience, education and literacy, respectively, have been identified as determinants of similar health outcomes and disparities. When deconstructed, health literacy, as it is currently measured and applied, may represent common factors underlying education and literacy as determinants of health outcomes and disparities.

PURPOSE: To consider evidence that: 1) the constructs of education, literacy, and health literacy represent a common 2-component phenomenon: academic achievement and social determinant factors that impact disparities in health outcomes, and 2) literacy, rather than education or health literacy, may be a basic skill that serves as a sensitive proxy for both the academic achievement and the social determinant factors that underlie the common phenomenon.
METHOD: Review of new research directions in public health and neuropsychology examining the constructs of education and literacy and their contributions to health outcomes; systematic review of the literature to determine patterns, prevalence and magnitude of discrepancies between education, literacy and health literacy and their associations with outcomes and disparities.
RESULTS: Recent research supports education, literacy, and health literacy each as associated with various health outcomes and disparities; however, no study was found that measured and determined differential contributions of each. Correlations between the REALM and TOHFLA and the long-standing Wide Range Achievement Test (WRAT), a standardized measure of educational achievement, range 0.74 – 0.88, suggesting a unified construct. Education is reported to predict poor health outcomes across race/ethnicity, age, and geographic region. However, cognitive research has identified literacy as a more sensitive proxy than education. Controlling for literacy (measured using WRAT) attenuates racial and ethnic disparities both in cognitive function and dementia that persist when controlling for education. Evidence supports a discrepancy between years of education and literacy across adult age, race/ethnicity, and geographic region. Reviewed studies show greater magnitude of discrepancy between education and literacy for minorities; 7-19% of Caucasian adults compared to 33-69% of African-American adults obtained literacy levels below their reported education level. The majority of health literacy studies reviewed did not include a measure of literacy/reading grade equivalent. Similarly, studies of numeracy did not include an arithmetic grade equivalent score to determine if it is in fact patterns of discrepancy, indicating lower academic *achievement*, as compared to years of educational *attainment*, underlying associations found between health literacy and health outcomes and disparities.
CONCLUSIONS: Current research from other fields highlights importance of greater specificity with regard to education and literacy, their differential impact on health outcomes, and understanding of the health literacy construct. A deconstruction approach may yield clearer and more scientifically sound solutions to health literacy measurement and intervention.

4. Maria-Rosa Watson
Socio-cultural factors, health literacy and health Knowledge Opinions and Practices in Latino Immigrants –A pilot Study.

Background: health literacy is of concern to everyone involved in health promotion, disease prevention, early screening, health care maintenance, and policy making. Low health literacy has been associated with increased use of hospital services, including inpatient and ED services, and disproportionately high rates of illness and mortality. The prevalence of low health literacy in recent Latino immigrants is unknown. Health behaviors and attitudes of Latinos are influenced by social and cultural factors that may be unique in their background; therefore, understanding health literacy as well as health behaviors and attitudes from a socio-cultural perspective, is critical for improving the health outcomes of this underserved population. The purpose of this pilot study was to qualitatively test, adapt, and validate several survey instruments including an

oral health knowledge, opinion, and practices (OH-KOP) questionnaire, to be administered together. Later on a cardiovascular risk KOP questionnaire was pre-tested as well. **Methods:** we conducted 8 focus groups with 64 participants, and pre-tested survey instruments with 61 additional persons --including 20 people who participated in pre-testing of adapted survey instruments, for a total participation of n=124 Latino immigrants in an inner-city community. The instruments that were qualitatively validated include, the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), a demographic questionnaire and an oral health KOP (both developed earlier with the same population), and a scale that assesses perceived social support (MOS). **Results:** Forty-nine percent of the respondents could correctly describe oral health knowledge items (i.e. what are fluorides?). When testing SAHLSA scores against responses on the OH-KOP, results yielded a strong relationship between SAHLSA scores and responses to one of the OH-KOP questions. In this pre-pilot calculation, estimates were not stable as the sample size was small. Regarding social support, many questions in the social support instrument used were repetitive and while a few questions may capture relevant information among Latinos, other sources of social support, such as community-based and networking support, were thought to be important. Suggestions for changes were discussed, implemented and pre-tested further. The shortened social support instrument in Spanish showed strong correlation with the longer MOS instrument, within this small sample. **Conclusions:** Quantitative testing with larger numbers—and in comparison with other tests measuring health literacy are needed to determine validity and applicability of our locally-developed questionnaires, in the context of a short survey for health literacy for use in primary care settings with Latinos. This qualitative data offer insight into socio-cultural issues that interplay with health literacy among Latinos. This project was funded by the National Institute of Dental and Craniofacial Research (1R03DE016913-01A1).

5. Deborah Begoray

Development of a Measure of Health Literacy for High-School Students

Background:

Health literacy has come to play a critical role in health education and promotion, yet it is poorly understood in adolescents and few measurement tools exist for this population. Standardized instruments to measure health literacy in adults assume it to be a derivative of general literacy. The purpose of the presentation is to report findings from a study to develop and validate a measure of health literacy for a high school-age population. Health literacy in this study is defined as students' ability to access, understand, evaluate, and communicate health information. The study focused specifically on measuring students' ability to understand and evaluate health information.

Methods:

In the spring of 2008, data were collected from 275, primarily 10^{th} grade students in three public schools in Vancouver Canada using a self-administered questionnaire. Abilities to understand and evaluate health information were assessed using 47 free-response questions. The questions were nested in nine health-related stimuli passages. Students' family and school background were also obtained. Forty-eight percent were male, and 69.1% spoke English as a second language (ESL). Bivariate correlations between background variables and the domain and overall scores were calculated. A regression model was developed using 15 explanatory variables.

Results:

The reliability estimates, as indicated by Cronbach's alpha, were 0.91, 0.81, and 0.93 for "understanding", "evaluation", and "total" health literacy respectively. Factor analyses showed that all health literacy was unidimensional and was predicted by ESL (-), GPA (+), frequency of skipping school (-), self-reported academic skills (+), and outside-of-school time studying (+). Students performed better in "understanding" health information (M= 27.47 out of 60) compared to "evaluating "health information (M= 8.35 out of 45). Lower scores were achieved by males, ESL students, those who immigrated to Canada at a later age, and those who skipped school more often. Family factors were found to be less important than school-based factors in predicting health literacy scores.

Conclusions:

This study generated valuable knowledge about students' thought processes, the types of cognitive skills in which students excel or lack, and the factors influencing students' health literacy level. This knowledge is useful for improving the curriculum design of heath education at schools, and, for in developing multiple-choice items for large-scale assessment of health literacy among students. The most significant contributions of this work include the creation of a concrete measurement framework and instrument for measuring adolescent health literacy and the provision of evidence in support of the notion that health literacy is a distinct construct from that of general literacy.

6. Ian Bennett

Failure of the Rapid Estimate of Adult Literacy in Medicine (REALM) in a Large Observational Study of Low Income Women

Background: The Rapid Estimate of Adult Literacy in Medicine (REALM) is the most commonly utilized screening tool for risk of low reading skill in the health care context, a proxy for health literacy. In a study of 1,034 low income women in pregnancy and postpartum the rate of low literacy identified by using the REALM was found to be much lower than expected (4.8%) based on socioeconomic and demographic risk factors such as income and educational attainment. We wished to determine if the measure had performed adequately.

Methods: A randomly chosen subset (n= 437, 38%) of English speaking participants in the original observational study were identified for re-assessment of reading skill in the health care setting. Repeat REALM assessment as well as the assessment of the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA) were carried out as comparison assessments (Pearson Correlation). Variation in score distribution by interviewer (F statistic) and agreement in original and repeat assessment (Kappa) were used to assess the characteristics of the REALM measure.

Results: 236 (54%) women from the random subset completed a repeat literacy assessment. The sample was comprised of young (mean age 23.4, SD= 5.4), low income (mean annual income 8,803, SD = 13,209), primarily African American (82%) women with a proportion of low educational attainment (34% <High School). REALM scores were significantly different between the initial (mean = 60, SD = 9) and repeat (mean = 56, SD = 12; $p<0.0001$) assessments and measure of agreement was lower than expected (Kappa = 0.344, $p<0.001$). The number of women with 6th grade or less literacy was significantly lower (6% versus 14.1%) in pre versus post assessments respectively ($p<0.001$). The variation in REALM scores between interviewer was greater than expected by chance for the initial ($F=15.7$, df = 9, $p<0.0001$), and for the repeat assessments ($F=3.2$, df = 6, $p=0.004$). Correlations between the initial REALM and the S-

TOFHLA (0.533) were lower than previously published assessments and than those between the repeat REALM and S-TOFHLA (0.741).
Conclusions: In this study of low income mothers we found evidence for failure of the REALM. Repeat REALM scores corresponded much better to the expected rate of low literacy based on risk factors and correlated with the S-TOFHLA, a written assessment of risk which is not dependant on interviewer interpretation for scoring. REALM scores varied more than expected between interviewers in both the initial and repeat assessments. While it is unclear why this measure did poorly it's reliance on interviewer interpretation of word familiarity is likely to be involved. Interviewers in the initial assessment included those who were from more similar socio-economic and cultural backgrounds whereas the interviewers in the follow up assessment were graduate students and more culturally distinct from the women being interviewed. It is possible that some interviewers will score the REALM differently based on their own language history. Studies of health literacy should consider this variability when determining which assessment to use.

7. Dharma E. Cortes – Measurement
The experience of shame during the assessment of health literacy

Background: The experience of shame during the process of completing health literacy assessments has not been documented at length, yet the experience of shame among individuals with low literacy has been well documented. The primary goal of this mixed methods study, conducted with U.S. veterans with uncontrolled hypertension (HTN), was to examine factors that influence patient self-management practices. One of the factors examined in the study was health literacy as measured by the S-TOFHLA and the Newest Vital Sign (NVS); since it has been documented that hypertensive patients with low health literacy had higher systolic blood pressure than those with adequate health literacy[1]. In addition, low health literacy is also associated with lower levels of knowledge about HTN[1,2] and less literate patients have difficulty using medications appropriately, leading to poor adherence[3,4]. The S-TOFHLA and NVS were administered at the end of a semi-structured interview designed to document participants' experiences managing their HTN.

Methods: The study used quantitative and qualitative research methods to assess factors influencing HTN management among 45 patients with uncontrolled hypertension recruited at two large Veterans Affairs Medical Centers. Medical records were reviewed to obtain information about comorbidities, high blood pressure readings, prescribed medications, and length of HTN treatment. Demographic data (i.e., age, race/ethnicity, education, income) was

[1] Williams M, Baker D, Parker R, Nurss J. Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of patients with hypertension and diabetes. *Arch Intern Med*. 1998;158:166-172.
[2] Gazmararian J, WIlliams M, Peel J, Baker D. Health literacy and knowledge of chronic disease. *Patient Education and Counseling*. 2002;51:267-275.
[3] Baker D, Parker R, Williams M, et al. The health care experience of patients with low literacy. *Archives of Family Medicine*. 1996;5:329-334.
[4] Kalichman S, Ramachandran B, Catz S. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*. 1999;14:267-273.

also collected. Semi-structured interviews were conducted in order to document patient explanatory models, patient lived experiences, and patient management of hypertension. Verbatim transcribed interviews— that included the dialogue between the interviewer and the interviewee as the latter completed the S-TOFHLA and the NVS— were analyzed using grounded theory analytic techniques. Statements indicating experiences of shame were coded during the analysis of the qualitative data.

Results: Although the relationship between health literacy (i.e., S-TOFHLA and NVS) and blood pressure reading was not conclusive, findings from the study's qualitative component shed light over participants' experiences during process of completing both measures. A significant number of participants expressed frustration and shame when they failed to understand the NVS questions and/or provide an answer to the NVS items. Also, many participants sought feedback and reassurance from the interviewer as they completed the NVS.

Conclusions: Qualitative findings related to the use and administration of health literacy measures shed light on participants' level of comfort and experience of shame in the process of completing health literacy assessments. The fact that the NVS requires oral administration, recommendations are provided as to how to reduce respondents' performance anxiety and potential feelings of shame when they face difficulties understanding the items and providing answers.

8. Laura P. Shone – Measurement
Performance of 'Health Literacy' Tools among Adolescents and Young Adults
Background:
The measurement of health literacy (HL) and its correlation with health skills has been studied in adults, however, less is known about adolescents. Therefore, we sought to evaluate the psychometric properties of the most common measures of functional literacy skills among a sample of adolescent and young adult subjects.

Methods:
We conducted a psychometric study of HL tools in a population-based sample of 189 youth in three age groups (16-17; 18-19, 20-23 years). Participants were recruited in primary health care settings and educational settings (e.g.: public schools, GED programs, vocational and technical training centers, and a community college) in Monroe County, New York between 1/08 and 8/09. We used random order of administration for four common HL tools: 1) S-TOFHLA); 2) REALM ($\geq$ 18 yrs) or REALM-Teen (< 18 yrs); 3) Newest Vital Sign (NVS); and 4) a five-question adaptation of Chew's "Brief Questions" plus the WRAT-3 for validation. We also measured participant skills in health tasks including use of OTC medicines, use of a health insurance card, and emergency-department discharge instructions for care of a laceration. These tasks involved: text search, reading comprehension, numeracy, calculation, reasoning, inference, problem-solving, application, and memory for a total of 0-60 possible points.

We used Crohnbach's coefficient alphas to examine reliability for each HL tool, and principal components analyses to identify a single factor structure per assessment. Pearson correlation coefficients were then used to validate each HL tool against a gold standard (WRAT-3) and to correlate scores on each HL measure with performance on everyday health tasks.

Results:
Instrument Performance: The REALM demonstrated the strongest internal consistency (REALM: Crohnbach's alpha (α) = 0.91, [Eigenvalue= 11.01]) compared to the STOFHLA (α=0.64 [Eigenvalue= 3.84]) and NVS (α=0.59 [Eigenvalue =2.03]). Internal consistency of the NVS was progressively better with age (ages 16-17, α=0.57; ages 18-19, α=0.64; ages 20-23, α=0.78). The five "Brief Questions" demonstrated the least internal consistency (α=0.42 [Eigenvalue= 1.92]).

Instrument Validity: Again, the REALM was most highly correlated with the WRAT-3 overall and by subgroup (overall 0.73, range 0.72 to 0.78 across age and gender stratifications). Correlations with the WRAT-3 for the NVS, STOFHLA, and Chew's "Brief Questions" were all below 0.50 (range 0.03 to 0.49).

Predictive Validity (See table, next page): Overall, the validity of HL tools in predicting health skills was neither strong nor consistent across age or gender stratifications. The strongest correlations were again with the REALM, for specific subgroups including: 20-23 year-olds ($r=0.69$, $p<.001$); females ($r=0.62$, $p<.001$), and 16-17 year-olds ($r=0.59$, $p<.001$).

Conclusions:
Among existing HL measures, the REALM demonstrated the best psychometric performance, whereas other common tools appeared to be more problematic. The S-TOFHLA, NVS, and Brief Questions demonstrated lower internal consistency, and both construct and predictive validity were questionable. The American Academy of Pediatrics has called for more HL research among adolescents. Given the current lack of literature regarding measurement of HL in this age group, future studies in adolescents and young adults should consider using the REALM until more comprehensive measures are developed.

9. Sandra Smith
Promoting Functional Health Literacy

Background

This interdisciplinary study advances the science of health literacy research by 1) proposing a theoretical framework that focuses on functional health literacy (FHL); 2) field testing an instrument for measuring FHL; and 3) investigating the impacts of home visitation on parental FHL. The theoretical framework incorporates Nutbeam's concept of health literacy as progressive levels of functional, interactive and reflective skills to measure FHL as corresponding progressive levels of health functioning. The intervention aimed to develop FHL as a personal asset through community-based health promotion efforts. The overarching goal, to enable parents to use health information and services in ways that maintain and promote health and so to exert greater control over family health and health actions, differs fundamentally from the clinical goal of overcoming deficient reading skill in patients in order to improve their health and ensure efficiency in the system.

Methods

In this action research* project, six home visitation programs implemented the Beginnings Guides Life Skills Development Curriculum to promote FHL in disadvantaged parents during the prenatal to preschool period. Visitors collected data on the health functioning of 2532 parent/child pairs during up to 36 months of service, using the Functional Health Literacy Measure (FHLM say *film*) developed for this project. The study employed both a longitudinal approach and a matched comparison group. Qualitative data from interviews with participating visitors and supervisors elucidated between-site differences.

The FHLM consists of two scales: The Functional Healthcare Literacy Scale (FHcL) rates parents' use of healthcare services and information; the Functional Selfcare Literacy Scale (FScL) rates self-management of personal and child health at home. The internal consistency of items was assessed by calculating Cronbach"s alpha: FHcL=.76 FScL=.74. Examination of test-retest reliability by computing correlations between the first and second observations for each scale showed the expected correlations. Rating of 5 case studies by 12 home visitors produced an estimated inter-rater reliability of 90%. Associations between scores on both scales and several other indicators conformed to theoretical expectations about their inter-relationships.

Results

Parents demonstrated statistically significant improvement after six months of service (p=.001), with continued progress over time. Lower functioning parents (p=.001) and those with lower estimated reading levels (p=.001) produced the greatest gains.

Conclusions

1) Home visitation promotes parental FHL. 2) It is possible to meaningfully measure FHL using the FHLM. 3) The public health model of health literacy promotion is practical for implementation, improves understanding of health literacy, and opens new directions for intervention. 4) Reflection emerged as a literacy skill potentially as fundamental as reading ability to attaining and promoting functional health literacy. A national response to health literacy may be feasible through existing national networks of home visitation programs with short and long term benefits accruing to entire families, the healthcare system, and the schools.

10. Ken Wallston

Can Subjective Measures of Health Literacy and Numeracy be used in Place of More Objective Assessments?

BACKGROUND: Brief subjective measures have been developed as screening tests for health literacy and numeracy. We examined whether these instruments could function as valid alternatives to more time-consuming, objective research measures in a busy clinical setting. METHODS: In the Emergency Department (ED) of a university medical center, we tested the performance of three brief health literacy questions (e.g., "How confident are you filling out medical forms by yourself?") advocated by Chew et al. (2008) versus the Rapid Estimate of Adult Literacy in Medicine (REALM). Numeracy was assessed objectively by the Wide Range Achievement Test (WRAT-3R) and subjectively by the 8-item Subjective Numeracy Scale (SNS; ex. "How good are you at working with fractions?" Fagerlin et al., 2007). Not all patients were administered (or completed) all measures. Two hierarchical multiple regression analyses were run predicting scores on the objective measure by the corresponding subjective measure controlling for patient's age, race, sex, and educational level. Then correlations among the

literacy and numeracy measures were run separately for those with less than college education and those who were college educated.
RESULTS: 303 patients [49% female; 76% white; mean age [sd] = 45.5 [15.2] years] were administered one or more of the four measures. The two measures of health literacy correlated 0.46 (n =195, $p < 0.001$), while the two measures of numeracy correlated 0.58 (n = 156; $p < 0.001$). In the multiple regression predicting REALM scores, the sum of the three health literacy questions explained an additional 8.9% ($p < 0.001$) of objective literacy scores above and beyond the 27.2% explained by the demographic covariates. In the regression predicting WRAT-3R scores, the SNS explained an additional 15.7% ($p < 0.0001$) in objective numeracy scores on top of the 28.6% explained by the demographics. The correlational analysis for those with a high school education or less showed moderately high concurrent validity for the subjective measures (rs = 0.46 and 0.55). Due to high ceiling effects on both measures, the three health literacy questions were uncorrelated with REALM scores for those patients with a college education, while the SNS was moderately correlated (r = 0.37) with the WRAT-3R for college educated patients.
CONCLUSIONS: It is feasible to collect valid information on health literacy and numeracy in acute care settings such as a busy ED. Subjective assessments, such as the SNS and the three health literacy screening questions, appear to be valid alternatives to more cumbersome and "costly" objective measures such as the REALM and WRAT-3R, especially for those patients with no college education--the group most likely to have literacy or numeracy deficits. The real test of whether subjective measures can effectively substitute for objective tests will depend on future research that also examines behavioral and clinical outcomes.

11. Richard White
Validation of a Spanish diabetes-specific numeracy measure: DNT-15_Latino

BACKGROUND: Disparate trends in care are well described among Latino patients with diabetes. The NAAL in 2003 suggested that nearly 65% of Latinos had limited health literacy skills. The relationships between health literacy, numeracy, glycemic control (HbA1c) and acculturation in this population are unclear.

METHODS: The study objective was to examine these relationships in a sample of adult Latino patients with type 1 or type 2 diabetes from two community health centers in Nashville, TN. In addition, we sought to establish the reliability and validity of a 15-item Spanish language, diabetes-specific numeracy measure (DNT-15_Latino). Surveys administered included: patient demographics and the previous validated Short Acculturation Scale for Hispanics (SASH), the Spanish Short Test of Functional Health Literacy in Adults (S-TOFHLA), and the math section of the Wide Range Achievement Test (WRAT-4). Most recent A1C data was collected from the medical record or by point-of-care testing.

RESULTS: Complete data are available on 144 participants. Participants averaged 47.8 years of age (SD=12.3), 63% were female, 81% were uninsured, 85% had incomes < $20,000, and 59% had less than HS education. Low levels of acculturation (SASH <3.0) were observed in 96% of participants. Mean HbA1c was 8.1% (SD=2.4). Health literacy as measured by the S-TOFHLA was inadequate or marginal in 37% of participants and numeracy skills were at the 7th grade level or less in 88% according to the WRAT-4. Mean score and time to complete the DNT-15_Latino

were 26.6% (SD=19.2) and 23.5 min (SD=10.9) respectively. Internal reliability of our scale was strong as demonstrated by a KR-20 of 0.783. Construct validity was strong as demonstrated by significant correlations between DNT-15_Latino scores and the WRAT-4 (Spearman's rho 0.53, $p<0.001$), S-TOFHLA (Spearman's rho 0.278, $p=0.001$), and education level (Spearman's rho 0.383, $p<0.001$). Univariate linear regression modeling failed to demonstrate predictive validity as no significant correlation between DNT-15_Latino score and HbA1c (β -0.035; $p=0.68$) was seen. Acculturation level was strongly correlated with both generalized numeracy (Spearman's rho 0.257, $p=0.003$), and diabetes-specific numeracy (Spearman's rho 0.193, $p=0.025$) skills but again no significant relationship was observed between acculturation level and glycemic control (Spearman's rho 0.01, $p=0.911$).

CONCLUSIONS: Our study reveals a population with many socio-demographic challenges and limited health literacy and numeracy skills. Our DNT-15_Latino scale appears to be a valid numeracy measure for Latino patients with diabetes and may facilitate development of effective interventions to improve diabetes care in this priority population. Addressing issues related to acculturation may also prove to be a useful target for improving diabetes care.

12. Kathleen Mazor
The Potential Use of Area-Based Population Characteristics for Targeted Selection and Balancing of Recruitment into Health Literacy Interventions

Background/Objective:
Individual-level measures of education or literacy are rarely available for enrollees of health care systems in the US. Thus, research or quality improvement interventions that target participation from enrollee subgroups defined by education or literacy must rely on other data sources. In this presentation, we will describe initial results from use of area-based, US Census measures of adult educational levels and African American (AA) residents to target participant recruitment into a health literacy study. Our objectives were to obtain balanced proportions of participants: 1) with low, moderate, and high levels of formal education, and 2) who were AA or white.

Methods:
Kaiser Permanente Georgia (KPG) is one of 3 sites participating in the NCI-funded study "Health Literacy and Cancer Prevention: Do People Understand What They Hear?" KPG is recruiting 300 participants for completion of a 2-hour, computer-based assessment of health literacy. The intervention is primarily an assessment of comprehension of 16 videoclips on cancer screening and prevention. Additional instruments include measures of cognition, print literacy, and cancer knowledge and history.

Potential participants were KPG enrollees 25-74 years of age who were geocoded to their US Census tract using MapMaker Plus (N=185,150). Census tracts were linked to US Census SF-3 data to obtain percent AA and percent of adults with a high school education or less in each tract. Census tracts were classified into tertiles of percent AA and, within each tertile of AA, into tertiles of percent of adults with a high school education or less to create a 3 by 3 sampling frame (9 recruitment cells). Classification of education within race controlled for the confounding of

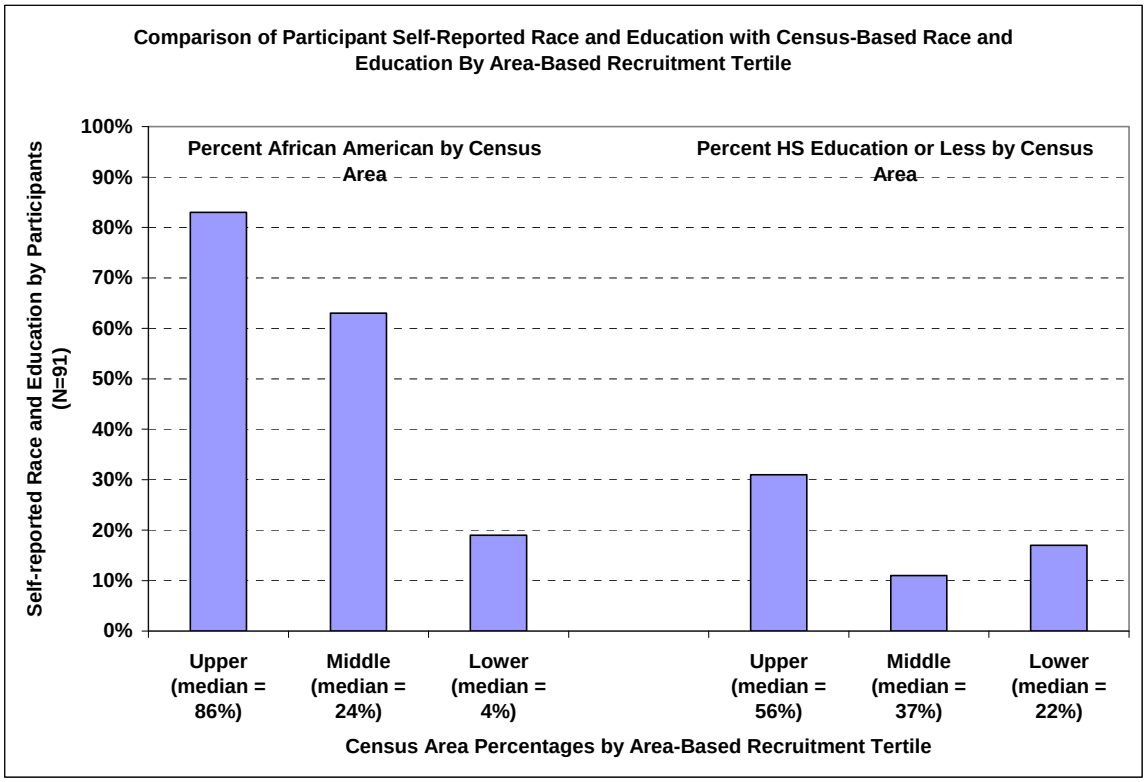
race with formal education. Random samples of approximately 400 eligible participants per cell were selected for recruitment.

Results:

As of 07/2009, 898 eligible participants had been invited to participate and 91 assessments had been completed (10% participation rate). 60% (n=55) of participants were AA; 33% (n=30) were white. Self-reported race paralleled the percent AA residents by US Census tract (Figure). The highest percent of participants with a self-reported high school education or less (31%, 8 of 26) was from US Census tracts with the highest percent of adults with a high school education or less (Figure). We have also found that the sampling frame is yielding a balanced recruitment by level of education within race. 15% of AA participants had a high school education or less (8 of 55); 23% of whites had a high school education or less (7 of 30).

Conclusions:

Initial results indicate that this sampling strategy is achieving our goals: recruitment balanced by race and the confounding of race with formal education is being mitigated. Meaningful numbers of participants with a high school education or less from a health plan with a predominantly middle-class membership and no Medicaid plan are being recruited. In conclusion, area-based measures of education may facilitate recruitment of selected subgroups of participants in the absence of self-reported education. Whether or not formal education is a proxy for functional health literacy remains to be determined.



13. Stephen Porter

Asking patients to self-report health data: does health literacy influence the quality of information shared and the burden of the reporting task?

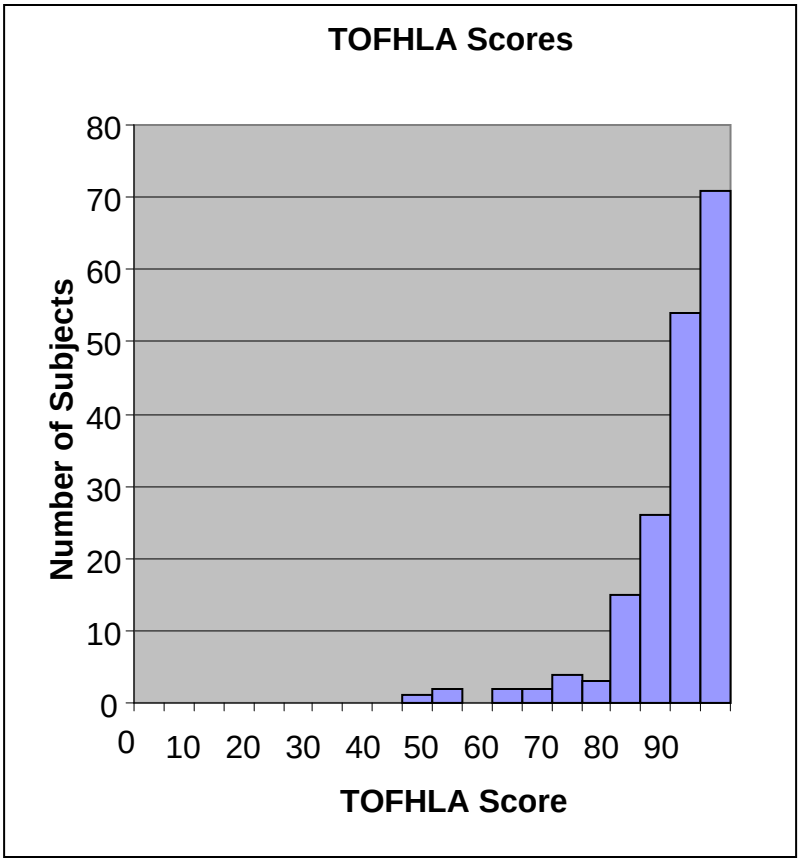
Background: Patients are increasingly expected to independently communicate health information needed to monitor chronic health conditions such as Attention Deficit Hyperactivity Disorder (ADHD). Design of data solutions that optimize patient-centered information exchange requires understanding how health literacy influences patients' capacity to report relevant data in varied task environments.

Objectives: 1) To examine the association between health literacy and data quality (complete data to support a behavioral screen and accurate report of medications) produced by parents' data entry efforts across paper-based and computer-based environments, 2) To determine the impact of health literacy on the task burden associated with parents' efforts across the task environments.

Methods: We completed a randomized controlled trial with English- and Spanish-speaking parents of children with ADHD. Parents were assigned to complete data entry within a paper-based or a computer-based task environment. The paper task environment included the NICHQ Vanderbilt (a structured, 55 item survey) and an open-ended written report of current medications used for the child's ADHD. In the computer environment, parents reported the same content using an application designed to facilitate data entry with a structured series of steps. Each subject completed the Test of Functional Health Literacy in Adults (TOFHLA). Total TOFHLA score and categorical health literacy (analyzed as adequate versus marginal/inadequate) were explored as predictors. Primary outcomes included: insufficient data to screen for subtypes of ADHD, accurate report of total daily dose of all prescribed ADHD-specific medicines, and the total task burden as measured by the NASA task load index. The gold standard for accurate total daily dose of an ADHD medication was a structured in-person interview with the parent.

Results: 271 parents were screened. Of those, 194 were found eligible and 182/194 were enrolled. Two parents were excluded post-hoc. 90 parents each were randomized to paper-based or computer-based tasks. 10/180 (5.6%) parents scored inadequate/marginal on the TOFHLA. Figure 1 shows the distribution of TOFHLA scores. Adequate health literacy was associated with a lower but non-significant risk of insufficient data (OR 0.66, (95%CI 0.2 – 2.4). Compared to parents scoring marginal/ inadequate, parents who scored adequate were more likely to give accurate medication reports (OR 4.5, 95%CI 0.5 – 38.5). Total TOFHLA score was significantly associated with medication accuracy (OR 1.1, 95%CI 1.0-1.1). Parents with adequate literacy were significantly more likely to report lower task burden (decrease in burden score of 1.15 SD, p=0.003). Notably, only the paper-based task environment demonstrated a significant relationship between task burden and categorical literacy - parents with adequate literacy were significantly more likely to report lower burden (decrease in score of 1.63 SD, p=0.0005). In generalized linear models controlling for task environment, parents with higher TOFHLA scores produced improved medication accuracy (p=0.012) and experienced lower burden (p=0.004).

Conclusions: Health literacy independently affects parents' ability to share information across paper-based and computer-based task environments. Lower health literacy is predictive of lower quality data and increased burden associated with data entry tasks. A computer application tailored to patients' literacy needs can mitigate the task burden associated with data entry.



14. Stephen Porter
Content and structural features of parents' written communication about their children's medicines

Background: Written fluency is central to the construct of health literacy, but little research informs what patients communicate when asked to provide health information in written form. Understanding the content and structure of patients' written communication is key to identifying how written fluency may affect patient-provider and patient-health system interactions.
Objectives: 1) To describe patterns of structure and content in parents' written communication about medications within a paper-based, unstructured task environment, 2) To explore the association between parental health literacy and the successful communication of a child's Attention Deficit Hyperactivity (ADHD) medications, 3) To investigate whether experience with a structured, computer-based, data entry application influenced parents' subsequent written report of medications.
Methods: We completed a secondary analysis of parents' writing samples collected as part of a randomized controlled trial. Using a crossover study design, English- and Spanish-speaking parents of children with ADHD were randomized to complete a paper-first versus a computer-first series of data entry tasks covering similar content. Each subject completed the Test of Functional Health Literacy in Adults (TOFHLA). On paper, parents were prompted to "write down all information about the medicines they used to treat their child's ADHD." On the computer, parents were led through structured prompts to provide medication-specific data. The

primary outcome was the successful written communication of ADHD medications, defined ordinally as follows: 1) accurate report of the total daily dose of medications from memory, 2) accurate report of medications aided by referencing prescription labels, 3) inaccurate report of medications from memory, 4) inaccurate report despite referencing. The gold standard for accurate reporting of medications was a structured in-person parent interview. Secondary outcomes included variables related to content (word count, use of medical terms, report of treatment rationale, inclusion of time-specific references) and structure (narrative versus list/phrases).

Results: 182/194 eligible parents were randomized; two were excluded post-hoc. 88/90 of the paper-first writing samples were analyzed for content and structure; two were eliminated as outliers (one blank, one with 7 medications). Median number of medications reported was 1, (range 1-4). Mean word count was 14.8 (SD 16.0). Written communication of medications was categorized as follows: accurate report (7 from memory, 5 with referencing); inaccurate report (25 from memory, 38 despite referencing). Table 1 summarizes secondary outcomes. In a generalized linear model, total TOFHLA was not associated with successful written communication of medications (Model R^2=0.043, F value=1.06, p=0.37). Total TOFHLA was associated with parents' use of medical terminology (Model R^2=0.167, p<0.0001) and a list/phrase structure compared to narrative (Model R^2=0.066, p=0.017). Prior exposure to the computer-based environment significantly increased the odds of accurately communicating medication data in writing (odds of accurate report from memory 26.2, 95%CI 8.4-82.5; odds of accurate report with prescription label 18.9, 95%CI 5.2-66.2.)

Conclusions: TOFHLA scores do not correlate with parents' successful written communication of medicines, but are associated with aspects of written structure and content. Exposure to a structured, computer-based method of reporting medications greatly increased the chances that parents successfully communicated accurate data about medicines in a later writing task.

Table 1. Description of content and structure*

Outcome	# subjects (percent)
Use of medical terms	
Yes	73 (83.0)
Structure**	
Narrative	53 (61.6)
List/Bullets/Phrase	33 (38.4)
Treatment rationale given	
Yes	12 (13.6)
Inclusion of time-specific reference	
Yes	46 (52.3)

*N = 88; two subjects were excluded as outliers (one subject with no written content, another subject who reported a total of seven medications.)

** Structure is based off of a sample of 86 subjects

15. Sean Arayasirikul
Putting Prevention into Practice: A Community-Based Participatory Research (CBPR) approach to incorporating prevention into a Community Health Center setting

Background: Opportunities to meet the health literacy needs of diverse safety net populations are often missing in the primary health care system. A number of healthcare models such as Community Oriented Primary Care and the Chronic Care Model emphasize prevention and the importance of patient-centered care, teamwork, productive interactions, and community-clinic connections. We leverage these models to investigate integrating prevention into the clinical workflow as a mechanism to achieve the distal outcome of improved health literacy and positive behavior change. This study uses a community-based participatory research (CBPR) approach to apply these concepts to developing a prevention intervention for a community health center serving a safety net population.

Specifically, this study evaluates the outcomes of an intervention in a Community Health Center (CHC) serving safety-net populations in order to improve health and disseminate prevention messages about smoking cessation and weight management. Concepts from the Chronic Care Model and Medical Home also informed the development of the intervention. This study included interpersonal messaging, evidence-based print and electronic materials and the use of outreach for patient support.

Methods: Three focus groups were conducted with patients to understand their prevention needs. Five facilitated meetings were held with a planning team including front desk staff, providers, patients, and community outreach workers. Based on input from the focus groups, the planning team developed an intervention for systematically incorporating prevention guidance into the health center visit and for continued support between visits.

Patients of one provider were invited to participate in a program that would offer team based support in making healthier lifestyle changes in weight management or smoking cessation. A pre/post clinical encounter survey measured patient reported self-efficacy and health seeking information preferences. Implementation lasted approximately six months and team coaching was provided for continuous quality improvement. A 30-day follow-up interview collected patient recall about the clinical encounter and whether behavior change occurred. Processes to extract qualitative and physiological EMR data were developed.

Results: The intervention developed by the planning team was complementary to the Center's current workflow and focused on smoking cessation and weight management. The following elements were also included:

- Interpersonal communication between patients and all members of the healthcare team
- User-friendly print and online information from healthfinder.gov
- Data collection through the Center's electronic medical record
- Community outreach staff to provide opportunities for additional counseling

Results indicate that patients were more receptive to weight management prevention information compared to smoking cessation. Patient reported levels of self-efficacy increased in pre/post survey data.

Conclusions: Despite some challenges with using a CBPR approach, the planning team developed a patient-centered intervention that involved all members of the healthcare team and represented best practices in behavioral counseling. We suspect that productive patient-provider interactions may have contributed to the higher levels of patient commitment to behavior change. Many challenges were identified in this complex system of patients, providers, community linkages, and information technology. These findings support bridging community and clinic gaps for prevention in an effort to promote and improve health literacy among a CHC safety net population.

16. Susan Centner
Health Literacy Missouri - A collaborative state-wide approach to addressing health literacy

Background: The Missouri Foundation for Health (MFH) developed the Missouri Health Literacy Enhancement priority area; now known as the HLM project to improve health literacy in the state of Missouri. MFH and health literacy stakeholders are focusing on the following goals: 1) improve the health literacy of Missouri's population in order to encourage better health decisions and healthy behaviors; 2) promote health literacy education and training for health professionals and community members 3) enhance communication between consumers and care providers.

To guide HLM, MFH formed a Health Literacy Coordinating Council. The Council has: 1) adopted a conceptual logic model; 2) formed subcommittees to conduct a statewide needs assessment and health literacy tool (resource) inventory; 3) recommended funding for health literacy demonstration projects and 4) developed a vision/mission statement.

Methods:
Utilizing theory-based models to drive the development and implementation of its logic model, HLM addresses health literacy interventions on multiple levels. HLM features multi-pronged approaches; relying on project partners from community based organizations, academic institutions, foundation program officers and demonstration projects staff.

This weaves a rich patchwork of highly skilled collaborators functioning at local, regional and statewide levels. Regional Community Advisory Networks led by Missouri AHEC provide advisory support to all HLM staff and demonstration projects. The HLM Team of librarians and health researchers are building a Resource Inventory Database to identify and screen health literacy literature, tools, and products.

HLM is developing assessment tools to help health facilities evaluate their own health literacy policies and procedures.

HLM has developed a series of health literacy education modules and workshops targeting both medical and health professionals and students.

HLM is launching its web portal at www.healthliteracymissouri.org which provides links to evaluated health literacy materials from the resource inventory database.

Results: HLM is working closely with the Missouri Hospital Association and the Missouri Primary Care Association to examine how existing standards and policies can be updated to provide more adequate support of health literacy practices.

HLM is also working closely with state agencies to provide recommendations for policy changes to encourage the use of health literate resources and services to MO HealthNet (Medicaid) participants and Missouri's citizens.

Conclusion: This panel will discuss the formation of HLM, the development and implementation of the theory-based logic model which lays the foundation for HLM, and highlight HLM's experiences building partnerships, providing education, collecting and evaluating data, and the construction of its flagship Health Resource Inventory.

17. Amy Chesser
Specific Care Recommendations from Information Prescription Therapy (SCRIPT): Using Information Therapy as a part of Patient Care

Background: The long-term objective of the SCRIPT project was to investigate a new model of primary care using "information prescriptions" in order to improve patient compliance, health outcomes, and reduce healthcare costs. Unaffordable healthcare is symptomatic of three root causes – (1) an inefficient healthcare delivery system, (2) American's poor health habits, and (3) medical illiteracy – all of which contribute to non-compliance with medication management of many conditions. Incentives to improve consumer health behaviors and medical provider performance hold a promising key to addressing these root causes and making healthcare affordable and accessible to all Americans.
The *MedEncentive* Information Therapy Program (hereafter "The Program"), has several years' experience in development and successful testing of using financial rewards to both providers and patients to encourage "mutual accountability". The Program has made an important contribution toward transforming health and healthcare as evidenced through previous pilot studies. *Medencentive* uses care guidelines from *Healthwise* ®, a national resource for evidence-based protocols. The term "information therapy", and its symbol "Ix®", were coined by *Healthwise* ® to mean: "providing patients with the right information at the right time, in understandable terms, so patients can make an informed decision about their health."
This study independently examined the Program's effectiveness, during a five year period, on key outcomes of: (A) provider and consumer participation, (B) patient satisfaction and information prescription compliance, and (C) changes in overall healthcare costs.
Methods: This study included a comparative effectiveness design to isolate each key outcome. Secondary, Retrospective Cohort Analysis was conducted. All participant data was transmitted to the Investigators from MedEncentive Inc. The informed consents for each employee and their dependents are a component of the insurance contract, which means that the study qualified for a waiver of consent. Usual care rates of outpatient and inpatient encounters and

expenditures were derived from the Kansas Health Insurance Information System (KHIIS) allowing system-level comparison for outcomes as listed in Table 1.

Table 1. Data sources, methods and analysis utlitzed

Aims	**Data**	**Data Source**	**Retrospective, Secondary Analysis Methods**	**Analysis**
1. Participation	Access to system; health literacy scores; mutual-accountability ratings; guideline use	MedEncentive Program	Questions presented on MedEncentive's online interface	SPSS for descriptive & content analysis, logistic regression of decision to participate
2. Patient Perceptions	Self-reported health-related quality of life; satisfaction	Participating patients	Annual surveys emailed from MedEncentive	SPSS for descriptive & factor analysis on satisfaction scores
3. Utilization and Cost	Encounters, hospitalizations, lengths-of-stay, costs of care	Insurance Claims	Claims denote: Date of service, Location and Provider, Primary and Secondary Diagnoses, Charges, Discounts and Reimbursed amounts	SPSS for descriptive frequencies by type of encounters and settings & non-linear regression of cost of care by condition to examine drives of expenses

Results: Preliminary findings indicate increased access to system, health literacy scores and guideline use. A key element in program economic impact is the degree to which both physicians and patients participated in the EBM and Ix programs, respectively. Forty-eight percent of Ix prescription physician opportunities were completed.
Preliminary results indicate improved cost containment for the plan. The data were analyzed to ascertain the sources of the observed cost savings in Intervention as opposed to Baseline years. As predicted, the vast majority of the cost savings occurred because of decreased hospital-related costs and pharmacy. While the costs related to program administration of EBM and Ix were slightly higher, they were negligible compared to the savings achieved.

Conclusions: Secondary data analysis indicates implementation of the Program (a P4P system characterized by use of EBM and Ix) could reduce global utilization of healthcare services resulting in lower global costs.

18. Kara L. Jacobson
How Health Literacy Friendly Are We? Use of a health literacy toolkit.

Background: Public hospitals generally serve a disproportionate amount of low-income, indigent patients who often have limited literacy skills. Hospitals should work to address these needs to ensure that all patients can access and understand important health information. We developed an assessment toolkit for the outpatient pharmacies to identify how to meet patients' needs.

Methods and Results: Using an organizational approach, the toolkit includes a: 1) pharmacy staff survey; 2) patient focus groups; and 3) an objective audit. Pharmacy staff respondents (n=53) were mostly female (71%) and African American (67%). Twenty patients participated in focus group discussions inquiring about the physical environment of the pharmacy, the readability of written materials dispensed within the pharmacy, and the demeanor and approachability of the pharmacy staff. Patients had a mean age of 47 years, were prescribed an average of 3.7 medications, and were mostly African American (85%) and male (60%). Three trained objective auditors assessed the pharmacies using a tool adapted from the *Literacy Alberta Tool Kit*. The assessments performed by each of the three components of the toolkit were aligned and similarities and dissimilarities were highlighted.

Only one-third of pharmacy staff agreed that the pharmacy staff, including management, had received awareness and sensitivity training about literacy and literacy issues. Twenty-eight percent of pharmacists reported receiving training in how to identify, prepare, and simplify materials to ensure that they are written in plain language. Yet, pharmacy staff members generally *agreed* that pharmacy print materials were health literacy friendly, while auditors and some focus group patients *disagreed*. Focus group patients voiced concerns about text size on prescription bottles labels and warning labels, while auditors found deficiencies in white space and graphics on various print materials and indicated the many materials were not easy to comprehend.

Half of pharmacy staff members reported having received training on how to communicate with patients using simpler language; however, 24% of pharmacy staff *disagreed* that medical jargon had been removed from medication counseling services. Auditors reported that pharmacy staff avoided using medical jargon when communicating verbally with patients; however, they noted that some improvements could be made. Focus group patients were generally positive about the use of medical jargon during medication counseling. "*They use the correct word and give you the explanation behind it.*"

Conclusion: These data indicate a need for heightened awareness of health literacy among health care professionals. Our three component audit toolkit is a useful way to assess how well an organization meets the needs of patients with limited health literacy skills and can be adapted for any health care environment

19. Kara Jacobson

Effect of a Pharmacy-Based Health Literacy Intervention on Medication Refill Adherence in an Inner-City Health System

INTRODUCTION

- Only 50-60% of patients take their medications as prescribed.
- Low health literacy, which affects 40% of adult Americans, contributes to poor medication management.
- The effect is pronounced in inner-city health systems, which have a high prevalence of low health literacy.
- A pharmacy-based intervention that addresses low health literacy may improve medication adherence.

OBJECTIVES

- Determine the effect of a multi-component, pharmacy-based, health literacy intervention on medication adherence.
- Assess the effect of health literacy on the success of the intervention.
- Understand the perceived utility of and satisfaction with intervention components.

METHODS

- Setting/Subjects:
  - Intervention Site: Grady Health System Pharmacies (N=3)
  - Control Site: Dekalb Grady Pharmacy
  - Pharmacy users for at least 6 months and who picked up their own medications

- Intervention components:
  1) Automated telephone reminder calls to refill medications
  2) PictureRx cards
  3) Clear health communication training for pharmacists

- Outcomes:
  - Refill Adherence: Cumulative Medication Gap (CMG)
    - CMG values range from 0 (adherent) to 1 (non-adherent)
    - Computed for 6 months pre-intervention (baseline) and 6 month study period (follow-up)
  - Utility of and satisfaction with intervention components
    - From patient interviews and focus groups

- Design/Analysis:
  - Non-randomized comparison of CMGintervention vs. CMGcontrol
  - Powered for 20% difference
  - Paired t-test among patients with baseline and follow-up data
- Patient focus group comments indicated:
  - Pharmacists' explanations were easy to understand and useful.
  - PictureRx cards were self-explanatory, useful for understanding the medication regimen, improved pharmacist counseling, good for patient-physician communication.

- Phone call reminders were easy to understand, were received at convenient times, and expedited the refill process.

DISCUSSION

- Multi-component, pharmacy-based intervention was well-received.
  - Improved pharmacist counseling
  - Patients found tools very helpful for understanding and remembering medicines
  - High patient satisfaction

- No significant improvement in refill adherence.
  - Analyses adjusting for site differences also showed no significant improvement (not shown).
  - Insufficient statistical power: only a 4% improvement observed
  - Intervention focused on understanding and reminders.
  - Other factors may have played larger role (transportation, cost, motivation, beliefs, etc).

- Limitations:
  - Controlled study, but non-randomized design
  - Approximately 90% African-American, other groups not well represented

- Future considerations:
  - Need to look at outcomes other than refill adherence.
    - Understanding, discrepancies, adverse drug events
  - Larger, 2-site, randomized study of pharmacist counseling with low-literacy aids is underway.

20. Gary L. Kreps

A Collaborative Model for Community-Based Health Promotion Interventions to Support the Information Needs of At-Risk Consumers: The Fairfax County Health Literacy Initiative

Background

A community-based collaborative, the Fairfax County Health Literacy Initiative (FCHLI), was established to address major disparities in health outcomes at the local level that result from limited consumer access and understanding of relevant health information. The FCHLI targets the health information needs of poor, elderly, minority, immigrant, and other at-risk populations. Partners in the FCHLI collaborative include leaders from the Center for Health and Risk Communication at George Mason University, the Inova Fairfax Health Sciences Library (the Inova Health System), the Fairfax County Public Library, the Fairfax County Health Department, area schools, health awareness and prevention groups, social service agencies, and other non-profit organizations to strengthen outreach to poor and vulnerable populations in Fairfax County. Limited health literacy is a primary problem that hinders access to health care, informed health care decision making, and participation in prevention behaviors, resulting in negative health outcomes. The FCHLI develops intervention to provide relevant and accessible

health information to improve health outcomes for limited literacy populations by encouraging early diagnoses, adoption of healthy behaviors, and cooperation with medical recommendations.

Methods

The FCHLI developed a collaborative model for helping at-risk populations within Fairfax County (a large culturally diverse metropolitan area with more than 1 million residents outside of Washington, DC), providing consumers with relevant and culturally sensitive health information to promote public health. This model uses the synergistic strengths of the partner organizations to design and implement concerted, strategic health communication programs to educate consumers, influence negative health-related behaviors, and enhance the quality of health care and health promotion efforts. The goal of the FCHLI is to improve patient outcomes through development and implementation of community health literacy programs that provide relevant and accessible health information for informed health decision making concerning early detection of health problems, adoption of health promotion behaviors, and adherence to medical recommendations.

Results

The FCHLI partners have collaboratively designed and produced innovative community programs for enhancing effective communication of relevant health information to at-risk populations. These health communication programs include:

- ✓ Culturally-sensitive health education materials for vulnerable community members,
- ✓ H1N1 influenza, AIDS/HIV awareness prevention, and immunization promotion health education campaigns,
- ✓ Consumer and health care provider educational programs to enhance health communication competence,
- ✓ "Ask the Expert" health series to interactively respond effectively to consumer health queries with culturally sensitive health information,
- ✓ Web portal to promote community (consumers, providers, and officials) access to health literacy resources and provide news about FCHLI activities
- ✓ Community-based health communication research projects to assess health disparities and develop strategic interventions.

Conclusions

This program reaches out to a large vulnerable population of consumers in Fairfax County, Virginia, providing consistent and effective health information messages delivered through multiple complementary communication channels. The FCHLI provides at-risk consumers with engaging, culturally-sensitive communication at optimal "teachable" moments, when they need support. This innovative community-based collaboration can become a model for leveraging resources to promote public health.

21. Susmita Pati

Literacy Level of Medicaid Applications and Child Medicaid Retention Rates: Comparison Across 50 States

Background: Gaps in health care coverage for children have been associated with poor child health outcomes. As studies have identified literacy-related difficulties as one of the primary barriers to Medicaid enrollment and retention, this study aims to compare the literacy level of

Medicaid applications across all 50 states and to quantify the association between the application literacy level and child Medicaid retention rates.

Methods: Retrospective cohort study combining state-level Medicaid application and renewal process data with administrative child Medicaid eligibility data for all 50 states. State-level characteristics were obtained through internet searches and surveys with Medicaid staff. They included renewal frequency, interview policy, 12-month continuous eligibility policy, use of joint SCHIP/Medicaid application, and literacy level of the Medicaid application. The literacy level of each application was measured using Readability Studio© software. Administrative Medicaid eligibility files for children (0-18 yrs) from 2001-2002 were obtained from the Center for Medicare and Medicaid Services. Retention rates for each child (percentage of the 24 month observation period with coverage) were analyzed in relation to individual and state-level variables. Individual variables included age, gender, race/ethnicity, presence of chronic conditions, state of residency and Medicaid eligibility category (i.e. income, medically needy, foster care, supplemental security income [SSI]).

Results: In 2008, 46 states had guidelines related to the reading level of Medicaid information. While 17 states' applications scored within their target range on at least one of three readability tests administered (Flesch-Kincaid, New Fog, FORCAST), 80.3% of the scores were above the corresponding state's target. Also, 93% of applications scored at or above a 5^{th} grade reading level. The mean cumulative duration of Medicaid coverage for a child in the 24-month period was 20.1 months. Coverage duration did not differ greatly between children from different age or racial/ethnic groups. On average, children with chronic conditions retained coverage for as long as their healthy peers (20.7 mths vs. 20.1 mths, $p = 0.03$). Of the 19 million children analyzed, 27.8% experienced at least one gap in coverage. The mean length of any single disenrollment was 6 months. Bivariate analysis showed that Medicaid recipients in states requiring eligibility recertifications every 6 months were 30% less likely to experience two years of continuous coverage than recipients in states with annual renewals. Recipients in states without 12-month continuous eligibility were 20% less likely to have continuous coverage. Preliminary results from proportional hazards multivariable regression models on a 5% sample of the Medicaid files demonstrate that children in foster care and those with SSI are 57% ($p<.0001$) and 70% ($<.0001$) less likely, respectively, to be disenrolled from Medicaid than income-eligible children. Analyses quantifying the relationship between application literacy levels and Medicaid retention rates are ongoing.

Conclusions: Medicaid renewal applications fail to comply with state literacy guidelines. Child Medicaid retention rates are more strongly associated with state Medicaid renewal characteristics than with individual child characteristics. To improve child Medicaid retention, efforts to simplify the renewal process merit serious consideration.

22. Paul D. Smith
Improving the Health Literacy of Wisconsin Hospitals—A Collaborative Model

Background: According to the 2003 survey of the U.S. Department of Education National Assessment of Adult Literacy, 36% of U.S. adults were found to have Basic or Below Basic health literacy skills. The ability of these individuals to understand and act upon basic health

information is very limited and can create crisis situations affecting their safety and quality of life.

The aim of this project was to test a collaborative model between hospitals and adult literacy students that identifies health literacy barriers and proposes effective solutions for improving patient safety, satisfaction, and health care outcomes. This project applies the concept of "universal design," in which the health care environment is designed for use by all people, without the need for adaptation or customization.

Methods: Fifteen students from Omega School, a provider of basic adult education, were trained as health literacy consultants to St. Mary's Hospital in Madison Wisconsin. Omega students and a staff team from St. Mary's Hospital independently critiqued a hospital admission form and commonly used patient information guides for readability and assessed the ease of navigating through the hospital using an adaptation of a nationally developed health literacy assessment tool. Following these assessments, focus groups comprised of hospital team and adult literacy student panels were convened to further prioritize barriers to health literacy and feasible solutions to reduce or eliminate these barriers. Based on the outcome of this qualitative research, recommended processes will be developed for literacy programs and health care systems that desire to address health literacy using a collaborative model.

Results: The foundation to this collaborative work is the formation of a successful partnership and ongoing relationship between a health care system and an adult literacy program. In the end, both literacy organizations and health care systems benefit from improved understanding of health care information.

The results of this study suggest that the collaboration between St. Mary's Hospital and Omega School was very valuable; both for the hospital staff and for the students. The hospital benefited from the unique, unvarnished feedback from Omega students who described their challenging experiences with complex and confusing health care information. The students were given an opportunity to learn more about the health care system and how to communicate more effectively when they did not understand. Roundtable dialogue offered a unique forum to describe and explore recurring systemic issues and to identify potential solutions to benefit all patients.

Conclusion: This qualitative study was designed to test a model of collaboration between hospitals and literacy providers. Through independent assessments and roundtable dialogue, hospital staff and literacy student teams identified health literacy barriers they experienced with hospital navigation and written patient communication. Focus group results confirmed the value of successful partnerships between health care systems and literacy organizations. Based on the outcomes of this study, recommended processes will be developed for other literacy programs and health care systems that desire to improve the health literacy of their environments.

23. Carol Teutsch

A coordinated multilevel organizational intervention to improve nutrition and physical activity habits among Head Start parents, staff, and children[3]

[3] Child data to be presented separately.

Background:

Obesity and overweight present a significant long term threat to the health of the Head Start population. A study conducted in 2004 found that 27% of children who enrolled in Head Start in New York city were obese, compared to 13% of three to five year old children nationwide, and 18% of three to five year old children whose families were below the poverty line (but were not enrolled in Head Start). This information suggests that Head Start participants are more likely to be obese than the nationwide population and than other low-income children, potentially creating a lifelong legacy of poor health with increased risk of obesity related complications. Risk factors for cardiovascular disease (hyperinsulinanaemia, impaired glucose tolerance, dyslipidaemia, and hypertension) have been found in overweight children as young as five years old. [1] Several nutrition and physical activity programs have been created specifically for Head Start, including *Little Bites, Big Steps* and *I am Moving, I am Learning*. However, these programs for children addressed nutritional and exercise issues separately and did not include parents in the education. To attain and sustain impact, a program of obesity prevention should be tested which encompasses a comprehensive organizational and family-centered approach. Programs targeting children while they are young before unfavorable life-long habits regarding nutrition and physical activity are established may be crucial. Additionally, Head Start parents frequently have low literacy and available nutritional resources may not be suitable, understandable, or actionable. This pilot is designed as a coordinated organizational and family-oriented approach to empowering vulnerable parents, children, and staff to make healthier choices regarding nutrition and exercise.

Methods: The UCLA/Johnson & Johnson Health Care Institute created a low health literacy training program on diabetes risk awareness, budget-conscious nutrition, and readily accessible physical activity for Head Start parents, children and staff. A classroom activity guide on physical activity and nutrition was developed consistent with curriculum standards and learning goals for Head Start children. Two hundred and six employees, including management, administrators, teachers and home visitation staff, participated in a day long training session on diabetes awareness, nutrition knowledge, and the importance of physical activity. Eighty seven parents were invited to four healthy living training sessions (held after work hours) as the core training. Reinforcement of learning and motivation was delivered through a workshop on healthy shopping, home visits with supplementary materials, newsletters, success stories of fellow attendees, and a graduation celebration that focused on budget-conscious nutrition and physical activity. Seventy seven families participated in at least two core trainings. Concurrently, 100 children received an interactive curriculum on nutrition and physical activity during class over a six month period.

Results: 77 parents and 187 staff participated in training and pre and post assessments over the 6 month intervention. Parents and staff showed improvement on a number of parameters related to eating and shopping knowledge and behavior, a few of which are featured here.

Among staff, the prevalence of morbid obesity decreased from 7% to 3% of all staff, while the prevalence of those classified as overweight decreased from 36% of participants to 31%. The percentage of staff who reported that they always read the nutrition labels on food increased 33% (from 30% at baseline to 45%). Exercise increased in frequency and duration of sessions per week. The percentage of staff that reported doing any form of exercise increased 23% percent (from 73% to 90%). The number who reported exercising 60 minutes or more per week increased 12 percent (from 67% to 75%).

Among parents, on average, body mass index (BMI) measurements decreased by 0.54kg/m^2, and average waist circumference decreased by 6.42 inches.. (Table 1) Among parents, ?overweight obesity decreased from a prevalence of 35% to 26%. There was a 75% increase in the percentage of parents who reported that they engaged in some form of exercise each week (57% to 100%). There was more than a two-fold increase in the percentage of parents who reported engaging in exercise for at least 60 minutes per week (43% to 91%). There were remarkable changes in eating behavior among parents as well. There was a 50% reduction in the percentage of parents who reported eating any fried foods following the intervention (70% to 35%). There was a more than a three-fold increase in the percentage of parents who reported drinking nonfat milk (13% to 48%). There was also a more than three-fold increase in the percentage of parents who reported they always understand nutrition labels (17% to 65%).
Conclusion: Following the health literacy intervention, improvements were seen in knowledge and behavior, such as frequency of exercise and food choice in staff and parents; BMI decreased in some groups. Staff, parents, and children reinforced each other's learning with coordinated activities for each level. These encouraging early results from this pilot call for more comprehensive study and refinement of the intervention.

24. Deena J. Chisolm
Adolescent health literacy and use of online health information

Background. The internet can be an important tool in helping teens to manage their chronic conditions. Online systems to enhance disease specific knowledge and to support proper self management behavior are currently available however it is unclear if limitations in adolescent health pose a barrier to effective use of these resources. This study examines health literacy, computer literacy, and computer self efficacy and their association with computer and internet access in adolescents with chronic disease.
Methods. Youth age 13-18 were recruited from asthma and diabetes clinics at Nationwide Children's Hospital and completed a battery of surveys including the Brief Test of Functional Health Literacy in Adults (TOFHLA), a computer and internet access survey (adapted from the Pew Internet and American Life Survey) and perceived computer literacy and self efficacy (adapted from the Beckers and Schmidt Computer Anxiety Scale). This preliminary analysis includes 145 youths, 91 diabetics and 54 asthmatics. Because health literacy in our sample is highly positively skewed, we used the nonparametric Wilcoxon rank sum and Spearman correlation tests to assess the relationships between health literacy and patient demographic characteristics, computer literacy, a computer self-efficacy. The relationship between health literacy and use of online health information was assessed using Fisher's exact test.
Results. Fifty percent of participants were female and 73.6% were white. One in thirteen (7.6%) had low or marginal health literacy levels. Health literacy scores ranged from 14 to 100 with a mean of 88.9. Health literacy was significantly associated with white race ($p<0.001$) and marginally associated with female gender ($p=0.09$) but was not associated with age or condition (asthma vs. diabetes). Ninety percent of participants reported going online for e-mail or web surfing. Nearly half of youth (47.9%) accessed online information on health, diet or fitness. Lower literacy youths trended toward higher internet use for finding general health information (54.5% vs. 47.3) and for finding sensitive health information (36.4% vs. 19.8%) but neither difference reached statistical significance. Health literacy was significantly correlated with

perceived computer self-efficacy (r= 0.21, p=0.01) but was not correlated with perceived computer literacy.
Conclusions. Half of teens with a chronic conditions sought health information online. Limited health literacy was not a barrier to seeking online health information. Our results show that lower literacy youths are at least as likely, if not more likely, to use the internet for health information. Online health information appears to be an efficient tool for reaching many teens with chronic conditions, however, web designers must be aware that some users will have limited health literacy and should consider this in their content design. Additional research, with a larger, more literacy-diverse population, is needed to determine if the trend toward greater use by lower literate individuals

25. Ruth S. Day
Understanding Risks: Health Literacy vs. Cognitive Accessibility

Background
It can be difficult to understand and remember prescription drug information, especially risks such as side effects. In fact, people understand and remember drug benefits much better than risks (Day, 2006). Although there are many possible reasons for this discrepancy, our research shows that "cognitive accessibility" plays a key role. Benefits are generally presented in ways that make them more accessible -- easier to find, understand, remember, and use.
Written information is especially problematic for people with low health literacy levels. Spoken information should be easier for such people, since it removes the burden of reading. Direct-to-consumer (DTC) television ads seem better for informing them, since risks are usually spoken rather than written. However cognitive accessibility is generally better for drug benefits than risks, even in television ads. For example, as the side effects are spoken, there can be more visual distraction than during presentation of benefits.
Methods
Participants were adults from the general community, with a wide range of ages, education levels, occupations, ethnicities, and health literacy levels. They watched a television ad for a prescription drug, "just as they would in everyday life." On a random basis, half saw an ad with distracting visual information during the side effects, while the others saw the ad without any visual distractions.
Participants were tested on their knowledge about side effects in the ad, using several cognitive tasks. In the Number Estimation Task, they estimated "about how many" side effects were in the ad – they did not have to say what the side effects were, just give a ballpark number. In the Free Report Task, they reported as many of the side effects in the ad as they could. In the Recognition Task, they heard one side effect at a time and said whether each had – or had not – been presented in the ad. These three tasks measured knowledge at successively "deeper" levels of processing.
Results
Even though side effects were spoken rather than written, the low literacy participants had less knowledge about the side effects in the ad. They substantially underestimated the number of side effects provided, were able to report fewer of them, and were less able to identify which side effects had occurred when given a list of possibilities. However those who viewed the ad without visual distraction had better knowledge.

Conclusions
Although spoken information may be easier for low literacy people to understand in general, understanding risks such as side effects is still difficult. The problems lie not just with the people though, but also in how risks are presented. When presentation techniques interfere with normal cognitive processing, people have considerable difficulty; however when such impediments are removed, they improve. These results are compared to those from a similar study using written materials. Overall this research shows that making risk information more cognitively accessible – removing impediments to cog cognitive processing – can enable low literacy adults to understand drug information more fully.

26. Sandra Williams Hilfiker
Limited Health Literacy and Designing Engaging Online Prevention Content: A Usability Study

Background: Choosing a healthy lifestyle and seeking preventive care require that people understand and use health information. However, much of today's health information is too complex for the average adult. According to recent national data, the majority of adults may lack the literacy skills needed to obtain, process, and understand basic health information and services. As more Americans are expected to take responsibility for managing their health, understandable and accessible health information becomes increasingly important.

The Internet has the potential to improve the health and well being of Americans, including the traditionally underserved. In fact, over 60% of Americans already use the Internet for their health information needs (Fox, 2009). In order for the Web to be an effective tool in improving health literacy and health outcomes, however, it must contain reliable and easy-to-use information. A 2006 PEW study found that a quarter of online health information seekers are overwhelmed by the amount of information found online and close to 20% feel confused by the information they find (Fox, 2006). In order for people to effectively manage their health, they must be able to successfully obtain, understand and use health information.

The purpose of this study was to test a Web-based prevention information prototype with a limited health literacy sample to explore the following research questions:

- Do participants find the information and tools in the prototype engaging?
- Do the information and tools in the prototype evoke self efficacy?
- Is the prototype easy to navigate and use?
- What specific characteristics of the prototype do participants find particularly useful or problematic?

Methods: A diverse group of 40 adult female participants between the ages of 25 and 64 was recruited for the study from a community health center patient population in Baltimore, MD. Specifically the recruiters looked for participants who made less than $40,000 a year, had a high school education or less, and who were not regular users of the Internet especially for health information. During a 1-hour session, participants were given tasks to complete using the prevention prototype. A usability test administrator recorded participant comments, facial

expressions, mouse behavior, and screen navigation. Participants were encouraged to "think aloud" during the session. Upon task completion they were then asked to respond to two questionnaires containing measures of self-efficacy and engagement. Finally, they completed a demographic survey.

Results: Overall participants agreed that the information presented was easy to understand, easy to use, and useful to them. Participants also reported high levels of engagement and self efficacy after using the prototype. Specific characteristics of the prototype related to content, navigation, and page design were also identified as particularly useful.

Conclusions: Health literacy is relevant to a number of key behaviors tied to health status and outcomes, including health information seeking, information processing, and decision making. To improve health literacy, the strategies discussed in this presentation will help eHealth providers redesign products and applications to fit the capacities and interests of populations with limited health literacy.

27. Lana V. Ivanitskaya
How susceptible are U.S. consumers to purchasing drugs from illegitimate internet pharmacies? An exploratory study of eHealth literacy.

Background. We examined health consumers' vulnerability to fraud by illegitimate internet pharmacies. Federal efforts may be insufficient to protect U.S. residents who purchase drugs online. Consumer education is likely to play an important role. An example of consumer education that build eHealth literacy is an FDA consumer update titled "The possible dangers of buying medicines over the internet." It instructs consumers to look for the following signs of trustworthiness: a U.S. location, a pharmacy license by the state board of pharmacy, complete contact information (patients can talk to a licensed pharmacist), and a requirement of a prescription from a licensed health care provider for any prescription medicine. It also lists signs that help detect rogue pharmacies: no phone contact with pharmacy staff, medicines that are priced much lower than the average market price, an illegal practice of requiring no prescription, and poor protection of consumers' personal information. This study examined how individuals evaluate the websites of two internet pharmacies that were specifically designed to show many of the unsafe signs modeled after five actual pharmacy websites that the researchers considered to be potentially dangerous to consumers (see Table 1). The two websites had no signs of trustworthiness, as specified by the FDA consumer education materials.

Methods. Two thousand and ninety-six students completed an interactive online assessment between September 2005 and March 2008 (participation rate was 78%) and evaluated pharmacy websites. The vast majority of students (75%) were enrolled in an undergraduate Healthy Lifestyles course. They were asked to evaluate each website and report on its trustworthiness. They also reported if they used online information to make health decisions.

Results. Over 22% of respondents recommended Pharmacy A to friends and family, as compared to 10% of respondents who would recommend Pharmacy B. While 16% said people should be advised to buy cheaper drugs at these internet pharmacies, 62% of respondents suggested that

people should be warned against buying drugs at Pharmacy A and Pharmacy B. Study participants who reported making health decisions using information they found by searching Google or another Internet search engine were less capable of judging pharmacy trustworthiness (n = 762, M = .61, SD = .23) than individuals who did not make such decisions (n = 1,152, M = .65, SD = .21). Similarly, individuals who helped another person (e.g., a relative or a friend) to make a health decision based on the information they located in Google or another Internet search engine had worse judgment of online pharmacies (n = 604, M = .61, SD = .24) than individuals who did not help others to make such decisions (n = 1,310, M = .65, SD = .21). Both t tests were significant, $t(1,912) = 3.62$, $p < .001$ and $t(1,912) = 3.75$, $p < .001$, respectively.

Conclusions. Health consumers are vulnerable to fraud by illegitimate internet pharmacies. More needs to be done not only to build health information literacy skills of students and other community members using the internet.

28. Dan Morrow

Patient Knowledge and Cognition Interact to Influence Health Literacy

Background

Health literacy couples task demands and patient abilities. However, we know little about these abilities. An important component is comprehension, as suggested by the definition of health literacy as the capacity to obtain, understand and use information to make health decisions. Reading is also required by common health literacy measures such as the STOFHLA and REALM. Comprehension depends on broader fluid mental abilities (e.g., working memory) required by processes such as word recognition, and crystallized abilities such as general knowledge about language and domain-specific knowledge (e.g., health). Aging is often accompanied by declining fluid ability but also by knowledge gains. While fluid ability can impair older adults' comprehension, these declines are sometimes offset by knowledge. We investigated trade-offs between fluid ability and knowledge as predictors of health literacy among older adults with hypertension, who experience fluid ability declines due to normal aging exacerbated by illness, but may also gain general knowledge from years of reading and health knowledge from illness experience.

Methods

Tests measuring health literacy, fluid mental abilities, domain-general knowledge, and hypertension knowledge were administered to 146 adults (60-87yrs old; 103 diagnosed with hypertension and 43 without chronic illness). 35% had high school or less education and 8% had less than adequate health literacy for both the REALM and the STOFHLA. A fluid ability composite was created from measures of working memory, processing speed and reasoning (Cronbach α=.83) and a crystallized ability composite from vocabulary and general literacy measures (α=.87). The hypertension knowledge measure (α=.90) was modified from Gazamararian et al. (2003).

REALM and STOFHLA scores were separately analyzed in regressions with the following predictor variables: 1) Age, 2) Education and Years of Illness (possibly related to illness knowledge), 3) Fluid ability, 4) General knowledge and Illness knowledge, 5) Fluid x Knowledge interaction terms to explore potential trade-offs between abilities.

Results

From the table it can be seen that better performance on the REALM was associated with more education, fluid ability, crystallized ability, and illness knowledge (ability measures explained education-related effects). Most important, the interaction terms were significant: Fluid ability was associated with performance for low but not high general and health knowledge. Fluid ability was more important in the STOFHLA analysis (accounting for three times the variance in the REALM and explaining age and education differences). High levels of general but not health knowledge offset the impact of fluid ability on STOFHLA performance.

Conclusions

Knowledge reduced the impact of fluid ability on health literacy performance. Trade-offs between fluid ability and knowledge suggest the importance of multiple abilities for determining health literacy such that patients can achieve adequate health literacy by different routes. The different pattern of predictors for the two tests is consistent with models where health literacy emerges from the interaction of abilities and task demands. Our findings also suggest the value of considering what tests are intended to measure. Measures of health literacy among older adults with chronic illness should capture illness knowledge in order to adequately capture how well patients manage their illness.

Variable	Step 1	Step 2	Step 3	Step 4	Step 5
Model R^2	-0.01%	11.8%**	16.1%**	22.6%**	31.9%**
Age	0.03	0.03	0.10	0.03	-0.03
Education, Years of Illness		0.37** -0.02	0.27** -0.004	0.15 0.06	0.14 0.11
Fluid Ability			0.25**	0.12	0.09
Crystallized Ability, Hypertension Knowledge				0.23* 0.19*	0.18 0.13
Fluid x Crystallized, Fluid x Knowledge					-0.21** -0.21**

** $p < .01$

29. Caroline K Shue

Low-Health Literacy: Message Construction and Measurement Challenges

Background: Individuals who have diabetes and experience low-health literacy often face challenges as they negotiate the demands of managing their disease, including acquisition of health-related knowledge and communication with their physician. A group of physicians, educators, and researchers collaborated to develop a patient education intervention in the form of videos to help patients experiencing low-health literacy better understand their disease and communicate more effectively with their physician. Specific principles of low-health literacy message construction were followed during the development of the intervention, including the use of simple graphic representations, clear concrete messages, realistic suggestions for incremental behavior change, and a relatable character. This presentation demonstrates how components of the video intervention met information acquisition needs of this priority population and how the intervention influenced patient-physician communication.

Methods: Prior to physician appointments, consenting patient participants were interviewed so they could share information regarding their experiences with diabetes and so interviewers could determine their health literacy level as measured by the single item literacy screener (SILS). These participants then viewed one of eight videos designed both to educate them on a particular element of diabetes (e.g., diet, exercise, warning signs) and encourage them to discuss their diabetes management with their physician. After the appointments, patient participants completed a post-intervention interview to share their perceptions of the intervention and to discuss the communication that occurred with their physician. Interviews were transcribed and authors used constant-comparative methods consistent with a grounded theory perspective to identify excerpts focusing on participants' reactions to the videos and the impact of the videos on the patient's appointment with their physician.

Results: In total, 45 patients with diabetes, 26 men and 19 women with a mean age of 59 (SD = 13.84, range = 28 – 85, median age = 63) viewed the video intervention. According to the SILS results, 11% of these participants experience low-health literacy. Participants, regardless of health literacy level, found the intervention to be helpful, informative, and accessible, with some reporting a post-intervention interest in considering health behavior change. Participants also provided specific examples of how the intervention prompted them to engage in diabetes-related conversations with their physicians.

Conclusions: This project provides empirical support for the efficacy of interventions using low-health literacy principles for both those who experience low-health literacy and for those who do not. Specifically, this finding suggests that low-health literacy principles may be useful for a broader range of patients. An overarching challenge we faced in this intervention, however, was accurately identifying those who experience low-health literacy from those who do not. This presentation emphasizes the need to develop even more effective and efficient health literacy screening instruments that can be used in the clinical setting as part of a more complete understanding of low-health literacy in the context of diabetes management.

30. Ingrid Taylor

My Health Companion Demonstration Project

Background:

Health literacy is the ability to obtain and understand basic health information. Overwhelming evidence shows people with limited health literacy have less understanding of disease management, report poor health status, are less likely to seek preventive services and encumber the health care system.

Purpose:
To determine the effect of supplying tools and basic information to a population with low health literacy. St. Louis ConnectCare shall distribute the *My Health Companion: A Portable Paper Health Organizer* and *Taking Control: Making the Most of Your Doctor's Visit DVD*. These planning tools are administered in two settings: chronic care clinics and at health empowerment parties (HEP). The goal is to allow patients to gain confidence and skills to discuss their medical conditions with their health providers.

We have completed one year of a two year demonstration project.

Evaluation Method:
Patients are administered a pretest prior to receiving the Organizer and DVD. The pretest measures participants' confidence, communication skills and satisfaction with healthcare interaction they have received. Participants are then given direction in how to use their Organizers.

Post-tests are administered one month after participants initially receive the planner, and every six months life of the project. Additional questions added in the later testing include assessment of the participants' level of use of the Organizer and understanding of the DVD. Survey questions are multiple-choice format graded on a Likert response scale.

Results:
The preliminary data on patients with both pre- and post-tests (n=35) indicate that slight improvements between pre- and post-test scores have occurred in 12 out of 19 items, e.g., finding information, compliance to medication regimens, the level of respect received from the physician regarding the participants' own opinions, and note-taking during the office visits. Additionally, the proportion of patients who reported "no emergency room visits" increased during the post-testing. Likewise, a slight increase was observed in the proportion of patients who reported "no hospitalizations" during post-tests.

Conclusions:
Early data suggest that use of the *My Health Companion: A Portable Paper Health Organizer* may realize intended results: participants report increased self-confidence in discussing their health concerns with health care provider, increased communication skills during the clinical encounter, and improved satisfaction with the decisions made about their care.

The reduction in emergency room visits and hospitalizations is promising. A larger sample size and results from physician interviews will strengthen these data and thus our findings. Innovative ways to ensure follow up are needed, as this population can be transitory.

31. Lynn Waishwell
Environmental Health Literacy: What Experts Say and What the People Understand.

Background

The overall goal of this presentation is to describe key findings of a project, *Environmental Health Literacy for Low Literate Groups*, funded by the National Institute of Environmental Health Sciences, which determined key concepts important for describing environmental health risks to the public and developed appropriate environmental health risk visual and written concepts for individuals with low literacy skills. The general public lacks an understanding of the relationship between environmental factors and disease; and, while the public has concerns about environmental health issues, they do not have adequate understanding and knowledge to take appropriate actions to protect the environment and their health. Increasing evidence suggests that disproportionate risk of exposure to environmental hazards among low-income and minority groups may contribute to health disparities, and these groups have been shown to have greater degrees of low literacy.

Methods

The focus of this project was to determine environmental risk images and messages appropriate for low literacy audiences. To create these messages, a fundamental understanding of the terminology and concepts that experts believe is needed to understand environmental risk was first developed. Twenty-three environmental health scientists or communicators were interviewed to determine what specific environmental health concepts these professionals considered essential to discuss when describing the environmental conditions and resulting health concerns with the public. Interviewees were asked to characterize how they approached talking to a community, what terms they felt were important to explain, what terms or concepts they though everyone knew, and if (and how) they made adjustments to their presentation or materials for low literate audiences. A content analysis was performed using Atlas.ti to characterize key concepts, the ways that environmental professionals presented them, and characterize ways that they adapted their concepts and presentations for low literate audiences. Key concepts were then discussed in focus groups (N=6) with low literate reading level participants to assess their perception of what the key concepts meant and explore ways to convey environmental concepts appropriately for this audience. Materials were then developed and pretested with focus groups (N=4).

Results

Commonly used terms used to convey environmental health concepts such as risk, contaminant, and dose are not well understood by low-literate groups and often have other interpretation. Perhaps more importantly, most environmental experts felt they could determine audience reading level by observation and few environmental scientists we interviewed made any accommodation for low literate groups when presenting material. The specific concepts identified as important to conveys to audiences by experts were fairly consistent. Focus groups also reported great mistrust of “experts” that influence the ability to communicate effectively.

Conclusions

There is a need to educate environmental health communicators about best practices for working with low literate audiences. As low literate audiences are often in environmentally comprised

areas, thus communication and outreach approaches should encourage participation rather than information giving. This presentation will provide suggestions on visual images and written terms that can be used to describe environmental health concepts and discuss ways that environmental health experts can better communicate with low literate audiences.

32. Charles Zei
Evaluation Of Tailored Education Using "Teach To Goal" In A Multimedia Type 2 Diabetes Education Program

BACKGROUND: When complicated health information is presented to patients, most cannot learn everything at once. Patients with low health literacy usually have lower baseline knowledge and, thus, more to learn. To address this, repeated assessments of knowledge gained and repetition of key learning goals that were not achieved has been recommended: the" teach-to-goal" (TTG) approach. We evaluated the effectiveness of TTG for improving knowledge gain and knowledge retention after patients viewed a multimedia diabetes educational program (MDEP).
METHODS: 100 patients, with and without diabetes, were recruited from primary care clinics at a federally-qualified health center and an academic health center. Patients were interviewed using a pre-test, post-test design to measure diabetes knowledge before and after viewing the MDEP. Knowledge was measured using open-ended questions, administered by the interviewer. Patients were allowed to answer in their own words, and the interviewer then coded whether the response was correct. The TTG intervention was tailored to each patient; if a patient was unable to answer a post-test question, the interviewer presented the information again using a script and teaching aids, such as sections of the MDEP or print materials with pictures from the MDEP. This process was repeated until the individual exhibited learning mastery of the information or for a maximum of two times. Knowledge retention was measured by telephone 2 weeks later. Health literacy was measured using the Short Test of Functional Health Literacy in Adults (S-TOFHLA), and categorized as "inadequate" (0-16), "marginal" (17-22) and "adequate" (23-36). The primary endpoints compared changes in knowledge and knowledge retention. Differences in knowledge gained and retained were compared by paired t-tests. We compared the MDEP-TTG groups´ results with a historical comparison group (n=190), recruited form the same clinics, who received the MDEP only.
RESULTS: Other than the MDEP-TTG group being slightly younger than the MDEP-only group ($p<0.01$), there were no significant differences in demographics or TOFHLA score between the two groups. The mean TOFHLA score for patients who completed follow-up in the MDEP-TTG group was 28.5, with 22.2% of individuals having inadequate or marginal literacy, and 77.8% adequate. After viewing the MDEP, all individuals had significant increases in knowledge. In the MDEP-TTG group, individuals with inadequate or marginal health literacy gained 6.9 points (SD=4.2), and those with adequate health literacy gained 6.6 points (SD=6.1). The MDEP-only group had similar knowledge gains. At the 2 week follow-up, there were no significant differences in knowledge retention for the inadequate/marginal group; the MDEP-TTG group had a knowledge decrease of 4.1 points (SD = 3.7) compared to 3.4 (SD=2.5) in the MDEP-only group ($p=0.56$).
CONCLUSION: TTG improved initial knowledge gain when used in conjunction with a MDEP; however, adding TTG to the MDEP did not improve long-term knowledge retention.

Additional research is needed to investigate the usefulness of TTG in effecting behavior change, improving health outcomes, and overcoming health literacy barriers. Other methods, such as problem based or active learning, may be more useful for long term retention.

33. Michael McKee
Cardiovascular Health Perceptions among a Deaf Linguistic Minority

Background: Persons who are culturally Deaf and use American Sign Language (ASL) as their primary language are an understudied group at high risk for poor health literacy with regard to health promotion and disease prevention, with limited data on their awareness of cardiovascular risk factors and risk reduction behaviors. For Deaf ASL users, both hearing loss and a different language create significant barriers to their access to healthcare and health information.
Methods: Prior to the development of an intervention targeting this group, we convened four focus groups in Rochester, NY with a total of 22 deaf participants. The objective was to learn more about the facilitators and barriers to cardiovascular risk-reducing behaviors and perceptions of cardiovascular health among members of this linguistic and cultural minority group. Focus groups were conducted in ASL by deaf moderators using video recording to document participants' input. A bilingual deaf transcriber both translated and transcribed the videotapes into English. For accuracy purposes, the research team reviewed the videotapes to verify the translation and transcription of the data. The research team reviewed the transcripts to identify recurrent themes under the five domains drawn from social marketing theory: knowledge, barriers, facilitators, practices, and information dissemination.
Results: The participants involved in the four focus groups were generally well-educated (13 of 22 participants had a college education or higher), overweight or obese (16 of 22 participants had a BMI $\geq$25) and mostly female (13 of 22). Despite a high educational achievement level among most participants, there were a number of key health knowledge gaps discovered in the focus groups. While their awareness of heart disease symptoms and the importance of exercise was high, participants in the focus groups showed limited knowledge of diabetes, stroke and high blood pressure. A key facilitator of risk reduction was social support among their Deaf community members for stress relief and health information exchange. To compensate for challenges in accessing health information designed for English language audiences, participants relied on friends and families for health information, leading to distorted perceptions of cardiovascular risks. Awareness about nutrition and medications varied by the participants' educational level.
Conclusion: Many of the participants as a result had superficial cardiovascular health knowledge that was easily distorted. This appeared to reduce effective risk reduction behaviors among the participants. It also increased reliance in obtaining health information through anecdotal stories shared by friends and families. For some of the stories shared by the participants at the focus groups, distortion of health information was common. This may be reflective to the group's poor health literacy secondary to reduced access to reliable health information that is required to correct any inaccuracies they may have learned. The findings support the need for language-accessible cardiovascular health information that can improve health knowledge among ASL users. Risk reduction programs designed in a group format could take advantage of the social closeness of the Deaf community to reduce risk.

34. Ogechi Dike

A 5-Step Methodology for Conducting Literacy Evaluation and Adaptation of Patient Health Education Materials

Background: Health literacy assessment tools and research have demonstrated that health literacy is strongly associated with literacy, suggesting that low literacy solutions must be a component of health literacy solutions. The 2003 National Assessment of Adult Literacy (NAAL) found that 43% of US adults fall within the lowest literacy ranges of *Basic* and *Below Basic,* with 67% of African Americans, 74% of Hispanics, and 61% of adults age >65 falling within these lowest ranges of literacy. Prior research by the research team has demonstrated that literacy-adapted patient education improves patient knowledge, understanding, and retention of health information. Yet, many publicly disseminated patient education materials do not meet the current recommended reading grade level of <5th grade.

Purpose: To examine utility and reliability of a replicable methodology for assessing and adapting readability characteristics of written materials for low literacy. Utilizing the methodology, the study aimed to: (1) conduct literacy evaluations to determine readability statistics of a set of widely disseminated Johns Hopkins Medical Institution patient education documents, (2) determine inter-rater reliability for the literacy evaluation method, and (3) adapt the patient education documents to meet recommended consensus criteria for low-literacy patient education materials.

Methods: A 5-step process was used to evaluate and adapt a set of nine diabetes patient education documents, averaging 1,063 words each, to meet a reading level of <5th grade. Primary criteria evaluated and adapted at the document, paragraph, and sentence levels were: 1) <5th grade reading level 2) <5% passive active voice 3) <15 words per sentence 4) ≤5 characters per word 5) no scientific jargon or unexplained medical terminology. The majority of readability statics were calculated in Microsoft Word 2003, which also determined the Flesch-Kincaid reading grade level. Two independent raters conducted literacy evaluations. Inter-rater reliability (Cronbach's alpha statistic) was calculated at the document level for each original and literacy-adapted document.

Results: Inter-rater reliability for the literacy evaluations ranged 0.99 – 1.00 for all original and adapted documents. Prior to low-literacy adaptation, 30% of the original documents met 2 of 5 low-literacy criteria, 30% of the original documents met 1 of 5 criteria, and 30% met none of the criteria. Reading grade levels for the original documents ranged from 8.6 - 12.3. Fewer than half of the original documents met the criterion of <5% passive voice. Number of words per sentence ranged from 17.0 - 22.2, and number characters per word ranged from 4.5- 5.5. Upon completion of low-literacy adaption, all documents met the 5 consensus criteria, and reading grade levels for the adapted documents ranged from 2.7- 4.6.

Conclusion: Adaptation of patient health education documents to a <5th grade reading level, while preserving content, was feasible. The 5-step method for literacy evaluation and adaptation has proven to be a systematic approach to achieve primary consensus criteria addressing literacy demand. This methodology may prove effective for a wide range of written patient education materials.

35. Chiung-ju Liu
Text cohesion and comprehension of written health information in older adults

Background. Text cohesion indicates the degree to which text content ties together. Text cohesion leads readers through the text by connecting ideas together. To increase older adults' ability to process and understand basic health information, text cohesion is an important factor in addition to readability, which is usually indicated by the length of words and sentences. The length of words and sentences is associated with reading grade levels. While many have suggested improve readability of written health information with low reading grade levels, little attention has been given to text cohesion. The current study aimed to examine: 1) how older adults' comprehension of common health-related written materials is affected by reading grade levels and text cohesion; and 2) how the comprehension is moderated by older adults' characteristics.

Methods. Sixteen short, senior health-related passages were selected from online or print materials. These 16 passages varied in health topics, reading grade levels, and text cohesion. One hundred and twenty-one community dwelling older adults (Mean age = 77) read these 16 passages. These passages were presented in random order to each participant. After reading each passage, 6 yes-no questions were given to assess comprehension. Multilevel modeling was conducted to analyze the data. Reading grade levels and text cohesion were the level-one units; older adults' working memory, verbal ability, prior knowledge, education, and age were the level-two units.

Results. All participants benefited when low reading grade levels were combined with high text cohesion. Participants with small working memory capacity had more difficulty understanding passages written with low reading grade levels ($\gamma 11 = .06$, $p < .05$). Additionally, text cohesion and reading grade levels interacted with participants' verbal ability and age to affect their comprehension. Participants with low verbal ability or older than 77 years of age had difficulty understanding passages high in text cohesion and also high in reading grade levels ($\gamma 34 = .007$, $p < .05$; $\gamma 36 = -.006$, $p < .05$, respectively).

Conclusions. Only lowering reading grade levels of written health information is not an effective strategy to improve older adults' ability to process and understand the information. Our findings indicate that health text written with low reading grade levels is difficult to understand, particularly for older adults with low working memory capacity. Health text written with low reading grade levels may omit critical connections among ideas as sentences by deleting causal and temporal subordinate clauses or phrases. Readers have to engage additional working memory capacity to understand it. Therefore, to ensure well understanding of health-related written information for older adults, health information writers must reduce reading grade levels without disrupting text cohesion.

36. Erin Marcus
Mammography Result Notification Letters: Can Most Women Understand Them?

Background

To prevent patients from being lost to follow-up, the 1998 Mammography Quality Standards Reauthorization Act requires that all licensed mammography facilities mail each patient a written summary of her mammogram report "in terms easily understood by a lay person." This project's goal is to assess the readability of the sample notification letters that many mammography centers use as a template for the letters they send patients about their results.

M**ethods**

We analyzed the sample mammography result notification letters made available on the American College of Radiology (ACR) website, as well as those provided to imaging centers by two widely used mammography transcription services. To assess text readability, we used the Flesch Kincaid reading ease and grade level scales. A Flesch reading ease score of 60 or above and grade level score of 4th to 6th grade are usually considered acceptable for health materials. To assess document suitability, we used the Suitability Assessment of Materials (SAM). A score of >40 % is considered adequate. One-way analysis of variance with Bonferroni multiple comparison tests was used to assess differences in the primary outcomes by diagnostic category (as indicated by BI-RADS level) or by the source of the letter (ACR or the two services).

Results

55 letters were analyzed. The Flesch reading ease ranged from 25 to 61, with a mean of 42 (S.D., 7.9). The Flesch Kincaid grade level score ranged from 6.7 to 13.5, with a mean of 10 (S.D., 1.2). The mean SAM score was 29% (S.D., 2%), with a range of 24% to 38%. Reading ease, grade level, and SAM score did not vary significantly by diagnostic category. These primary outcomes did differ by source of letter ($p<0.05$), but none were in acceptable range.

Conclusion

The letters evaluated in this analysis were written at readability and suitability levels that are too difficult for many patients to understand. These findings suggest there is a need to develop means of communicating mammography results in a way that accounts for low health literacy.