

## Diversity & disparities in health and health care



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#### COVER THEME: Diversity and disparities in health and health care

The best way of caring for someone from a very different background than our own is to ask them to be our teachers. In this issue of WMJ, 3 papers look at diversity from different perspectives: maternity care for women from different racial and ethnic backgrounds, cancer prevention and mortality, and enrollment of minority patients in clinical studies. As our nation continues to grow more diverse, understanding differences among patients is essential for achieving best patient outcomes.

Cover design by Mary Kay Adams-Edgette.

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# WMJ

### Thank you to our reviewers

The *WMJ* would like to thank everyone who served as manuscript reviewers in 2010. Manuscript review is an important collegial act and is essential to the integrity of *WMJ*. We are grateful for the assistance of these individuals in ensuring authors receive prompt, objective, and insightful feedback on their work.

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### Diversity in health, health care...and WMJ

John J. Frey, III, MD, Medical Editor

s the 2010 census likely will show, the most racially and ethnically diverse nation on earth continues to grow more diverse, despite discussions about restricting immigration and citizenship. This issue of *WMJ* contains 3 papers that look at diversity from different perspectives: prevention and cancer mortality, enrollment of minority patients in clinical studies, and delivery of maternity care services to women and their families from different racial and ethnic backgrounds. Understanding differences will be essential, challenging, and increasingly a focus for research in the next decades.

Lepeak and colleagues1 report on data from the Wisconsin Cancer Reporting System and found that, over the period 1995-2005 both white and African-American women in Wisconsin saw a decrease in breast cancer diagnosis and mortality from breast cancer compared to US women as a whole. But the persistence of a disparity in mortality between African American and white women in the state remains a source of concern. Disparities between blacks and whites are clearly related to many things-each of which, and in combination-have the potential to affect patient outcomes. What clinicians can do is know our populations of patients, recognize those with a higher potential for disparities, and do our best to identify and reach out to higher risk women rather than waiting until they come to our offices.

In their honest and thoughtful review of what went wrong in their attempts to enroll

Latina mothers to discover possible risk factors for iron deficiency in their babies, Phillips and her colleagues<sup>2</sup> really bring the struggle to engage patients from minority communities to light. Their paper could serve as a guide for all investigators who want to work in communities where history, language, trust, and tradition all require a different and more collaborative approach ing for someone from a very different background than our own is to ask them to be our teachers – about their lives, traditions, and how they expect their pregnancy and delivery to go.

Torre and colleagues<sup>4</sup> report the results of a study comparing a traditional paper method of collecting data on third-year clerkships in internal medicine with a method

The best way of caring for someone from a very different background than our own is to ask them to be our teachers

to population research. The authors clearly show why community-based participatory research (CBPR) is a necessary skill set for research with any population, whether one is studying dairy farmers or Latina mothers.

This leads well into the review by Schrager and colleagues<sup>3</sup> of maternity care of women with different racial and ethnic backgrounds. While emphasizing the racial and ethnic groups most common in Wisconsin, the authors cover issues that every state in the nation faces in this century. While pregnancy and childbirth are common among women, the experience of that pregnancy and childbirth follow strongly held beliefs and practices that are quite different for different groups. This nice review should be required reading for medical students on their maternity rotation. The best way of carcollecting the same data using a handheld PDA. Sometimes technology may not, in fact, improve a process, despite a widespread belief that it will. To Torre and colleagues' credit, they put their intervention to the test and found that learners preferred it to pen and paper and that, on all the parameters of learning from counseling skills through the physical exam, residents scored better when using the PDA. The only hitch was that the supervisors preferred paper, which is consistent with most studies of new technology that demonstrate that old dogs aren't all that anxious to learn new tricks...but will, eventually.

Identifying early in a hospitalization which patients are at higher risk for developing serious complications would be a tremendous advantage for clinicians who could aggressively treat and monitor those patients. The study by Godar and her colleagues<sup>5</sup> does just that with communityacquired pneumonia, finding that the severity of the patient's illness directly correlated with their admission blood sugar, regardless of whether they had a preadmission diagnosis of diabetes. An inexpensive test that we usually always get on any hospital admission deserves attention, then, as a predictor for who has a higher likelihood of prolonged and serious illness.

Rounding out the manuscripts in this issue is an unusual case study of carditis related to Henoch-Schoenlein's Purpura that once again alerts us to be on guard for the unusual, even in the midst of the unusual.<sup>6</sup>

Finally, readers-whether electronic or paper-will notice a new layout and format for the journal that we all feel looks and is more professional. Staff worked hard to find the right fit and did spectacularly well. And, with this issue, the WMJ is beginning to forge new relationships with medical societies and researchers from other states in the Midwest-we could call this the Snowbelt medical network. As one of the few state medical society-sponsored medical journals that publishes a large amount of original research and academic content, we want to extend a welcome and invitation to our colleagues from Nebraska and Iowa, as a start. We hope to see some of their work here as well.

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# Comparing PDA- and Paper-based Evaluation of the Clinical Skills of Third-Year Students

Dario M Torre, MD, MPH, PhD; Robert Treat, PhD; Steven Durning, MD; D. Michael Elnicki, MD

#### ABSTRACT

**Background:** The mini-Clinical Evaluation Exercise (mini-CEX) is used to assess medical students' clinical skills during medicine clerkships.

**Purpose:** To evaluate reliability, feasibility, and user satisfaction of a paper vs PDA-based mini-CEX in a third-year medicine clerkship.

**Methods:** The mini-CEX was reformatted as a PDA-based rating form for a medicine clerkship over 1 year. Faculty and residents were instructed to use either paper-based or the PDA form to assess clinical skills of students. A 9-point Likert scale was used to assess clinical skills and user satisfaction. Independent *t*-tests were used to assess differences between delivery formats.

**Findings:** Nearly all (98%) students completed 2 Mini-CEXs, with 275 PDA- and 101 paperbased records performed. Form reliability (Cronbach alpha) exceeded 0.9 for both. Overall resident satisfaction scores with the PDA form (7.2 ± 1.8) were higher (P=0.01) than the paperbased form (6.6/1.7). However, faculty satisfaction scores with the PDA form (6.9 ± 1.6) were significantly lower (P=0.01) than the paper form (7.6 ± 1.5). Mean scores for all 7 clinical competencies of PDA format (7.9 ± 0.9) were higher than the paper-based (7.6 ± 1.1) version (P=.01). Mean observation (26 min; ± 16) and feedback time (11 min ± 8) were longer (both P<.05) with PDA-based form compared to the paper version (22 min ± 14);(8.7 ± 6.3). Student and evaluator satisfaction ratings were not significantly different by form.

**Conclusions:** Both PDA- and paper-based mini-CEX delivery was acceptable to evaluators and students with both formats demonstrating high reliability. However, because evaluators' satisfaction, observation, and feedback time differed by form, further studies are needed to determine factors influencing rating variability.

#### BACKGROUND

Personal digital assistants (PDAs) are used with increasing frequency in clinical and medical education.<sup>1-6</sup> PDAs have been used to gather data on student learning activities, to facilitate documentation that feedback has been provided,<sup>7-8</sup> and to

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enhance learning of evidence-based medicine.<sup>9,10</sup> Direct observation of clinical skills is a crucial learning activity in medical education<sup>11-13</sup> and provides numerous benefits to learners, such as formative evaluation, feedback, and enhancement of problem formulation skills.<sup>14,15</sup> The mini-Clinical Evaluation Exercise (CEX) originally developed by the American Board of Internal Medicine (ABIM) has been used to assess the clinical skills of internal medicine residents<sup>16-18</sup> and, less frequently, medical students.<sup>19,20</sup>

Students graduating from medical school must acquire the core skills essential for patient care and must be able to demonstrate competency in performing related clinical tasks.<sup>21</sup> Although direct observation of medical students' clinical skills is a worthy goal for all clerkships, students report they are directly observed performing a history and physical examination 4 or fewer times throughout medical school training.<sup>22</sup> In 2005, only one-fourth of graduating seniors reported that a faculty member observed them

performing a physical examination during their medicine clerkship.<sup>23</sup> Because students' clinical skills are observed so infrequently, faculty and residents often rely heavily on distant recollections of learning activities, whether patient presentations or classroom discussions, that are then generalized to the evaluation of students' actual bedside skills and clinical performance.<sup>24</sup> Additionally, the direct observation and clinical assessment of trainees in the midst of real patient care is invaluable and might yield unique information that could fill in gaps of clinical skills that otherwise would go unrecognized or be detected too late.<sup>25</sup>

A previous study showed that PDA-based mini-CEX can be a reliable and feasible tool to assess students' clinical skills by direct observation.<sup>26</sup> However, it is not known whether there are differences in reliability, users' satisfaction, and clinical skills ratings between use of a PDA vs a paper-based mini-CEX during a medicine clerkship. New approaches to facilitate direct observation and immediate formative evaluation of students' clinical skills must be sought, assessed, and compared. Hence, the objective of our study was to evaluate and compare the 2 mini-CEX forms during a medicine clerkship.

#### **METHODS**

#### Participants

Project participants were 192 third-year medical students at the Medical College of Wisconsin (MCW) who rotated on their required 2-month medicine clerkship during the period September 2006 to June 2007. All third-year medical (M3) students at MCW receive a PDA at the beginning of the academic year and also attend a mandatory 1-hour orientation session on its use.

At MCW, all M3 students complete 1 month of inpatient medicine during their required 2-month medicine clerkship; students can then choose to complete another month of inpatient medicine at a different clinical site or elect to do their second month in an ambulatory setting. Eighty-eight students (46%) chose the 1-month ambulatory medicine option during the project period.

#### **Measurement Instrument**

After receiving permission from the ABIM,<sup>27</sup> we adapted the ABIM's mini-CEX form to a PDA-based form using Pen Dragon<sup>™</sup> software, and a paper form for medical students. The adapted PDA-based mini-CEX form was uploaded onto the PDAs of all M3 students at the beginning of each 2-month medicine clerkship. Consistent with the ABIM's mini-CEX rating form, students were evaluated on 7 clinical competencies. Each competency area was listed on the PDA-based form and was assessed via a 9-point rating scale where 1-3 is unsatisfactory, 4-6 satisfactory, and 7-9 superior. The PDA-based mini-CEX form also captured information about the focus of each clinical encounter and used the aforementioned 9-point scale to record satisfaction scores of the evaluators (faculty member or senior resident) as well as those of the medical students.

Check boxes were used in order to shorten the form, enhance compliance, and reduce completion time. The paper-based mini-CEX was an adapted 1-page form containing exactly the same type and number of items as the PDA-based form, and was provided to students at clerkship orientation.

All student participants were oriented to both the PDAbased and the paper-based mini-CEX form procedure by the clerkship director during orientation. The students also were told they could choose the mini-CEX format and were advised that the clinical ratings recorded on the PDA- or paper-based mini-CEX would not impact their final clerkship grade or evaluation. All evaluators (faculty and residents) received an orientation packet and e-mail before the start of each 2-month rotation explaining the purpose of the mini-CEX, the key features of both forms, and instructions on how to structure the exercise and complete the form. Detailed guidance on how to deliver feedback at the conclusion of the mini-CEX was not formally discussed with the evaluators.

#### **Data Collection**

Students were asked to select a patient of their choosing and complete the mini-CEX while being directly supervised by an evaluator. All students were required to complete 1 mini-CEX each month (2 per clerkship) at their assigned inpatient and/or outpatient site. Students were given the option to select either a senior resident or a faculty member to supervise their clinical encounter and complete either the PDA-based or paper form.

#### **Data Analysis**

We calculated the percentage of students who completed the form and determined the overall mean satisfaction ratings for both students and evaluators. A Cronbach alpha was calculated for both forms to assess reliability (internal consistency). Two sample *t*-tests with equal variances were then performed to detect if there were significant differences between the following: mean student satisfaction by evaluator type (resident vs faculty), clinical domain competency ratings by evaluator type (resident vs faculty), and student and evaluator satisfaction scores by setting (inpatient vs outpatient) between the PDA- and paper-based form. To calculate the magnitude of effect size of the differences between means, we used Cohen's d. Cohen's rule for effect size considers 0.2 as small, 0.5 as medium, and 0.8 or greater as large.<sup>28</sup> All analyses were performed using SPSS (version 15).

Because the use of PDA-based and/or paper-based mini-CEX tools is an integral educational component of the medicine clerkship and part of a formative evaluation process to improve the quality of students' education during the rotation, this project was exempted from Institutional Review Board.

#### RESULTS

Each M3 student completed 2 mini-CEX forms during their required 2-month medicine clerkship; during the 10-month study period, 376 records were collected and analyzed (98% completion rate). Overall, 73% (275) were PDA-based and 27% (101) were paper-based mini-CEXs, 35% were completed by faculty and 65% were completed by residents. Overall, 69% percent of the mini-CEXs (n = 258) were completed in the inpatient setting and 31% (n = 118) in the outpatient setting. In the inpatient setting, 69% (177) of mini-CEX were PDA-based and 31% (81) were paper-based. In the outpatient setting, 68% (80) were PDA-based and 32% (38) were paper-based.

Overall the most common focus of the encounters was data gathering alone (23%), followed by data gathering/diagnosis/therapy (19%), and data gathering/diagnosis (15%). The most common focus for the clinical encounter for both PDA-based and paper-based was data gathering alone (PDA 23%, paper 22%), data gathering/diagnosis/therapy (PDA 19%, paper 17%), and data gathering/diagnosis (PDA 15%, paper 13%). The overall self-described complexity was moderate in 61%, high in 28.5%, and low in 10.5% of patients.

The most frequently evaluated competencies were humanism (93% PDAbased, 82% paper-based), organization and efficiency (93% PDA-based, 83% paper-based), and overall clinical competence (93% PDA-based, 82% paper-based). Other mean clinical skills ratings by PDA vs paper are shown in Table 1.

Form reliability (Alpha Cronbach reliability coefficient) was similar and exceeded 0.9 for both the PDA- and

paper-based versions. Mean scores for overall clinical competencies, regardless of evaluator type, were high for both versions. There was statistically significant difference in mean evaluator ratings for all individual competencies and overall clinical competence between PDA (7.9; SD 0.9) and paperbased mini-CEX (7.6; SD 1.1) (P=.01). (Table 1)

Mean satisfaction ratings as well as mean feedback and observation times, by PDA vs paper, are reported in Table 2. Almost half of the paper-based forms included written comments, 48/98 (49%) while less than one-third of the PDAbased mini-CEX 75/275 (27%) had written entries in the comment section.

#### DISCUSSION

Our findings demonstrate that both PDA- and paperbased mini-CEX delivery was acceptable to evaluators and students, with both formats demonstrating high reliability. Clinical competency scores and observation and feedback times were higher in the PDA-based mini-CEX compared to the paper-based.

Data gathering was still the most common encounter focus, regardless of whether the PDA or paper format was used. Such prominent focus on data gathering is consistent with the Pangaro RIME (Reporter, Interpreter, Manager, Educator)

Table 1. Overall Mean Clinical Skills Ratings for both Paper-based and PDA-based Mini-CEXs

Clinical Skills (domains)ª	PDA-based mean (SD)	Paper-based mean (SD)	<b>P</b> -value <sup>b</sup>
Medical interviewing	7.9 (1.0)	7.6 (0.9)	<0.01
Physical examination	7.6 (1.0)	7.1 (1.0)	<0.01
Humanistic qualities	8.5 (0.8)	8.2 (0.9)	<0.01
Clinical judgment	7.6 (1.0)	7.2 (1.1)	<0.01
Counseling skills	7.9 (0.9)	7.7 (1.0)	0.04
Organization/efficiency	7.8 (1.0)	7.4 (1.1)	<0.01
Overall clinical competence	7.9 (0.9)	7.6 (1.1)	0.01

<sup>a</sup> Clinical skills are indicated as clinical domains of the mini-CEX forms.

<sup>b</sup> *t*-test with equal variances (*P*-value) statistically significant

Table 2. Faculty, Residents, Students' Satisfaction Ratings, Mean Overall Clinical Competence, and Observation and Feedback Times of PDA-based vs Paper-based Mini-CEX<sup>a</sup>

	PDA-based mean (SD)	Paper-based mean (SD)	<i>P</i> -value <sup>b</sup> (Cohen's d <sup>c</sup> )
Faculty satisfaction	6.9 (1.6)	7.6 (1.5)	< 0.01* 0.41
Resident satisfaction	7.2 (1.2)	6.6 (1.7)	< 0.01* 0.35
Student satisfaction	7.0 (1.6)	6.8 (1.7	0.22 0.12
Overall clinical competency	7.9 (0.9)	7.6 (1.1)	0.01* 0.35
Observation time (min)	26 (16)	22 (14)	0.04* 0.26
Feedback time (min)	11 (8.0)	8.7 (6.3)	0.02* 0.32

a (Range 1-9)

<sup>b</sup> t-test with equal variances (P-value)\* statistically significant

<sup>c</sup> Cohen's d: 0.20 small, 0.50 medium, 0.80 large

evaluation framework in which students' clinical skills follow a developmental progression from reporter to interpreter to manager and finally to educator.<sup>29</sup> The focus on data gathering (reporter) and diagnosis (interpreter) provides evidence that the clinical encounters reinforce crucial and important goals for the development of M3 students.

Residents showed a higher satisfaction with the use of a PDA-based mini-CEX compared to a paper-based. Previous research has shown a high rate of PDA use by residents who perceive PDAs as a valuable resource at the point of patient care.<sup>30,31</sup> Whether this was related to a user preference of residents toward technology-based tools is still unclear, though there is evidence of high use of PDAs by medical residents<sup>32</sup> and research showing that residents and young physicians are more likely to use PDAs compared to attending physicians for patient care in hospital settings.33 On the other hand, faculty members indicated a higher level of satisfaction with the paperbased version. Such differences may suggest that a mixed use of electronic and paper-based mini-CEX formats within a clerkship, based on whether the evaluator is a faculty or a resident, may be most appropriate to meet the needs and preferences of instructors and learners.

Residents' overall ratings of students in our study was higher than faculty for both PDA- and paper-based mini-CEX. This is consistent with findings of previous research where either PDA-based<sup>26</sup> or paper-based mini-CEX formats were used,<sup>34-35</sup> hence minimizing concerns that PDA-based delivery significantly impacts mini-CEX clinical skills rating scores.

Our study also indicated a difference in observation and feedback time between the 2 formats, suggesting perhaps that the use of an electronic-based device may result in a gain of clinical skills observation time and feedback delivery. Although differences between the 2 forms were detected in our report, it is difficult to establish whether a PDA or portable electronic device-based mini-CEX is superior to that of a paper-based one, especially if you also take into consideration a small to medium magnitude of the effect size for the differences detected (Cohen's d ranging from 0.26 to 0.42).

There are advantages in using a PDA-based mini-CEX. First, it allows evaluators to document and record direct observation of students' clinical skills in a timely and efficient manner, saving the time and effort typically associated with data gathering and data entry, an important consideration in the venue of a multi-site clerkship. Second, the ease of an electronic data collection and analysis supports its use for formative and longitudinal learner assessment, thus allowing clerkship directors to provide additional individualized feedback and/or remediation to students during the clerkship. However, a paper-based form also has certain advantages. Using paper would avoid the startup cost for the electronic device, as well as cost related to the development and maintenance of the database needed to store and access the data. The paper-based form also may facilitate or encourage evaluators to write more comments, thus helping with the documentation of specific and immediate feedback given to students. However, the rising popularity of new portable devices with multimedia capabilities coupled with the more affordable prices of today's portable electronic devices may provide new educational opportunities and ultimately not constitute a significant barrier to their use.<sup>36-38</sup>

Several limitations of this study should be noted. Due to resource limitations and time constraints, no direct observation of the mini-CEX was conducted by any of the study investigators to confirm the content of each clinical encounter or to validate the type and quality of feedback received by students. Although the study cohort consisted exclusively of M3 students from 1 institution, our medical students are demographically similar to those of other medical schools with respect to gender, undergraduate grade-point average, and United States Medical Licensing Exam Step 1 scores. While M3 students were formally oriented to the PDA-based mini-CEX, evaluators did not receive formal and experiential training with either the PDAbased or the paper-based mini-CEX. However, most evaluators were familiar with the mini-CEX form and process due to its use in the residency-training program and from when PDA-based mini-CEXs were first introduced in the medicine clerkship at MCW in 2004. Finally, a qualitative analysis of the written mini-CEX comments was not performed because it was not within the scope of this paper; however, it may represent inquiry for future research. Finally, students were asked to perform a limited number of mini-CEXs (2 mini-CEXs per 2-month medicine rotation), which may have facilitated compliance. Our findings demonstrate that both PDA-based and paper-based mini-CEXs represent feasible methods to record direct observations of students' clinical skills in both inpatient and outpatient settings.

Additional studies are needed to further explore differences, advantages, and disadvantages among formats in relation to users, students' learning, clinical context, and possible impact on patient care and patient satisfaction.

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### The Impact of Serum Glucose on Clinical Outcomes in Patients Hospitalized with Community-Acquired Pneumonia

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#### ABSTRACT

**Purpose:** Community-acquired pneumonia (CAP) is a common medical condition resulting in excess morbidity, mortality, and high rates of hospitalization. Despite high hospitalization rates for CAP, the relationship between abnormal glucose levels (hyperglycemia and hypoglycemia) and the seriousness of the illness as measured by length of stay (LOS) is not well established. We examined relationships of CAP to multiple factors that impact predictability and severity of the disease process. They include glycemic control; hospital utilization, including LOS; 30-day hospital readmission; intensive care unit (ICU) admissions, adjusting for comorbidities; illness severity; and timing of antibiotic treatment.

**Methods:** We conducted a retrospective observational cohort study of adult patients hospitalized for CAP between January 1, 1992 and June 23, 2007. Case screening was conducted electronically using *International Classification of Diseases, 9th Revision (ICD-9)* codes 480.0-487.9. Subsequent medical record abstraction yielded 969 qualifying cases with comprehensive data on past and current medical problems.

**Results:** Serum glucose levels at admission were independently associated with LOS for CAP patients. Patients with levels between 90 mg/dL and 140 mg/dL on admission had shorter LOS compared to those with levels of < 90 mg/dL and >140 mg/dL (median 3.9 vs 4.2 days, P=.04). Multivariate analyses confirmed the univariate results. Serum glucose levels at initial hospitalization were not associated with 30-day hospital readmission (P=.34) or ICU admission (P=.48).

**Conclusions:** Abnormal glucose levels are an independent predictor of increased LOS for CAP. Control of blood glucose may lead to improved outcomes, including shortened LOS, and should be a priority in CAP management.

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#### INTRODUCTION

Community-acquired pneumonia (CAP) and hyperglycemia are common medical conditions resulting in increased morbidity, mortality, and high rates of hospitalization. Both have been associated with prolonged hospitalization and higher mortality rates in patients undergoing cardiovascular surgery; with acute coronary syndrome, stroke, and trauma; and in surgical and medical intensive care unit (ICU) settings compared to nondiabetics and normoglycemic patients.1-12 Higher rates of infections and infectious complications in the perioperative period have been described in diabetic patients, and it has been suggested that the cellular components of the immune system are contributing factors.13-17

In addition to host immune response, CAP severity is influenced by a number of factors, including immune comorbidities and the virulence of the causative organism.<sup>18-20</sup> The relative impact of glycemic control on length of stay (LOS),

readmission rate, and mortality among CAP patients has not been well established. A retrospective study of 2030 community teaching hospital patients diagnosed with CAP reported that 38% were hyperglycemic (blood glucose  $\geq$  126 mg/dL or 2 measurements  $\geq$  200 mg/dL).<sup>1</sup> New onset of hyperglycemia in the absence of a history of diabetes was also predictive of increased LOS, higher ICU admission rates, higher in-hospital mortality rates, and long-term care with frequent follow-up visits.<sup>1</sup> A recent study of hospitalized CAP patients showed that secondary medical complications were more prevalent among those whose admission blood glucose exceeded 198 mg/dL.<sup>12</sup>

Evidence that hyperglycemia affects the outcomes of other

conditions suggests a need for its evaluation in the context of CAP-hospitalized patients.1-12 Indirect evidence from these studies suggests that hyperglycemic patients may have more severe episodes of pneumonia, as evidenced by longer hospitalization periods, more intense resource use during hospitalization, and potentially higher mortality rates compared to normoglycemic patients. To further investigate these relationships, we systematically evaluated the association of serum glucose levels with LOS, 30-day hospital readmission, and mortality in patients with CAP, while controlling factors previously determined to impact CAP severity, including antibiotic use.

#### **METHODS**

This study was approved by the Institutional Review Board of Marshfield Clinic/St. Joseph's Hospital with waiver of informed consent.

We conducted a retrospective observational cohort study of all adult patients admitted to St. Joseph's Hospital (Marshfield, Wisconsin) for CAP between January 1, 1992 and June 23, 2007. Initial screening was performed electronically using International Classification of Diseases, 9th Revision (ICD-9) codes 480.0-4879 followed by manual chart review. The manual review was intended to restrict CAP cases with bacterial pneumonia accompanied by new radiographic evidence and 1 or more symptoms that were highly consistent with acute lower respiratory infection. These criteria are summarized in Table 1. Study inclusion and exclusion criteria are summarized in Table 2.

Table 1. Case Definition of Community-acquired Pneumonia

 New radiographic evidence dictated on an x-ray report containing any of the following terms:
 S

 Infiltrate
 Air bronchogram

 Interstitial
 Air space disease

 Consolidation
 Opacity

 Pneumonitis
 Pneumonitis

Symptoms of acute respiratory infection including 1 or more of the following:

Documented evidence of fever (≥ 38°C/104°F) or hypothermia (≤ 36°C/96.8°F) Rigors or chills Sweats or diaphoresis New cough with or without sputum production Change in color of respiratory secretions in a patient with a chronic cough Chest discomfort or chest pain Onset of dyspnea or shortness of breath

#### Table 2. Study Inclusion and Exclusion Criteria

#### **Inclusion Criteria**

Density

Age >17 years at diagnosis

Radiologic evidence of CAP within 6 hours of presentation, including pulmonary infiltration, air space disease, consolidation, interstitial, density, infiltrate, opacity, or overt pneumonitis

One or more symptom(s) of acute lower respiratory tract infection, including fever ( $\geq$  38°C or 100.4°F) or hypothermia ( $\leq$  36°C or 96.8°F), rigors or chills, sweats or diaphoresis, new cough with or without sputum production, or the worsening of a chronic cough (frequent/more intense), increase in the quantity of respiratory secretions, appearance of new secretions, or change in color of respiratory secretions associated with a chronic cough, chest discomfort or chest pain (included "chest pressure"), and onset of new or worsening dyspnea or shortness of breath

At least 1 fasting glucose measure within 6 hours of presentation

Hospital admission to a short-term general-stay hospital

#### **Exclusion Criteria**

Antibiotics initiated for respiratory symptoms within 3 weeks prior to reference hospitalization Intensive care unit admission or transfer within 12 hours following reference hospital admission Patients transferred from another hospital Patients who left the hospital against medical advice during reference hospitalization Hospital discharge <30 days preceding reference hospital admission date (to rule out nosocomial pneumonia) Pneumonia diagnosed ≥48 hours after reference hospital admission date

History of or suspected:

Aspiration, fungal, or viral pneumonia at reference hospitalization (ie, influenza pneumonia, RSV, adenoviruses, aspergillosis, histoplasmosis, coccidoidomycosis, blastomycosis, sporotrichosis) Pulmonary tuberculosis or pneumocystis carinii pneumonia within 1 year prior to admission Acquired immune deficiency syndrome or human immunodeficiency virus infection Tracheostomy

We validated electronically obtained diagnoses, hospital admission and discharge dates, and 30-day readmission dates. Patient demographic and clinical data relevant for CAP were abstracted, including timing and quality of antibiotic treatment, alcohol abuse, diabetes, current treatment for malignancy, antihyperglycemic control, and corticosteroid use 3 weeks prior to hospitalization. Serum glucose levels were obtained at admission and periodically during the remaining hospital stay. Hyperglycemia was defined as a serum glucose measurement ≥ 140 mg/dL. Comorbidities applied to any medical conditions recorded at presentation and up to 1 year prior to admission.

Timing and appropriateness of antibiotic treatment during the first 24 hours of care were developed to assess initial CAP management. The former was based on the difference in time (in minutes) between the first documentation of medical



care for CAP and antibiotic administration. Appropriateness of initial antibiotic treatment was determined based on Infectious Disease Society of America (IDSA) guidelines that were first developed in 1998 and subsequently revised in 2000 and 2003.<sup>21-23</sup> The 1998 guidelines were applied to hospitalizations that occurred in 1999 and 2000, the 2000 guidelines were applied to hospitalizations that occurred from 2001 to 2003, and the 2003 guidelines were applied to hospitalizations from 2004 to 2007. Since IDSA guidelines did not exist before 1998, we applied the 1998 IDSA recommendations retrospectively to assign "approximate appropriateness" of antibiotic selection for hospitalizations that occurred between 1992 and 1998.

The Pneumonia Severity Index (PSI)<sup>24</sup> and the Charlson Comorbidity Index (CCI)<sup>25</sup> were used to stratify illness severity and the number and severity of comorbid conditions. High CCI scores have been shown to be predictive of hospital readmission at 1 year or death in elderly patients with CAP.<sup>26</sup>

#### **Statistical Analyses**

A Wilcoxon rank-sum test was performed to evaluate the association between LOS and other factors, including demographic characteristics, diabetes and other comorbid conditions, clinical measurements, PSI, and CCI. Univariate logistic regression analysis was applied to determine which factors were associated with ICU admission. In addition, univariate analyses (including Wilcoxon rank-sum test and logistic regression) were used to analyze factors related to 30-day readmission. Finally, multivariate logistic regression analyses were conducted to build the predictive models of mortality at various time periods (1 year, 90 days, 60 days, and 30 days).

#### RESULTS

Initial electronic screening identified 1641 potential cases. Subsequent chart review validated 969 CAP cases. The most common reasons for exclusion were a normal chest x-ray (44%), antibiotic treatment within 3 weeks prior to presentation (20%), and no symptoms (12%) (Figure 1). Because the vast majority of subjects were Marshfield Clinic patients, there were no systematic data problems, including data needed for PSI and CCI measures, which are believed to have affected results.

Data on demographic factors and selected clinical measures related to CAP are summarized in Table 3. The mean age of subjects was 74 years. There were 544 males (56%) and 425 females (44%). Hyperglycemia (ie, glucose  $\geq$  140 ml/dL) at admission was documented in 38.2% (370/969) of subjects, including

19 subjects with serum glucose levels  $\geq 200 \text{ mg/dL}$  who did not have a diagnosis of diabetes prior to admission. Median time to antibiotic intervention was 4.9 hours (interquartile range [IQR] = 3.0, 7.1). Median LOS was 4.0 days. The 30-day readmission rate was 8% (77/969).

#### Length of Stay

Median LOS for admission glucose levels between 90 mg/dL and 140 mg/dL was 3.9 days compared to 4.2 days for glucose levels outside this range (P=.04). Univariate results for the other demographic and clinical factors are summarized in Table 4. History of diabetes did not demonstrate a strong univariate statistical relationship to any outcome measure; its strongest relationship was to LOS (P=.24).

#### **30-Day Hospital Readmission**

Overall, 8% of CAP cases (77/969) were readmitted for various causes. We examined univariate relationships between readmission probability and demographic and clinical factors relevant for CAP including glycemic control, diabetes, and the timeliness and quality of antibiotic therapy. Only age demonstrated an association with 30-day readmission; the median age for readmitted subjects was 80.6 years compared to 76.9 years for those not readmitted (P<.01).

#### Treatment with Hyperglycemic Agents and Corticosteroids

Changes in serum glucose are reported as the difference between the patient's first glucose measurement occurring within 6 hours of admission and median glucose levels obtained during their hospitalization. Patients treated with antihyperglycemic medications during hospitalization (n = 212) experienced a large decrease in serum glucose levels (median = 37.7 mg/dL [P < .01]). Patients not treated with corticosteroids within 3 weeks prior to hospital admission (n = 839) also experienced a decrease in serum glucose levels (median 5.6 mg/dL [P = .09]). Patients with a low PSI score (n = 925) (PSI = high if >4, and PSI = low if <3) demonstrated a significant decrease in serum glucose during hospitalization (median difference of 4.5 mg/dL [P < .02]).

#### **ICU Transfer**

High risk glucose levels were not associated with ICU admission. However, patients who were not treated according to IDSA guidelines were more likely to experience an ICU admission (OR = 3.24, P < .02), as were patients who developed at least 1 medical complication (ie, sepsis, neurological, cardiac, renal, pulmonary) (OR = 8.22, P < .01). Additionally, those with a high PSI score ( $\geq 4$ ) and CCI score ( $\geq 5$ ) were also more likely to develop medical complications (Table 5).

#### Mortality

Approximately 21% of study subjects (205/969) died within 365 days of the reference hospital admission. Multivariate predictive models were constructed to investigate the relationship between mortality and study demographic and clinical factors. Although serum glucose levels were not predictive of mortality in any time interval, treatment with corticosteroids was positively associated with mortality at 1 year (OR = 1.80, P < .01). Risk factors associated with mortality at 30 days, 60 days, 90 days, and 1 year are reported in Table 6.

#### DISCUSSION

Recent studies have shown that patients with elevated blood glucose at hospital admission experience a more complicated medical course, higher infection rates, higher mortality rates, and longer length of hospitalization than those with normal blood glucose levels.<sup>1,2,4,5,11,12</sup> Despite these findings and the high frequency of CAP hospitalizations, there is a paucity of literature regarding the effect of hyperglycemia and/or diabetes mellitus on clinical outcomes for these patients.<sup>1</sup> Results of previous studies suggest that elevated glucose levels are a contributing factor to increased morbidity and mortality in patients with CAP.

Our study validates previously published findings showing that admission glucose values are useful in predicting clinical outcomes such as LOS in hospitalized patients.<sup>12</sup> In contrast, a past history of diabetes did not demonstrate strong association with any study outcome measure and for that reason was excluded from multivariate analyses. Together these findings reinforce results from a few other studies that found that admis-

Factor	N/Measure	%
Study subjects	969	100.0
Age (mean)	73.8 years	
Gender		
Male	544	56.1 (544/969)
Female	425	43.9 (425/969)
Diabetes Diagnosis	212	21.9 (212/969)
PSI Risk Group		
PSI ≥91	35	3.6 (35/969)
PSI <91	934	96.4 (934/969)
CCI Class		
0	185	19.1 (185/969)
1-2	437	45.1 (437/969)
3-9	334	34.5 (334/969)
≥10	13	1.3 (13/969)
Glucose at Admission (mg/d	L)	
<90	22	2.3 (22/969)
90-139	577	59.5 (577/969)
≥140	370	38.2 (370/969)
1-year mortality	205	21.16 (205/969)
Admission Symptoms		
Fever	473	49.22 (473/961)
Chills	494	51.30 (494/963)
Sweats	161	16.91 (161/952)
New cough	819	84.78 (819/966)
Change in secretions	63	6.57 (63/959)
Chest pain	327	34.06 (327/960)
Shortness of breath	699	72.29 (699/967)

PSI=Pneumonia Severity Index; CCI=Charlson Comorbidity Index.

sion blood glucose level may be a more useful prognostic tool than a past history of diabetes, especially as a predictor of mortality among patients both with and without a pre-admission diagnosis of diabetes.<sup>12,27</sup> Although this finding may reflect the incidence of undiagnosed diabetes, it nonetheless reinforces the importance of obtaining glucose measurements upon admission for suspected CAP.

Our *a priori* expectation, that patients with hyperglycemic glucose levels (>140 mg/dL) would experience longer LOS, was confirmed.<sup>12</sup> However, we also found that patients with glucose values <90 mg/dL also experienced a longer LOS. The latter finding was unexpected, and the underlying reasons for it are unclear. Intensive control of blood glucose levels has been found to be associated with a higher incidence of significant hypoglycemia as well as increased mortality.<sup>28-30</sup> A recent publication in a population-based sample of patients hospitalized with pneumonia and hypoglycemia (defined as <4 mmol/L [72 mg/dl]) showed increased in-hospital and 1-year mortality in patients with an admission glucose <4 mmol/L.<sup>31,32</sup> Thus, our study confirms findings from prior studies showing that suboptimal control of serum glucose—hyperglycemia as well

Table 4. Association between Risk Factors and Length of Stay, Univariate Analysis			
Factor	LOS median days (N)	P-value	
PSI (≥4 vs ≤3)	6.95 (35) vs 4.02 (934)	0.0016	
CCI (≥5 vs ≤4)	4.19 (107) vs 4.02 (862)	0.1856	
Complication <sup>a</sup> (at least 1 vs none)	7.52 (124) vs 3.84 (845)	< 0.0001	
Smoking (current/previous smoker vs never smoked)	3.78 (507) vs 4.10 (462)	0.0064	
Alcohol (current/previous abuse vs never abuse)	4.89 (71) vs 4.02 (898)	0.0109	
Corticosteroids use (yes vs no)	4.69 (121) vs 3.97 (848)	0.0098	
Treatment for malignancy (yes vs no)	5.82 (41) vs 4.02 (928)	0.0193	
Transfer to ICU (yes vs no)	13.26 (29) vs 4.00 (937)	< 0.0001	
Admission glucose (90 < Glu < 140 vs $\leq$ 90 and $\geq$ 140)	3.99 (572) vs 4.16 (397)	0.0398	

PSI=Pneumonia Severity Index; CCI=Charlson Comorbidity Index.

<sup>a</sup> Complication includes diagnosis of sepsis, neurological, cardiac, renal, and pulmonary.

Table 5. Univariate Analysis of Potential Risk Factors Associated with	Development of Complications
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Risk Factor	Odds Ratio	<i>P</i> -value
High Pneumonia Severity Index Score <sup>a</sup>	3.033	0.0067
High Charlson Comorbidity Index Score <sup>b</sup>	1.853	0.0269

as hypoglycemia—may contribute to poorer outcomes among hospitalized patients with CAP.

#### **Time to Administer Antibiotics**

Previous guidelines recommended that antibiotics be administered within 4 to 8 hours of presentation because mortality rises when first administration occurs beyond an 8-hour time frame. However, analysis of 13 observational studies comparing outcomes associated with early versus delayed antibiotic treatment did not provide sufficient evidence that antibiotic treatment within 4 hours yields better outcomes.<sup>33</sup> Studies assessing an 8-hour cutoff time also did not produce significant evidence of improved patient outcome.<sup>33</sup> As a result of these conflicting findings, the validity of a 4-hour or 8-hour time frame in which to initiate antibiotics remains controversial.<sup>34</sup>

Adherence to IDSA guidelines has been shown to reduce LOS and mortality rate.  $^{35,36}\,$ 

In our study, we developed a continuous measurement of time-to-antibiotic using initial presentation time, whether in the emergency department or urgent care, as the index time. However, despite this approach, we did not identify an association between the time-to-antibiotic treatment and LOS, medical complications, 30-day readmission, or mortality. We did find an association between ICU admission and lack of adherence to IDSA guidelines for the treatment of CAP that is suggestive of a relationship between ISDA guideline adherence and LOS through ICU admission effects on LOS. This finding is consistent with results from an earlier study that found hospitalized CAP patients not treated according to IDSA guidelines were more likely to be transferred to the ICU.<sup>34</sup>

#### PSI

Over 96% of our study cohort were classified as PSI risk level III and below, and over 90% were level II or below, indicating generally low levels of severity that can often be successfully treated on an outpatient basis.<sup>21</sup> Our results differ from other studies that reported only 31%-43% of patients categorized into PSI risk levels III and below, when PSI values were used as a guide for needed hospitalization.37 Some of these differences may be attributable to socioeconomic factors and/or medical needs not accounted for by the PSI, including lack of home-care support, medication compliance, social disposition, differences

in the structure of CAP treatment guidelines, and failure of outpatient treatment.

In addition, the study periods also may have affected these results. The first published report of the PSI appeared in 1997,<sup>21</sup> and although it appears to have been rapidly accepted into medical practice, its adoption was likely not widespread until over halfway through our study period, resulting in a larger proportion of low-risk PSI patients in our cohort. The mid-study period diffusion of the PSI into hospitalization decision for CAP patients combined with our older study cohort (mean age 73.8 years) also likely contributed to higher levels of hospitalization among otherwise low risk PSI patients. Prior to the widespread use of the PSI, there appears to have been a significant bias in physician decision toward hospitalizing older CAP patients (65 years and older).<sup>38</sup>

#### Limitations

Our study cohort comprises a disproportionately large number of less severely ill CAP patients. More than 90% of the cohort was classified in PSI categories I and II, which are indicative of an expected 30-day mortality risk of <1%. Only 1 study subject was classified in PSI category V, which is associated with a >10% 30-day mortality risk. This somewhat healthier CAP cohort may have made it more difficult to detect LOS and mortality risks associated with CAP complications stemming from serum glucose levels. It also may have made it more difficult to isolate the effects of appropriate and timely antibiotic

#### Table 6. Multivariate Logistic Regression Results for Mortality Risks at Various Time Periods

Mortality	30-Day		60-Day		90-Day		1-Year	
Risk Factor	Odds Ratio	P-value	Odds Ratio	P-value	Odds Ratio	P-value	Odds Ratio	P-value
PSI ≥4	6.97	< 0.0001	6.63	< 0.0001	8.85	<.0001	4.62	< 0.0001
CCI ≥5	_	_	_	_	_	_	1.70	0.0264
Complication	2.48	0.0052	2.09	0.0137	_	_	1.74	0.0138
Comorbidities	4.93	0.0290	6.93	0.0078	5.44	0.0045	3.85	0.0002
Transfer to ICU	3.56	0.0122	4.13	0.0021	4.23	0.0011	_	_
Corticosteroid	_	_	_	_	_	_	1.80	0.0091
Alcohol abuse	_	_	_	_	2.10	0.0351	1.94	0.0191
Malignancy treatment	_	_	_	_	_	0.0218	2.23	_
Concordant (%)	54.1		51.3		45.3		58.3	
AUC	0.724		0.711		0.682		0.691	

PSI=Pneumonia Severity Index; CCI=Charlson Comorbidity Index; ICU=Intensive Care Unit; AUC=Area under curve.

administration on clinical outcomes.

We relied on fasting blood glucose measurements as our indicator of glucose level and differences in glucose levels during hospitalization as our measure of glucose control. It may have been more beneficial to measure glucose control using a broader-based measure, such as the hyperglycemic index.<sup>39</sup>

#### CONCLUSION

Further investigation and elucidation of the impact of serum glucose on hospital outcomes in patients with CAP should expand our understanding with direct translational benefit on informed care management decisions. Prospective studies are needed to compare clinical and mortality outcomes associated with intensive versus conventional hypoglycemia/hyperglycemia treatment in patients hospitalized with CAP.

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### Persistence in Breast Cancer Disparities Between African Americans and Whites in Wisconsin

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#### ABSTRACT

**Background:** Breast cancer (BC) mortality is higher in African American women compared to white women despite having a lower incidence. The reasons for this remain unclear, despite decades of research. Reducing BC health disparities is a priority but has had limited success.

**Objective:** To assess progress in eliminating breast cancer-related health disparities in Wisconsin by comparing trends in breast cancer outcomes in African American and white women from 1995 to 2006 and comparing results nationally.

**Methods:** Age-adjusted breast cancer (BC) incidence and stage data from the Wisconsin Cancer Reporting System and age-adjusted mortality data from National Center of Health Statistics were used to evaluate trends in incidence and mortality from 1995 to 2006 for African Americans and whites. The relative disparity was evaluated by rate ratios. Trends in distribution of in situ vs malignant disease were examined. National trend data were obtained from the National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) database.

**Results:** Age-adjusted incidence decreased 10% in Wisconsin compared to 7% nationally. Incidence of BC was lower in African American compared to white women. BC mortality in African American women declined in Wisconsin, but remained higher than white females. Ageadjusted mortality in Wisconsin declined approximately 23%, matching national trends. Non age-adjusted stage data trended toward a decrease in malignant, but increased in situ disease.

**Conclusions:** Despite an overall reduction in BC mortality from 1995 to 2006, a persistent disparity in mortality remains for African American women, demonstrating no significant progress in reducing BC health disparities.

#### INTRODUCTION

Breast cancer is the most frequently diagnosed cancer in women. An estimated 192,370 women were diagnosed with, and over 40,000 American women died from the disease in 2009.<sup>1</sup> In Wisconsin, approximately 3800 women were diagnosed annually over the period 2002-2006, while 770 women died due to the disease.<sup>2</sup> There have been many successes in

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battling breast cancer (BC), with incidence and death rates among American women decreasing nearly 2% per year over the period 1998-2006.<sup>3</sup> Survival improvements have been attributed to advances in treatment as well as to early detection. The reduction in new cases has been credited to changes in primary care clinical practice, such as reduction in the use of hormone replacement therapy following the Women's Health Initiative in 2002.<sup>4</sup>

However, not all women have benefitted equally from these successes. National studies have established that while BC incidence rates among whites are higher than among African Americans, mortality rates are higher and have declined more slowly among African American women.<sup>5-10</sup>

Previous reports from Wisconsin reveal disparities in breast cancer rates.<sup>2,11-13</sup> The most recent report from the Wisconsin Cancer Reporting System

(WCRS) shows that age-adjusted incidence of breast cancer was 124 per 100,000 for white women compared to 109 per 100,000 for African American women over the period 2002-2006. Despite this lower incidence, African American women had higher BC mortality than whites (26 vs 23 per 100,000).<sup>2</sup> Nationally, these disparities have changed over time.<sup>5</sup> However, trends in Wisconsin BC disparities have not been reported for African Americans, the largest minority population in Wisconsin.<sup>3</sup>

The purpose of this paper is to describe trends in disparities in BC incidence and mortality between African Americans and whites in Wisconsin, and compare them to national trends. We also examine disparities in BC staging at diagnosis in Wisconsin and highlight ongoing clinical, policy, and programmatic activities in the state that seek to address these disparities.



**Figure 1:** Age-adjusted breast cancer incidence (A) and mortality rates (B), females, by race, Wisconsin and the United States, 1995-2006. Source: Wisconsin Cancer Reporting System (Wisconsin incidence), National Center for Health Statistics (Wisconsin mortality), Surveillance, Epidemiology, and End Results (SEER) Registry<sup>3</sup> (US incidence and mortality).

#### METHODS

#### **Data Sources**

*Wisconsin.* We obtained female BC incidence data from the WCRS for the period 1995-2006, the most recent years for which data were available. As required by state law, cancer cases are reported to WCRS by Wisconsin hospitals, clinics, and physician offices. All invasive and noninvasive malignant tumors, except basal and squamous cell carcinomas of the skin and in situ cancers of the cervix uteri, are reportable to WCRS. Incidence rates were age-adjusted using the 2000 US standard population and were calculated using NCI's SEER\*Stat software.

We obtained stage at diagnosis information for all incident female BC cases from WCRS, which codes cases based on Surveillance, Epidemiology and End Results (SEER) staging guidelines. Breast cancer was described as either in situ or malignant. Malignant breast cancer was further classified into localized, regional, distant/systemic, and unknown/unstaged. Precise American Joint Commission on Cancer staging is not currently available from WCRS.

Mortality data used in this study reflect Wisconsin resident death records from the Vital Records Section, Wisconsin Department of Health Services. We accessed female BC mortality data from the National Center for Health Statistics (NCHS) public use data file of Wisconsin deaths for the period 1995-2006. Population data used in calculating cancer rates are obtained periodically by NCHS from the Census Bureau; those used in this study were age-adjusted to the 2000 US standard population.<sup>14</sup> We used the SEER\*Stat software package to calculate mortality rates. We also applied race categories used by NCHS.<sup>15</sup>

United States. We obtained US female BC incidence and mortality rates between 1995 and 2006 from NCI's SEER public-used database.<sup>3</sup> SEER collects data from population-based cancer registries covering approximately 26% of the US population. Mortality data reported by SEER are provided by NCHS. All SEER rates are age-adjusted using the 2000 US standard population.

#### Analysis

In 2006, Wisconsin's overall population was 6% African American and 88% white, compared to 12% African American and 74% white nationally.16 There were relatively few African American BC cases in Wisconsin each year; thus, we calculated averages over 3 years of the incidence, mortality, and stage data during the period 1995-2006. We plotted the average female BC incidence and mortality rates over the period by race. To smooth the yearly fluctuation in rates, we plotted linear trends over the decade for the Wisconsin incidence and mortality data, as well as actual rates for US data. Next, we calculated the ratio of the African American incidence and mortality rates to the white rates (rate ratio) at the beginning and end of the period (1995-1997 and 2004-2006). This ratio constitutes our measure of relative disparity.<sup>17</sup> For stage data, we examined trends in the percentage of malignant cases by stage among African Americans and whites in Wisconsin for the period 1995-2006. Due to the small number of malignant cases, we were unable to age-adjust stage data.

#### RESULTS

#### Incidence

From 1995 to 2006, breast cancer was diagnosed in 46,266 Wisconsin women (44,156 whites and 1465 African Americans). During this period, age-adjusted BC incidence decreased 10% from 130 per 100,000 in 1995 to 117 per 100,000 in 2006. This was greater than the 7% reduction observed in the United States over the same period (132 per 100,000 to 123 per 100,000). BC incidence among African Americans was less than that of whites in all years dur-

Table 1. Age-Adjusted Breast Cancer Incidence and Mortality Rates<sup>a</sup>, Females, African Americans and Whites, Wisconsin and the United States, 1995-1997, 2004-2006

	1995 - 1997			200	2004-2006		
Rate	African American Rate	White Ratio <sup>b</sup>	Rate Rate	African American Rate	White Ratio <sup>b</sup>	Rate	
Wisconsin							
Incidence	108.3	131.1	0.8	103.0	121.2	0.8	
Mortality	29.1	27.7	1.1	24.2	22.9	1.1	
National							
Incidence	124.0	139.4	0.9	118.0	128.4	0.9	
Mortality	37.6	28.9	1.3	32.3	23.4	1.4	

<sup>a</sup> Rates are per 100,000 population and age-adjusted to the 2000 US standard population. Rates presented are 3-year averages.

<sup>b</sup> Ratio of African American rate to white rate.

Source: Wisconsin Cancer Reporting System (Wisconsin incidence); National Center for Health Statistics (Wisconsin mortality); Surveillance, Epidemiology, and End Results (SEER) Registry<sup>3</sup> (US incidence and mortality).

ing 1995-2006 in both Wisconsin and the United States (Figure 1). Compared to the national rates, BC incidence rates among whites were slightly lower in Wisconsin during 1995-2006. For African Americans, national incidence rates were nearly 15% higher than the Wisconsin rates in the beginning and end of the period, but slightly less than Wisconsin rates from 1998 to 2003. The relative disparity in BC incidence rates between African Americans and whites persisted in both Wisconsin and the United States over the period 1995-2006. The African American to white rate ratio was slightly higher nationally compared to Wisconsin (0.9 vs 0.8) during both 1995-1997 and 2004-2006 (Table 1).

#### Mortality

Between 1995 and 2006, there were 9610 deaths due to breast cancer among Wisconsin women (9192 whites and 353 African Americans). During this period, age-adjusted BC mortality decreased 23%, from 30 per 100,000 in 1995 to 23 per 100,000 in 2006. This was nearly the same as the reduction observed at the national level (26% reduction from 31 per 100,000 in 1995 to 23 per 100,000 in 2006). BC mortality rates were higher among African Americans than whites during the period 1995-2006 in both Wisconsin and nationally, although the absolute disparity in rates was greater nationally than in Wisconsin (Figure 1). While white rates were similar in Wisconsin and the United States, the mortality rate among African Americans was 4 to 8 points higher nationally. The relative disparity in BC mortality rates between African Americans and whites persisted in Wisconsin over the period (rate ratio 1.1 in 1995-1997 and 2004-2006). The national rate ratio was greater, and increased slightly, over the period (1.3 in 1995-1997 and 1.4 in 2004-2006).

#### Staging

Figure 2 shows breast cancer type at diagnosis over the period 1995-2006 for African Americans and whites in Wisconsin. For both racial groups, the proportion of all BC cases that were diag-

nosed as in situ increased over the period (from 12% to 20% for whites and from 14% to 23% for African Americans). Figure 3 shows that a greater percentage of malignant BC was detected at a later (regional or distant) stage for African Americans than whites (30% to 32% for whites compared to 41% to 48% for African Americans) during 1995-2006. The stage distribution in Wisconsin paralleled national patterns over the period 2000-2007.<sup>18</sup> Because stage data were not age-adjusted, these findings must be interpreted cautiously since differences in the age distribution of African Americans and whites may play a role in the distribution of breast cancers by stage.

#### DISCUSSION

Breast cancer incidence and mortality decreased over the period 1995-2006 among all women in Wisconsin, similar to declines observed nationally. In Wisconsin, incidence was consistently higher among white women than among African American women, while the opposite was observed for mortality. This pattern was similar to national trends. Wisconsin also paralleled national stage distribution data, revealing that a higher percentage of BC was detected at a later stage for African Americans than for whites. The relative disparity in cancer incidence and mortality between African Americans and whites in Wisconsin and nationally persisted over the period. Other Wisconsin reports have found that African Americans have a lower risk of receiving a diagnosis of BC but higher risk of dying from it.2,11-13 These reports aggregated data over several years, but did not present trends. The comprehensive analysis by Foote<sup>12</sup> from 2003 is the only Wisconsin report to measure relative disparities, but the author did not report change over time. By measuring trends in rate ratios, the present study provides evidence that while BC incidence and mortality have declined in general, Wisconsin has not made sufficient progress reducing BC mortality to eliminate racial disparities in survival.

A number of limitations should be considered when inter-



Figure 2. Distribution (percent) for breast cancer type at diagnosis, females, by race, Wisconsin, 1995-2006. Source: Wisconsin Cancer Reporting System.



preting the results of this study. First, the scope is limited to differences in BC incidence and mortality rates between African Americans and whites. The decision to focus on these 2 groups was determined by the demographic composition of Wisconsin and the rarity of cancer events. Wisconsin has relatively small non-white populations, making the comparisons in this report difficult to replicate between other racial or ethnic groups in the state. Second, WCRS, as a central state cancer registry participating in the National Program of Cancer Registries, maintains a passive system of data collection, and therefore, the various reporting facilities are largely responsible for the quality and timeliness of the data submissions to WCRS. The reliability of WCRS data has been detailed in previous reports.<sup>2,12</sup> In short, reporting variability may impact the relatively small numbers used in this analysis. In addition, there was an unknown degree of misclassification or underreporting of race.

Nevertheless, our results demonstrate that the "unacceptable reality"19 of BC disparity persists not only nationally, but within Wisconsin. The higher mortality rates observed in Wisconsin and nationally can be partially explained by the more advanced-stage distribution at diagnosis observed among African American women.14 Others have attributed the disparity to evidence that African American women are at greater risk for early onset of breast cancer and are often diagnosed with biologically more aggressive forms of disease.<sup>16,17</sup> Social, economic, and cultural factors may impact African American women disproportionately and may mediate the biological expression of disease.<sup>17, 20-21</sup> As many of these factors-such as poverty, inadequate health insurance, poor access to prevention, screening, treatment, fear of testing, and provider bias-are potentially modifiable, future efforts to reduce BC disparities should address them.

Many organizations in Wisconsin have focused on reducing disparities in breast cancer survival. The Wisconsin Well Woman Program, funded by the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program, provides breast and cervical cancer screening each year to approximately 10,000 low income, uninsured, and underinsured women, of whom approximately 10% are African American (compared to 6% of the general population). Various organizations, such as Susan G. Komen for the Cure, the American Cancer Society, the Wisconsin Women's Health Foundation, and the Kohl's Corporation, support programs that provide BC outreach and education, and facilitate access to BC clinical and treatment services for African American and other underserved populations. The state's Minority Health Program by the Wisconsin Cancer Council and the Wisconsin Breast Cancer Coalition, among others, succeeded in passing the Breast and Cervical Cancer Prevention and Treatment Act in 2000 and further ensured that the state of Wisconsin exercised its option to provide medical assistance through Medicaid to eligible women who are screened through the Well Woman program and who require treatment for breast or cervical cancer. More recent advocacy activity resulted in legislation that established an income tax check off box, creating the Wisconsin Breast Cancer Research Fund.

The Wisconsin Comprehensive Cancer Control Program, in collaboration with the Milwaukee Regional Cancer Care Network and the Center for Urban Population Health, created a publication titled *"Expanding Pathways to Care: Assessment of Cancer Care Capacity for Milwaukee and Waukesha Counties."* This publication is a reference with online access for providers to review recommendations for implementing Wisconsin's Comprehensive Cancer Control Plan and Healthiest Wisconsin 2010. This resource is important because a large portion of Wisconsin's African American population lives in Milwaukee County.<sup>16</sup> Finally, implementation of the 2010 Patient Protection and Affordable Care Act will expand access to BC prevention and screening services, particularly among Medicaid recipients.

However, these efforts also fail to address important new revelations about BC in African Americans. Recently presented data suggest that even when all suspected sources of disparity are controlled for (including socioeconomic status, stage, and hormone and human epidermal growth factor [HER2] receptor status), disparities in recurrence and survival still persist between African Americans and whites.<sup>22,23</sup> This suggests an underlying and probably biologic difference. This can be further elucidated only by evaluating these differences in a controlled clinical trial setting. However, a review of 197 trials found only 17% reported accrual by race and only 2% analyzed by race.22 Inclusion of diverse groups, including African Americans, in clinical trials will be crucial to interpret and extrapolate results to a diverse population. Increasing accrual of minority populations and improving reporting should be a priority in Wisconsin to reduce health disparities and achieve cancer control.

#### CONCLUSIONS

This study provides the most recent assessment of breast cancer health disparities in Wisconsin. Despite reductions in breast cancer mortality among both African American and white women during the period 1995-2006, disparities in BC mortality persist. This study identified a continued local need to evaluate and conduct research that targets disparities in BC outcomes. Understanding the causes of these disparities, barriers to access to prevention, screening and treatment, and obstacles to accruing minorities in clinical trials will help to reduce BC disparities.

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### Recruiting Latina Families in a Study of Infant Iron Deficiency: A Description of Barriers, Study Adjustments and Review of the Literature

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#### ABSTRACT

**Background:** Maternal minority status is a risk factor for iron deficiency in infancy and pregnancy. Because language and cultural differences may limit research participation, a prospective study examining iron deficiency included maternal minority status as an inclusionary criterion. Cognizant of potential barriers to recruitment, goals were to quantify eligible Latina enrollees and refusals, examine participation barriers, and devise possible solutions.

**Methods:** Mothers and their full-term newborns were eligible if the women were anemic, diabetic during pregnancy, of minority and/or lower socioeconomic status, and/or delivered an infant outside the average weight range for gestational age. Self-reported ethnicity and reasons for participation refusal were documented.

**Results:** During the first 18 months, 255 mothers and their infants were enrolled. Based on inclusionary criteria and the percentage of minority women admitted to the birthing center in a year, we anticipated 25% minority enrollees, with 16.3% Latina. Although 27% minority enrollment was obtained, only 8% were Latina (P < 0.01). System barriers, researcher perception barriers, and participant perception barriers were encountered. Over the next 8 months, addressing these recruitment barriers improved Latina enrollment.

**Conclusion:** Enrollment barriers are significant hurdles to overcome, but with increased understanding and effort, more successful inclusion of Latina families can be achieved.

#### INTRODUCTION

Adequate representation of ethnic and racial minorities in clinical health research is challenging yet necessary to evaluate and reduce health disparities among minority groups. Progress is often hindered by low overall rates of minority participation in studies and the paucity of information regarding the influence of these demographic variables in many clinical situ-

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ations.<sup>1,2</sup> Increased awareness of minority under-enrollment among health care professionals and researchers may motivate increased representation of minority groups in clinical studies, allowing for the discovery of scientific knowledge that could benefit diverse populations.

In 1993, the National Institutes of Health (NIH) implemented the Revitalization Act to mandate the inclusion of women and people of minority status in all NIH-funded clinical trials.<sup>2,3</sup> The NIH also required that clinical research grant proposals include recruitment strategies that enable addressing the impact of racial and ethnic minority status on clinical outcomes.<sup>4</sup>

The rapidly growing nature of the Latino population in the United States further highlights the need for adequate minority representation in clinical

research.<sup>5,6</sup> In Wisconsin, the site of this study, the Latino population has increased by 48.2% since 2000 and now constitutes 5.1% of the state's total population.<sup>7</sup>

The results being reported are a small portion of a larger prospective study in Madison, Wisconsin, that is investigating whether iron deficiency anemia (IDA) in infancy can be predicted by screening at-risk newborns for iron status at birth. Among other factors, maternal minority status is an important inclusionary criterion because iron deficiency is more prevalent among minorities.<sup>8-10</sup> Moreover, up to one-fifth of Latinas may not see a physician before the mid-trimester, likely impacting iron nutrition and the use of prenatal vitamins.<sup>11</sup> Inclusion of this at-risk and fast-growing population in clinical research is vital.

The research team anticipated the potential of recruitment barriers, although not to the extent that they were encountered. In the first 18 months of the study, half of the anticipated Latina enrollment was achieved, but enrollment improved as study adjustments were made. The goal of this paper is to increase awareness of several recruitment challenges by describing the barriers to Latina participation encountered in a prospective study of infantile IDA. We also describe adjustments to recruitment strategies as the study progressed and provide recommendations for optimizing minority representation in clinical research.

#### STUDY OBJECTIVES/METHODS Subjects

Joint approval from the Meriter Hospital and University of Wisconsin Institutional Review Boards (IRBs) was received and recruitment of English-speaking patients began in June 2008. After a 3-month delay for a formal Spanish-language translation process, joint approval to recruit Spanish-speaking patients was obtained. Following delivery, but before hospital discharge, mothers and newborns meeting inclusionary criteria were recruited.

#### **Inclusion Criteria**

Risk for IDA in infancy includes a number of pregnancy and demographic factors, including at least 1 of the following: maternal minority status, low socioeconomic status, maternal anemia, maternal diabetes during pregnancy, and/or infants showing evidence of fetal overgrowth or undergrowth.9,10 In this report, the term "Latina" refers to women who selfreported to be of Hispanic background. Mothers  $\geq 18$  or  $\leq 40$ years old with healthy term newborns born  $\geq$  35 weeks gestation were enrolled. From June 2008 to August 2010, research personnel screened electronic medical records for births with 1 or more of the 5 listed risk factors. According to IRB guidance, approval from the bedside nurse was required before approaching the mother for informed consent. When bedside nurses disapproved of approaching a screened candidate, the patient's ethnic background was recorded. For potential enrollees whose primary language was Spanish, a hospital-approved interpreter was required to interpret the consent process. For those who refused participation, ethnic background and reasons for refusal were recorded.

#### **Study Procedures**

Study requirements included the authorization to release maternal and child computerized medical records, including labor and delivery data, and follow-up data. Umbilical cord blood from delivery was obtained. To measure iron status, the study requested follow-up blood draws on the infant at an outpatient laboratory, and subsequently, in the second year of the study, in the participant's home upon request. The study was lowrisk, non-interventional, and minimally invasive. Participants received a grocery store gift certificate worth \$25 upon completion of each follow-up blood draw.

#### **Data Management**

The Meriter Hospital Birthing Center delivers approximately 3800 newborns per year. Using the hospital's electronic database, the ethnic and racial minority demographics of deliveries were collected. Chi-square and Fisher exact testing were used to examine observed and predicted enrollment rates on the basis of enrollee ethnicity.

#### RESULTS

#### Enrollment

In the first 18 months of the study, 255 mothers and their newborns were enrolled. Based on demographic information about ethnicity of deliveries from the prior year, 25% minority enrollment was predicted. Minority recruitment of 27% was observed, consistent with prior predictions. Using the African American enrollee percentage (13.5%) as the criterion to gauge the participation of other minorities, 16.3% Latina enrollment was anticipated. Although the expected values for other minority enrollees (ie, Asian) were observed, the number of Latina enrollees was half of the anticipated amount (P < 0.005). Recruitment strategies were adjusted by increasing identification of Latina enrollees, increasing recruiter work hours, involving family members earlier in the study consent process, and working more closely with hospital interpreters. Over the next 8 months of the study, 20% of the additional enrollees were Latina, increasing Latina enrollment to 10% of the overall study population.

#### Refusals

For the study's duration, there were 167 refusals, 65 (39%) of which were from women of minority status. Of the minority refusals, 18 were Latinas. Rates of refusal, based on potential enrollees screened are portrayed by race/ethnicity in Figure 1.

#### DISCUSSION

The goal of this paper is to increase awareness of barriers to enrolling Latino subjects in clinical studies by describing our experience and to provide recommendations from the literature for optimizing minority representation in clinical research. Although similar overall refusal rates were seen for each ethnic group, lower than anticipated rates of Latina enrollment were observed initially. One unique reason for Latina refusal was a disinterest in the study from other family members. However, the percent refusing did not fully account for the 50% lower initial Latina enrollment. It is probable that a culmination of factors initially prevented a proportionate number of Latina women from being approached by recruiters. With recognition of the hurdles discussed below and adjustments made to recruitment strategies, improved Latina participation was observed.

Problems with recruiting minority populations are often attributed to 3 barrier types.<sup>3,6,12</sup> System barriers are caused by



issues in study design and implementation, participant perception barriers are due to their understanding of research based on their personal history and prior experiences,<sup>12</sup> and researcher perception barriers are attributed to research staff avoidance of hard-to-reach populations due to limited time and resources.<sup>1</sup> All 3 barrier types were experienced during our study of IDA. The system barriers included difficulties with the IRB approval process, challenges in obtaining interpreters within the required window of time, and a shortage of bilingual study staff. Researcher barriers included recruiter and bedside nursing bias. Participant perception barriers included language and cultural barriers, and family members discouraging enrollment.

#### System Barriers—IRB Process and Expense

Better anticipation of expenses and delays is important for ensuring recruitment success. Although our hospital has a teaching mission as a component of the university's obstetrical service, it supports fewer active research protocols than a typical university hospital. Consequently, our research protocol was the first in this clinical setting to require and offer Spanish-translated study consent forms and materials, making the translation and approval processes challenging. In an effort to protect the rights of the study subjects, an independent, forprofit translation service was required to convert study materials to Spanish. At study conception, it was not anticipated that the translation process would cost \$800 and delay our ability to enroll Spanish-speaking participants by 3 months. Based on data from computerized medical logs, we estimate that at least 17 potential Spanish-speaking participants were excluded during this delay.

#### System Barriers—Interpreters

Understanding IRB requirements and/ or the process by which an interpreter becomes approved was also a critical issue, as a hospital-approved interpreter was required to translate the consent process. This requirement was not evident initially and proved to be challenging. In our study, women delivering vaginally were hospitalized for only 36-48 hours, offering a small window of time to allow for recovery, screening of potential participants, and obtaining interpreters. Because of their other important responsibilities, the interpreters' schedules were often unpredictable, and part-time research recruiters or potential subjects commonly could not wait for the interpreter. Recruiters estimated that at least 11 Spanish-speaking potential partici-

pants were missed because the interpreters were unavailable.

Although interpreters are present to ensure linguistic proficiency, other researchers have noted that interpreters not directly involved with a study may also inadvertently impersonalize communication, making it more difficult to engender and build trust with the research team.<sup>13</sup> While well-trained for clinical duties, interpreters may not necessarily be trained or as invested in clinical research. This experiential background may be critical, because precise wording during recruitment is essential, ie, the use of the Spanish word for "study" rather than the more threatening "experiment."<sup>3</sup>

#### System Barriers—Resources

In our study, the lack of full-time, approved bilingual research staff may have impaired recruitment of Latina subjects. Sources explain that a lack of research staff diversity may be detrimental, as potential participants prefer study personnel who "look (and speak) like them."<sup>14,15</sup> Financial support for bilingual perinatal research nurses was not available through our Clinical Research and Translational Core grant. E-mail correspondence with staff from the Wisconsin Nurses Association revealed no mechanism to quantify the number of bilingual nurses currently practicing in the state. However, the Wisconsin Nurse Faculty Task Force has acknowledged, "the current workforce and the nurse educator workforce does not reflect the diversity of the state."<sup>16</sup>

This type of staffing problem seems to be less salient in the geographic West and Southwest, which have larger bilingual health care workforces, as compared to a region such as the Midwest. Perinatal studies in the Southwest with similar sample sizes report more Latina enrollees, supporting fewer barriers to enrollment.<sup>17,18</sup>

#### System Barriers—Study Design

Recognizing potential barriers in study design is important to ensure a more diverse representation. Previous reports recommended using community outreach and direct access to clinics serving hard-to-reach targeted populations.<sup>6,14,19</sup> Both approaches were investigated but proved unhelpful, because Latino health fairs were held infrequently, and the prenatal clinics predominantly serving Latinos were not interested in collaborating.<sup>5</sup> Our project was somewhat constrained by limited budgetary resources to support research nurses, deeming inpatient screening to be more time efficient than clinic screening.

#### **Perception Barriers—Researcher Bias**

While other published reports have noted some mistrust and misperception of Latinos toward research, a reverse bias may be as important.1 Because refusal rates were similar between all ethnic groups, it is probable that in the first 18 months of the study, recruiters did not approach qualified Latina candidates at a rate proportional to other groups. In the next 8 months, after adjustment of recruitment strategies, improved Latina recruitment was seen. Although candidates were identified by the use of electronic census logs, additional required steps were necessary to determine whether a Spanish interpreter was necessary. If so, time invested for recruitment of Latinas was commonly doubled, likely causing the busy recruiters to preferentially seek easier-to-identify subjects. The literature discusses the theory of "The Good Study Patient," which proposes that with a short timeline, unpredictability of interpreter arrival, limited resources, and need for follow-up, recruiters may be pressured to seek out participants implicitly perceived to be most compliant.<sup>1,14</sup> Additionally, bedside nurses may inadvertently introduce some bias because they determine whether researchers are allowed to approach potential enrollees. Six of the 18 Latina refusals were because bedside nurses suggested avoiding potential subjects due to their perceived likelihood of poor follow-up, social issues, or because the patient "appeared" overwhelmed.

#### **Participant Perception Barriers—Communication**

Translating legal terminology and the sometimes subtle intent of an English consent form into a written Spanish document can be challenging. Additionally, the enrollee's spoken and written Spanish proficiency may not be equivalent.<sup>15,20</sup> Many Spanish dialects are spoken, and assuming "one Spanish translation of a consent form fits all" is unrealistic.<sup>5</sup>

The support and involvement of "la familia" is crucial.<sup>6,15,21</sup> Ineffective communication with the potential participants may cause a reliance on family members for the information,<sup>3,6,13,22</sup> potentially contributing to miscommunication and lower enrollment. We observed a reliance on family and hesitation to independently make participation decisions by Latinas more often than in African American or white mothers. In at least 1 situation, English proficiency of a mother, but not of other family members, negatively influenced enrollment, suggesting that using interpreters involved with the study may be helpful, even with a mother who comfortably speaks English.

#### **Participation Perception Barriers—Culture**

Despite the use of interpreters and translation services, it is important to recognize that a study is not guaranteed to be culturally appropriate.<sup>5</sup> Minority mistrust and fear of medical research is widely recognized,<sup>23</sup> with the expectation of poor service, lack of culturally competent providers, and long waiting times for interpreters.<sup>24</sup> In research involving genetic testing, where the donation of a blood or tissue sample was required, minority status was linked to lower rates of participation, with concerns about data misuse, racial discrimination, and unequal access to the potential research benefits.<sup>25</sup> History of inappropriate use of minorities in medical research is also of concern, specifically as a result of the infamous Tuskegee Study on syphilis for African Americans.<sup>2,23,25</sup>

Undocumented immigrant status among the Latino population may contribute to under-enrollment because of a fear that their status may be discovered.<sup>5,6,15</sup> Because of this concern, grocery cards or check rewards may not be culturally appropriate participation incentives as identifying documents are required for redemption.<sup>26</sup> Cash as a research incentive may be optimal, but university policies may require social security numbers and contact information for tax and accounting purposes.

Changes of contact address and phone number were often encountered, illustrating the more transient nature of the Latino population. To compensate, the study design allowed tracking of the updated address and/or 12-month hemoglobin value, the primary study endpoint, in the electronic medical record. Literature demonstrates that mobile residency patterns have also been an issue in other clinical studies.<sup>19,21</sup> Other researchers have speculated that potential Latina participants are unwilling to commit to long-term research when their living situations are temporary, the study is a low priority for them, and medical concerns of potential participants and researchers are mismatched.<sup>6,12,14</sup> For example, when surveyed, neonatal and immediate pediatric care were reported as being of utmost importance to health care professionals, but not for the Latinos.<sup>24</sup>

#### **CONCLUSIONS AND SUGGESTIONS**

The difficulty in recruitment and retention of Latinos in clinical health research is an ongoing challenge. The list of barriers to recruitment is substantial, but with careful study design and practice, can be minimized or largely eliminated.<sup>15</sup> The goal of sharing this experience is to offer suggestions for improving recruitment of Latino, as well as other minority and hard-to-reach populations.

More collaboration between researchers, providers, and the surrounding community is key. An initial step could be gaining better support from community gatekeepers, ie, church leaders, civic leaders, and community health care professionals to help garner trust within a community.<sup>6,13-15</sup> Researchers and community leaders can then help to refine a greater awareness of the health priorities of a given community.<sup>14,27</sup> and when possible, frame study goals within these priorities. Although most studies, like this one, set forth a broad goal to include minorities as a critical subset of the participants, the study name and materials could be modified to be more appropriate for all subgroups. For example, in our case, some Latinos were more familiar with the term "low hemoglobin" than "iron deficiency," so the study name could ideally accommodate this cultural preference.

Some of the steps toward a balanced representation in clinical research likely will be costly, and funding agencies will need to recognize the added cost. The availability of some financial support from the university or hospital to cover required professional translation expenses would be helpful. Institutions should focus on training more bilingual clinical and research personnel or increasing training of clinical hospital interpreter teams in research methodology.<sup>16</sup> Ideally, bilingual research team members could make recruitment and follow-up phone calls to help build more empathetic relationships between the subject and the researcher,<sup>15</sup> and generally, to serve as health care advocates for the participant.<sup>23,26</sup>

Sensitive approaches to recruitment begin with recognizing cultural values.<sup>6,14,15</sup> Because of the importance of family in the Latino community,<sup>6,15,21</sup> research methods should encourage family involvement. The study budget could also include the cost of taxicabs to transport participants without vehicles to and from follow-up appointments, as well as to provide a child-friendly research site for the other children.<sup>11,15,21,26</sup> Flexibility with the times of phone calls and appointments and Spanish signage in clinics where follow-up appointments take place would increase ease of participation. Incentives should be culturally appropriate, including cash rewards if possible. To give more back to participants, researchers should provide study updates and employ results in a way that would benefit the community,<sup>14,27</sup> including the distribution of educational materials to promote health and well-being.<sup>6,26</sup>

Despite lower than anticipated initial enrollment in our study, Latina representation was improved after awareness of several of the discussed barriers to participation. By increasing the availability of the recruiters, employing a native Spanish speaker to make study-related phone calls, recognizing some of the culturally sensitive issues for the participants, and accommodating family involvement in the consent process, a more balanced study population was achieved.

As maternal minority is a risk factor for iron deficiency and other health disparities, it is imperative that the mothers and infants of diverse populations be adequately represented. Although it may require an extra investment of time and resources, communities, health care professionals, and researchers must continue to prioritize the attainment of greater diversity in studies to achieve the goal of improving health among all populations.

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### **Culturally Specific Maternity Care in Wisconsin**

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#### ABSTRACT

There are significant health disparities in maternity care in the United States. One way to decrease these disparities may be to improve prenatal care among underserved minority women. This article reviews cultural and ethnic issues that may impact maternity care within 5 different groups of women commonly seen by maternity care providers in Wisconsin: African American, Latina, Hmong, Amish, and immigrant women. Understanding concerns that are specific to each group (such as higher rates of gestational diabetes in Latina women or desires to limit pelvic exams among Hmong women) may help clinicians provide more patient-centered maternity care.

#### INTRODUCTION

There are significant health disparities in maternity care in the United States. One way to decrease these disparities may be to improve prenatal care among underserved minority women. A tenet of the patient-centered medical home model includes patient-centered care. In order to provide patient-centered maternity care, the clinician must be knowledgeable about each woman's culture, race, and ethnicity and the unique risks that each may bring to her pregnancy. By being patient-centered, the clinician may be able to positively impact pregnancy outcomes. This article provides culturally specific information about 5 groups of women: African American, Latina, Hmong, immigrant, and Amish.

#### **AFRICAN AMERICAN WOMEN**

There has been a marked decline in maternal mortality in the United States for African American and non-Hispanic white (white) women since the 1940s. Historically, the maternal mortality ratio has been consistently higher for African American women.<sup>1</sup> (Table 1) The causes of maternal mortality—includ-

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ing hypertensive disorders of pregnancy, postpartum hemorrhage, and cardiomyopathy—are equally prevalent for African American women as for white women, but mortality from these conditions is 2 to 3 times higher for African American women.<sup>2</sup>

The African American infant mortality ratio (IMR) also has been consistently higher than that of whites. From 1980 to 2000, the white IMR declined from

10.9 to 5.7 per 1000 live births while the African American IMR declined from 22.2 to 14.0 per 1000 live births.<sup>3</sup> In 2006, the overall IMR was 6.69 per 1000 live births with African American IMR being 2.4 times greater than the white IMR.<sup>4</sup> Madison, Wisconsin, is an exception to this comparative difference in infant mortality. From 2002 to 2007, the African American IMR equaled that for whites. It is not certain why African American IMR seem intractably higher in much of the country, or why it dropped so markedly in Madison.<sup>5</sup>

An important factor contributing to the higher African American IMR is the higher rate of preterm delivery and low birth weight (LBW) and very low birth weight (VLBW) babies. Preterm delivery accounts for 70% of perinatal deaths not attributable to chromosomal anomalies.<sup>6</sup> In 2000, the African American rate of LBW infants was 13% and VLBW infants was 3.7%, compared with 6.5% and 1.14% respectively for white.<sup>3</sup> In Madison, the drop in African American rate of VLBW infants to 2% and in delivery at 28 weeks or earlier to 1.1%, which may be a causative factor.<sup>5</sup>

Sickle cell disease is an autosomal recessive disease. One in 12 African Americans has sickle cell trait and 1 in 300 has sickle cell disease.<sup>7</sup> The American College of Obstetricians and Gynecologists<sup>7</sup> recommends that women of African descent be offered sickle cell screening with a complete blood count and be offered genetic counseling.<sup>7</sup> Women with sickle cell disease in pregnancy are at increased risk of miscarriage, stillbirth, intrauterine growth restriction, and preterm labor.<sup>8</sup>

Lack of access to prenatal care may contribute to inferior

perinatal outcomes. In a study of over 14 million births, the preterm birth rate was 15.1% for African American women who received prenatal care and 34.9% for those who did not.<sup>6</sup> African American women are 3.2 times less likely to have prenatal care than are white women.<sup>6</sup> Lack of preconception care (care prior to pregnancies), inter-conception care (care between pregnancies), and primary care may play as much of a role in pregnancy outcomes as care during a pregnancy.<sup>9,10</sup>

Being healthy prior to pregnancy with the help of quality primary care affects outcomes. A 50-state study found that an increase of 1 primary care doctor per 10,000 population is associated, on average, with a 2.5% reduction in infant mortality and a 3.2% reduction in LBW infants.<sup>9</sup>

Racism and the legacies of racism may play a role in worse prenatal care outcomes for African American women. Examples of racism in health care include the Tuskegee study where the US government conducted syphilis experiments on African Americans without their knowledge, as well as birth control/ eugenics practices/forced sterilization, and neglect of black patients. Less than 60 years ago, health facilities were legally separated by race, and today many clinics and hospitals with mostly African American clients are underfunded and understaffed.

Interviews of African American women found that stress and racism play a part in their reported pregnancy experiences.<sup>11</sup> Racism has many layers including "women's childhood experiences and their potentially enduring impact, perceptions of institutionalized racism and internalized negative stereotypes, vicarious experiences related to their children, vigilance in anticipating future racism events, as well as the pervasiveness and chronicity of racism exposure."<sup>12</sup> Distrust of the health system is a complex topic and studies show varying results; 1 study suggests that African Americans value characteristics such as provider respect, care, and confidentiality more than technical competence.<sup>13</sup> The experience of racism has been linked to VLBW infants in African Americans.<sup>14</sup> However, African American women who see their provider as caring and competent will use the health system more.<sup>15</sup>

Beyond provider attitudes and interactions, economic racism and structural racism are intangibles that may affect pregnancy outcomes of African American women. While African American women face racism and often have worse birth outcomes, there are many strengths commonly found in African American communities. Intergenerational family support and multigenerational families have been an asset for many African American women.<sup>16</sup>

#### Latina Women

The Latino population in the United States is made up of a diverse group of people from Spanish-speaking regions in North and South America as well as in the Caribbean. Despite the fact that Latinos are among the most socioeconomically

Table 1. Maternal Mortality Ratio between African American and White
Women (African American Maternal Deaths per 100,000 Live Births/White
Maternal Deaths per 100,000 Live Births)

Year	Ratio
1940	2.4
1950	3.6
1960	4.1
1970	3.9
1980	3.4
1990	3.3

disadvantaged groups in the United States, Latina women have some of the most favorable birth outcomes. This has been called the Latina Paradox.<sup>17</sup> The most favorable outcomes occur in women from Mexico and Central America who have recently immigrated to the United States, compared with more acculturated women.

Latina women often enter prenatal care late in pregnancy. Only 57.7% of Latina women receive prenatal care in the first trimester, as compared to 76.2% of white women.<sup>18</sup> However, despite this difference, Latina women still have better birth outcomes with less fetal demise and preterm birth than most other ethnic groups. Latina women have a higher risk of congenital abnormalities. There is a higher incidence of neural tube defects among Latina women—4.18 per 10,000 births compared to 3.37 and 2.9 per 10,000 births for white and African American women.<sup>18</sup> According to data from the Centers for Disease Control and Prevention (CDC), adequate intake of folic acid remains low in the Latino population in the United States. One subgroup of Latina women, women from Puerto Rico, is at higher risk for preterm and low birth weight births.<sup>18</sup>

Latina women have lower risk of maternal mortality compared to other women.<sup>18</sup> The risk of hypertensive disorders is low in Latina women. However, Latina women have twice the rate of preeclampsia when compared to white women.<sup>19</sup> Latina women have higher rates of obesity and diabetes before becoming pregnant. In addition, they have higher rates of gestational diabetes. In a retrospective cohort study of almost 140,000 women, 4.9% of Latina women developed gestational diabetes as compared to 3.4% of white women and 3.2% of African American women. In this study, Asian women had the highest risk of gestational diabetes mellitus (GDM) at 6.8% (P<0.001).20 During delivery, Latina women are at a higher risk of having a caesarean section. In 1 study, Latina women had a 1.19 times greater risk of c-section despite adjusting for known risk factors such as pre-existing disease and pregnancy complications.21

The Latina Paradox does not apply only to birth outcomes. There is a lower all-cause mortality among Latinos in most age groups except for young adult males. It remains unclear what accounts for the Latina Paradox. Some researchers have attributed the improved health outcomes to only healthy immigrants coming to this country. Others feel there are cultural and social protective factors. There is strong cultural support for maternity and healthy behaviors as well as social support of other family members—sisters and extended family—in new immigrants.<sup>17</sup> These protective factors seem to disappear in future generations.

#### **Hmong Women**

The Hmong people, native to Laos, were forced to flee due to persecution after US troops left Vietnam. The United States accepted a majority of these refugees as immigrants. Based on 2000 US Census data, the Hmong population in the United States is 169,428. California, Minnesota, and Wisconsin, respectively, have the largest reported Hmong populations in the United States.<sup>22</sup>

There are 18 recognized clans in the patriarchal Hmong society. Decisions are made by the eldest male family member with input from other male members of the clan.<sup>23</sup> The Hmong place a significant emphasis on large families. Hmong culture traditionally views pregnancy and childbirth as the "major contribution" that a woman makes to the family.<sup>24</sup>

There are many barriers to integrating into the Western medical system for Hmong patients.<sup>23</sup> The largest barrier is language. There are no Hmong words for many Western medical and anatomical terms.<sup>23</sup> Another barrier for Hmong women, who are extremely modest, is the physical exam. Not understanding the different perspectives on health may present another major barrier between Hmong people and Western medicine.<sup>25</sup> Hmong patients seek trusting relationships and behaviors that demonstrate caring. These have greater value than medical skill.

A study of 648 Hmong women found that one-third did not start prenatal care until the third trimester and only one-sixth sought care in the first trimester.<sup>24</sup> Another study of 141 Hmong couples reported that 60% began prenatal care in the first trimester when delivering infants in the United States.<sup>26</sup> A study of 52 Hmong women found that common barriers to initiating early prenatal care included transportation, language, and not wanting to be examined.<sup>24</sup> Some Hmong patients believe that being touched by a doctor or having an ultrasound in the first half of the pregnancy may cause a miscarriage.<sup>24,27</sup> Others believe that Western medical care is for illness, and pregnancy is not considered an illness.<sup>28</sup> Many Hmong women believe that pelvic exams violate their privacy.<sup>25,28,29</sup> Many Hmong women experienced sexual assault and rape in refugee camps, and pelvic exams may cause significant emotional trauma for these women.<sup>28</sup>

Traditionally, Hmong women follow a healthy diet and very rarely use caffeine, tobacco, and alcohol;<sup>28</sup> however, younger Hmong women assimilated to American culture should be asked about the use of these substances during pregnancy.

Whereas pregnancy is considered a "hot" state, the delivery

process is considered a "cold" experience and puts the Hmong woman at risk of soul loss.<sup>25</sup> To protect modesty, drawing curtains, draping appropriately during pelvic exams, and limiting vaginal exams during labor may be helpful, when appropriate.<sup>25</sup>

Protective jewelry, which can include silver or copper necklaces and string or yarn bracelets, should not be removed unless absolutely necessary.<sup>25,28</sup> These are believed to tie the soul to the person's body and removal could cause soul loss, illness, and/ or death.<sup>28,30</sup> Review of herbal medications being used by the laboring patient is important so any potential interactions with pharmaceuticals can be avoided.<sup>25</sup>

Preterm deliveries are less frequent in the Hmong population. Only 1% preterm deliveries were reported in 1 study, compared to 11.9% in the general US population during the same time period.<sup>26</sup> In 1 study of 430 Southeast Asian (SEA) women in the United States, grand multiparity, short interpregnancy intervals, anemia, parasitic infections, and hepatitis B were frequent findings.<sup>31</sup> Fetal distress, dystocia, and cephalopelvic disproportion are uncommon in Hmong women.<sup>28,31</sup> Birth weights are similar to the comparison non-Hmong population until 39 weeks gestation, after which Hmong neonates are significantly smaller.<sup>31</sup> Invasive procedures are discouraged in the Hmong culture and low rates of amniotomy, episiotomy, and cesarean sections were noted.<sup>31</sup>

#### **Perinatal Health and Immigration**

Research on the impact of migration status on perinatal health outcomes has shown conflicting results. Some studies show negative associations between maternal and neonatal mortality and complications in labor,<sup>32,33</sup> while others demonstrate "the healthy migrant effect" in which immigrants have less preterm birth or low birth weight compared to the host country women.<sup>34-37</sup> These observations are based on the theory that people who are more able to migrate and be mobile are healthier and generally have better birth outcomes than those who do not move. Thus, the better birth outcomes observed among foreign-born women, compared to US-born women, stem in part from a "selection bias" prior to conception. Additionally, acculturation and the incorporation of the norms and behaviors of the host country may negatively impact the health of subsequent generations after immigration.<sup>34-37</sup>

One of the largest studies on pregnancy outcomes in immigrant women included a retrospective cohort study of all deliveries at Grady Memorial Hospital in Atlanta, Georgia, from 1991 to 2002. A total of 49,904 deliveries were analyzed, and 27% were foreign-born from 164 countries. Compared with US-born women, foreign-born women had a higher mean birth weight (3315 g vs 3083 g), and a lower risk of preterm delivery, perinatal mortality, hypertension, and HIV infection. However, foreign-born women had an increased risk of diabetes, perineal laceration, and postpartum hemorrhage. The reasons for these population differences were not well understood.<sup>37</sup>

One recent systematic review included 23 studies of maternal fetal health outcomes for immigrant women in western, industrialized countries including the United States, Europe, and Canada. Most studies used populationbased data registers. Migrants' results for preterm birth, low birth weight, and health-promoting behavior were as good as or better than as those for receivingcountry women in greater than 50% of all studies. Meta-analyses of different ethnic groups, however, found that Asian and sub-Saharan African migrants

were at slightly greater risk of feto-infant mortality than "majority" receiving populations. Additionally, Asian and sub-Saharan African migrants were at greater risk of preterm birth. The same study showed that Latin American migrants in the United States had a lower risk of preterm birth.<sup>38</sup> A separate study of Latina women in the United States found evidence to support infants born to Mexican migrants had a lower risk of low birth weight and small-for-gestational age compared to those who were of the same ethnicity but did not migrate.<sup>36</sup>

Results of epidemiologic data must be interpreted with caution as experimental design varies considerably across studies. Socioeconomic factors or whether comparison groups included all host-country women or host-country women from the same general ethnic group are of particular importance. The circumstances of immigration and refugee status, time in country, and language fluency preclude making generalizations about the health status of immigrants.

#### **Maternity Care of Amish Women**

Old Order Amish adhere to Christian traditions dating to 17th century Switzerland. Amish believe in remaining separate from the world, so they avoid having electricity or telephones in the home. Each congregation of 20 to 40 families is autonomous, with a set of rules, the Ordnung, and male leaders are selected by drawing lots. Amish people marry young and contraception is not condoned, so families are often large.<sup>39</sup> A retrospective study of 475 Amish women in Ohio found that women over 44 had an average of 8.3 live births during their lifetimes.<sup>40</sup> Livelihoods typically revolve around small farms, carpentry, and crafts.<sup>41</sup> Families can theoretically live as they choose within the bounds of the Ordnung, but in practice, community norms dictate many details of daily life. Families

#### Box. Clinical Pearls for Maternity Care Providers in Wisconsin

Screen pregnant African American women and those considering pregnancy for sickle cell trait with a hemoglobin electrophoresis.

When treating immigrant women, don't make assumptions because immigration status is a broad concept depending on length of time in country, economics, language, and circumstances of migration.

Hmong women are extremely modest; therefore, protective measures such as drawing curtains, draping appropriately during pelvic exams, and limiting vaginal exams during labor, should be considered by health care providers, when appropriate.

Hmong society is patriarchal, and decisions are often made by the eldest male family member with input from other male members of the clan.

Amish do not participate in insurance schemes and are very sensitive to cost. It is helpful to provide the cost of any visit, procedure, or intervention along with counseling of risks and benefits.

Amish families have wide latitude to do what they think is right within the bounds of the community's Ordnung, so don't assume an Amish patient will automatically decline an examination or intervention on religious grounds.

Latina women have lower rates of maternal mortality, but higher rates of pre-eclampsia and gestational diabetes as compared to white women.

are patriarchal and submission to church, husband, or father is enforced.

Amish people generally enjoy good health thanks to a lifestyle that includes plenty of exercise, a healthy diet, and low rates of tobacco and alcohol use. There is not a lot of evidencebased research within this community.<sup>42</sup> One populationbased survey of 288 Amish women in Pennsylvania found that Amish women had fewer LBW babies but the same number of preterm babies as a comparison group.<sup>43</sup> Amish women have similar infant mortality to a comparable white population.<sup>40</sup>

Several Amish health care beliefs pose challenges to medical providers. Support is limited for preventive measures, although some families are open to Rhogam. Medical interventions may be shunned in favor of natural remedies or sham treatments that are actively promoted to this community. Women may delay entry into prenatal care or seek care from lay providers instead of medical professionals.<sup>44</sup> Women who suffer miscarriage or stillbirth may struggle with what they've done to precipitate "God's wrath." Financial and legal concerns prevent some Amish people from seeking care from physicians. The cost of a hospital birth may exceed a family's annual cash income.<sup>44</sup>

Certain Amish cultural norms present challenges to maternity care providers as well. Children are told that babies arrive directly from heaven so one cannot discuss peripartum issues in the presence of adolescents or children. The man often speaks for his wife, and makes health-related decisions, and may decline or delay treatment, raising concerns for control or abuse issues.<sup>45</sup> Barriers to the identification of abuse include male domination and pressure to resolve issues within the community. Genetic disorders including maple syrup urine disease and Crigler-Najjar syndrome are prevalent among Amish people because of "founder's effect": most Amish descend from about 200 18th century immigrants.<sup>46</sup> Amish people are aware of health risks of consanguinity and do not marry close relatives. Spontaneous chromosomal anomalies including Down syndrome are seen at rates similar to other communities. Routine genetic screening is not done, so careful reviews of family history are essential to identify risks of genetic disorders.

#### CONCLUSION

Maternity care providers will benefit from more culturally specific information about their patients. Understanding the unique characteristics of each pregnant patient may improve care and reduce disparities.

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## Rare Association of Henoch-Schönlein Purpura with Recurrent Endocarditis

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#### ABSTRACT

We report a rare association of Henoch-Schönlein Purpura with recurrent endocarditis in a 36-year-old man presenting with rash and renal failure. Bacterial endocarditis can be complicated by renal failure of various etiologies. Biopsy may distinguish these and guide therapy as seen in this case. Here, timely diagnosis of Henoch-Schönlein Purpura in the setting of recurrent methacillin sensitive staphylococcus endocarditis led to steroid therapy and renal recovery. This is a rare reported case of Henoch-Schönlein Purpura during an episode of recurrent adult endocarditis that also highlights the complex interplay between genetic susceptibility and immune responses.

#### **CASE REPORT**

A 36-year-old man with a history of intravenous drug use initially presented with 3 weeks of fevers, chills, night sweats and malaise. He had a history of remote native tricuspid valve endocarditis with methacillin sensitive staphylococcus aureus (MSSA) 6 years earlier. Then, septic embolic complications required debridement of his tricuspid valve and several months of antibiotic therapy. He had recovered and was in good health until his current illness began sub-acutely with daily fevers greater than 101°F. At his first clinic evaluation, a white blood count of 22,000 prompted an injection of intramuscular ceftriaxone followed by oral cephalexin. No blood cultures were obtained. The next day he developed a diffuse, tender, purple raised rash on his arms and legs and then abdomen. Four days later, at a local emergency department, cephalexin was stopped, based on possible drug-induced vasculitis, and he was given a short course of dexamethasone. He had had no previous history of cephalosporin allergy, purpura, or leukocytoclastic vasculitis. A week later, with ongoing fevers and rash, he was admitted to the hospital. Then the patient reported diffuse

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**Corresponding Author:** Jilaine Bolek Berquist, MD, Mercy Health System, Mercy Clinic East, 3524 E Milwaukee St, Janesville, WI 53546; phone 608.756.7100; e-mail jbolek-berquist@mhsjvl.org. arthralgias and abdominal pain without hematochezia. Steroids were stopped. A urinalysis showed hematuria and pyuria, and he was treated with levofloxacin for presumed urosepsis. Biopsy of a rash lesion was sent for pathology. On hospital day 2, blood cultures returned positive for MSSA. Antibiotic coverage included vancomycin, followed by daptomycin. Computed tomography of the

chest showed multiple abscesses. A transesophageal echocardiogram showed a 1.6-cm vegetation on the lateral leaflet of the tricuspid valve and severe tricuspid regurgitation.

Upon rheumatology consult after transfer, the patient reported improving arthralgias, ongoing abdominal pain, and remaining rash on his extremities without evolution. His exam was notable for a pansystolic murmur heard best over the left lower sternal border, lack of synovitis, and numerous 1- to 3-mm, non-blanchable, dark-red macules and voilaceous papules. About 90% of his body surface area was involved, with the extremities being more severely affected, and sparing of the head, neck, palms, and soles. Laboratory data at the time are provided in Table 1.

Review of the prior skin pathology report described leukocytoclastic vasculitis with IgA deposition on immunoflourescence. Nevertheless, given worsening renal function and potential therapeutic implications, a renal biopsy was obtained. This demonstrated focal, segmental proliferative glomerulonephritis with IgA and C3 staining and few subendothelial deposits (Figure 1). Staining was negative for immune complexes, and no thrombi or crescents were noted on light microscopy with H+E staining. The patient's clinical picture and biopsy results confirmed a diagnosis of Henoch-Schönlein Purpura (HSP) with renal involvement in the setting of recurrent native tricuspid valve endocarditis with MSSA.

#### DISCUSSION

We present a rare association of Henoch-Schönlein Purpura with endocarditis in an adult patient. As in this case, renal failure may accompany one-third of endocarditis cases, and pathology is often imperative, particularly in light of the broad differential diagnosis (Table 2).<sup>1-3</sup> Renal pathology was instrumental in this case to unify the skin pathology and renal disease, and reach a definitive HSP diagnosis. When HSP was confirmed, this case was particularly interesting in light of his prior MSSA endocarditis episode that did not precipitate vasculitis.

HSP is characterized by the triad of arthritis, purpura (Figure 2), and colicky gastrointestinal symptoms.<sup>4</sup> Histological evidence of granulocytes in the walls of small arterioles or venules plus IgA-dominant immune deposits confirms the diagnosis in appropriate clinical settings. HSP is primarily a disease of children that is typically self-limited, but 10% of cases occur in adults where features and outcomes may vary. In both children and adults, HSP often spontaneously resolves. More severe renal disease imposes significant morbidity and is often an indication for steroid treatment. When compared to children, adults with HSP have a lower frequency of abdominal pain and fever, a higher frequency of joint symptoms, and more frequent and severe renal involvement.<sup>5</sup> Adults are therefore more likely to require aggressive therapy, including steroids or cytotoxic agents. The prognosis for adult patients with HSP nephritis is also worse than in children. In a large cohort of 250 cases of HSP nephritis in adults, 11% reached end-stage renal failure and 13% had severe renal failure defined by creatinine clearance < 30 ml/min.6 Full renal recovery was achieved in only 20%. Survival was only 74% at the end of follow-up after a median of 14.8 years.

The underlying pathogenesis of HSP remains unknown. Streptococcal infections, staphylococcal infections, vaccinations, medications, and even insect bites all have been implicated as possible triggers, although some cases lack a clear precipitating event.<sup>5</sup> In cases with an identifiable trigger, upper respiratory infections and medications, including beta-lactam or cephalosporin antibiotics, are the most frequent culprits. One study of 6 cases with staphylococcus-associated HSP nephritis demonstrated a unique profile of T-cell receptor activation and cytokine production that normalized following clearance of infection.<sup>7</sup> The outcome of these 6 patients was poor, including 2 deaths and 2 patients requiring maintenance hemodialysis.

To date, only 2 cases of adult endocarditis-associated HSP have been described in the English literature, and no cases involved recurrent endocarditis. The first case report described a 21-year-old man with a history of IV drug use and right-sided staphylococcal endocarditis who developed skin and renal-biopsy-proven HSP.<sup>8</sup> When the endocarditis was initially diagnosed, prior to the onset of HSP, he received cloxacillin and netilmicin, so it was impossible to know whether the drug or the infection was the precipitating event. Like our patient,

Test	Patient Value	Normal Range
WBC (K/uL)	4.9	3.8-10.5
Hemoglobin (g/dL)	8.7	13.6-17.2
Hematocrit (%)	28	40-52
Platelet (K/uL)	160	160-370
Creatinine (mg/dL)	2.0	0.6-1.3
Albumin (g/dL)	1.7	3.3-4.7
CRP (mg/dL)	4	0-1
ESR (mm/Hr)	94	0-15
Urinalysis	6-10 RBC	0-2
	2-5 WBC	0-2
Protein/creatinine ratio	1.6	0
C3 (mg/dL)	139	90-180
C4 (mg/dL)	17	10-40
IgA (mg/dL)	586	50-450
c-ANCA, p-ANCA	Negative	Negative
Cryoglobulin	Negative	Negative
ANA	Negative	Negative
HIV 1 and 2 antibody	Negative	Negative
Hepatitis B surface antigen	Negative	Negative
Hepatitis C antibody	Negative	Negative

WBC=white blood count; CRP=C-Reactive Protein; ESR=erythrocyte sedimentation rate; C3=complement component 3; C4=complement component 4; ANCA=anti-neutrophilic cytoplasmic antibody; ANA=anti-neutrophilic antibody.



Figure 1. Immunoflourescence of the patient's renal biopsy showing a glomerulus with diffuse and segmental IgA staining.

he had multiple pulmonary cavitary embolic lesions and large bilateral effusions. At discharge, that patient had mild proteinuria, but did not require steroids, though he was lost to followup. The second report described a 41-year-old woman with left-sided streptococcus sanguis subacute bacterial endocarditis who presented with a purpuric rash prior to the diagnosis of endocarditis.<sup>9</sup> The rash was biopsy-proven to be consistent with HSP. She was started on ampicillin and gentamicin, and eventually underwent mitral valve replacement. Due to renal fail-



ure, she received methylprednisolone, although a kidney biopsy was not performed. Renal recovery status was not reported.

Our patient went on to develop more severe renal failure, with a peak creatinine of 5.3 mg/dL. He required a short course of hemodialysis and a prolonged steroid taper, but subsequently regained his renal function. He received a prolonged course of antibiotics, and his tricuspid valve was ultimately replaced successfully.

#### CONCLUSION

Henoch-Schönlein Purpura is a vasculitis that is frequently triggered by upper respiratory infections, though less commonly specifically linked to endocarditis. In contrast to the classic pediatric presentation, HSP in adults is characterized by more severe renal disease that often requires renal replacement and steroid therapies. Our case was unique given that the patient did not develop HSP during his first episode of MSSA endocarditis, but developed biopsy-proven HSP during his subsequent episode years later. This case highlights the complex interplay between genetic susceptibility and infection-specific immune triggering in HSP.

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Figure 2. Classic ankle distribution voilaceous palpable rash seen in Henoch-Schönlein Purpura.

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### When to 'friend' a patient: Social media tips for health care professionals

Michelle Leiker, JD

In July 2010, Facebook reported over 500 million users,<sup>1</sup> and the use of social media through social networking websites such as such as Facebook, Twitter, LinkedIn, MySpace, Bebo, and Sermo continues to grow at an almost unbelievable pace. Indeed, it is hard to find someone today who

a physician's willingness to embrace social media will have a direct impact on a physician's success. Popular medical blogger Kevin Pho, MD (KevinMD) noted in an op-ed published by *USA Today* that physicians who fail to embrace social media do so at their own peril and risk becoming irrelevant.<sup>2</sup>

The relevancy of social media will intensify as technology and health care grow more intertwined, resulting in social media activities playing an even bigger role in a physician's professional reputation.

is not engaged in social media via social networking websites. Physicians, hospitals, and health systems are no exception, using various forms of social media to mark their services and communicate with colleagues and patients; and the number doing so increases daily. While there are many benefits to engaging in social media, there are also disadvantages to consider.

A well thought out, planned social media presence can be tremendously valuable to a physician, their peers and patients. Social media has the ability to facilitate medical discussions, increase awareness of health issues, educate consumers, improve communication with patients and serve as a marketing and recruiting tool. Some believe that

• • •

**Michelle** Leiker, JD, is Associate General Counsel for the Wisconsin Medical Society.

As patients increasingly use online search engines to find physicians, clinics, and hospitals and to "Google" information about physicians, it will be beneficial for a physician to have a strong and positive online reputation. Through strategic use of social media, physicians have the ability to build, frame, and leverage their online reputation.

At the same time, engaging in social media presents a host of potential professional and legal risks for a physician. This makes it critical for physicians to know and understand the benefits and risks of social media and to manage and mitigate potential risks in a manner that capitalizes on the value of social media while limiting the physician's exposure to liability. Failing to know, understand and mitigate the associated risks can have significant consequences for physicians including, but not limited to, damaged personal and professional reputation, ethical violations, investigation and discipline by a licensing body or regulatory entity, patient abandonment claims, malpractice exposure, criminal prosecution, fines, termination of employment, difficulties securing future employment, and legal action by social networking sites or services.

The relevancy of social media will intensify as technology and health care grow more intertwined, resulting in social media activities playing an even bigger role in a physician's professional reputation. Thus physicians will need to weigh the benefits and risks and determine how best to manage their online reputation.

To assist physicians in knowing, understanding, and mitigating these risks, a list of tips and additional resources is provided below. These are by no means exhaustive, but serve as a springboard for further education on social media issues.

#### Tips

- Take advantage of the privacy protections and settings available to you on the various social networking websites. Review your settings regularly—social networking sites are constantly evolving, as are their features, default privacy settings, and terms and conditions.
- Pause before you post. Remember that anything you post could and very well may become public, be shared with your patients, colleagues and employer(s) and follow you around for the rest of your career.
- The Internet is forever. Even if you opt for the most secure privacy settings and delete a posting, it likely still will exist in different forms.

- Know that you are never anonymous when posting online. Google indexes anything you write on Twitter or your blog. Subpoenas can be issued requiring Internet service providers, social networking companies, and websites to produce IP addresses or e-mail addresses that identify the source of the content.
- Keep in mind that comments and pictures you post online can be misinterpreted outside their initial context.
- Frequently monitor your online presence and reputation. Many people have had their online profiles hacked and subjected their friends, followers, and fans to spam postings. Regular and frequent monitoring is especially important for physicians who enable patients to communicate with them online since patients may send urgent messages or provide vital medical history via such communications.
- Know, understand and comply with patient privacy and confidentiality laws.
   Many times even descriptions of a specific case or patient history can be enough to identify a patient and violate privacy and confidentiality laws.
- Know, understand and comply with all institutional and employer policies.
- Remember that copyright, trademark, slander, and libel laws apply to content posted online.
- Respect and maintain the boundaries of the physician-patient relationship in accordance with professional ethical guidelines. This can be challenging when a physician receives a friend request from a patient. See the next two tips for more on this issue.
- Keep your personal and your professional content separate. For example, a physician could create a personal Facebook page for friends and family and a separate page where patients, colleagues and others can "like" and follow the physician's professional postings. The physician could then refer friend requests from patients and others they have a professional relationship with to the professional page.
- · If you accept patients as friends on your

personal Facebook page you should take extra precautions such as: (1) not posting anything too intimate, contentious, or that could be viewed as disrespectful of patients; (2) advising patients that the confidentiality of the existence of a patient-physician relationship between them may be compromised once they are identified as a "friend," and (3) limit the ability of "friends" to post to your wall or account.

 If you blog, don't blog on subjects outside of your area of expertise. Keep your blog focused on general information, taking care to avoid identifying a patient or colleague without their consent. While this may seem like common sense, research has shown differently. Researchers who examined 271 medical blogs found that 17% included identifying information about another provider or patient and 3 contained patient photos.<sup>3</sup>

#### **Additional Resources**

The American Medical Association (AMA), at its Interim Meeting of the House of Delegates in November 2010, adopted new policy that aims to help physicians maintain a positive online presence and preserve the integrity of the patient-physician relationship.<sup>4</sup> The "Professionalism in the Use of Social Media" policy sets forth a number of considerations the physician should weigh when maintaining a presence online.<sup>5</sup>

The Ohio State Medical Association

developed a free tool kit to help physicians better prepare for the legal and employment ramifications of engaging patients through social media websites. In addition to an overview of the key issues, the tool kit includes best practices, sample policies and links to numerous other helpful resources.<sup>6</sup>

KevinMD regularly blogs on social media issues and has an entire collection of social media-related postings. There is often a lively and informative exchange of ideas from readers on his postings<sup>7</sup> in the comments section.

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### Collaboration forms basis for activities that engage community, combat disparities

John R. Raymond, Sr., MD President and CEO, Medical College of Wisconsin

L was evident to me immediately upon joining The Medical College of Wisconsin as President and CEO that the College has spent years cultivating strong community-academic partnerships. I have seen the value of this model first-hand, and it is proven to be highly effective for addressing important public health issues.

Collaborations provide perhaps the best opportunity to address the pressing health care needs of those in our state and region who suffer from health disparities, hopelessness and the cycle of poverty. By committing to and investing in community-based research, the Medical College has developed numerous initial projects derived from collaborative relationships.

Our growing efforts have precipitated the need for a dynamic community engagement infrastructure to help coordinate, build and sustain the partnerships essential for success. The Institute for Health and Society recently established by the Medical College meets this need by advancing the integration of public and population health across research, clinical care, education and community initiatives both locally and globally.

Directed by Cheryl A. Maurana, PhD, Professor and Senior Associate Dean for Public & Community Health at the Medical College, the mission of the Institute is to improve health and advance health equity through community and academic partnerships. Its programs reflect the 4 missions of the Medical College and span approximately 300 diverse community partners including Federally Qualified Health Centers, clinics in federally designated physician shortage areas and social service and faith-based organizations. More than 150 Medical College faculty members collaborate with communities across the state to support over 100 programs The national average infant mortality rate is 6.7 per 1,000 births, yet Milwaukee has an infant mortality rate of 10.8 per 1,000. Even more pronounced is the teen birth rate, which in Milwaukee is 60.3 per 1,000 females between the ages 15-19. This significantly

### The mission of the Institute is to improve health and advance health equity through community and academic partnerships.

serving Wisconsin's health needs through the Institute's Healthier Wisconsin Partnership Program.

The Institute is one of many initiatives supported, in part, by funding from the Advancing a Healthier Wisconsin endowment given to the Medical College during the Blue Cross Blue Shield privatization.

The Institute is developing a framework for community partners to mutually identify avenues of inquiry and research best tailored to deliver answers that address the health care inequalities that burden our state by translating results into successful health promotion practices.

There is a sense of urgency in Wisconsin for the inspired ideas that evolve from collaboration. Health disparities are especially critical in the state's largest population center, Milwaukee, as evidenced in the 2010 *Milwaukee Health Report*. exceeds the US average of 42.5. Wisconsin has a higher percentage of smokers (19.9 percent) than the US average of 18.4 percent, with an especially high concentration in Milwaukee, where 24.2 percent of people smoke. Another preventable cause of death and disability, binge drinking, is excessive in Wisconsin, where 22.8 percent of residents say they engage in this behavior. Milwaukee has a rate of 21.1 percent, while 15.6 percent is the average nationally.<sup>1</sup>

In addition to being timely, the Institute is designed to be results-oriented. It will support translating research into action so these disturbing health trends may be mitigated. Through its Health Equity and Urban Clinical Care Partnerships program, the Institute will team with community leaders, academics, policy makers and funding entities to identify and dismantle the barriers that contribute to these disparities. Since research is fundamental to accomplishing this goal, a resource center within the Institute will feature services that build upon the Medical College's successful biostatistics consulting services and epidemiology data services. A key benefit will be the Institute's ability to marshal funding opportunities for researchers that might not be available to them as individuals, such as program project grants.

It is our hope that the Institute will serve as a gateway to new community-academic partnerships and house the technical resources to facilitate collaboration and communication among faculty members and diverse partners. As home to those health professionals committed to community-engaged scholarship, the Institute for Health and Society fosters the mentoring of faculty new to the field while supporting the bioethics, biostatistics and public and community health PhD, MPH, and MA programs within. Several initiatives that advance cross-cutting, interdisciplinary research and education including Biostatistics, the Center for Bioethics and Medical Humanities and the Global Health Program within the Institute, will better position the Medical College to collaborate with other academic institutions in the state, including University of Wisconsin-Milwaukee. UW-Madison. Marguette University, Milwaukee School of Engineering and the Clinical and Translational Science Institute of Southeast Wisconsin.

Our inclusive and thoughtful approach should benefit the people of Wisconsin and the

physicians who care for them. A sustainable infrastructure enables meaningful, far-reaching collaborations throughout the region now and in the future. This will support education at the Medical College dedicated to developing generations of physicians and researchers with strong community health competencies. Consequently, the long-range outlook for Wisconsin will improve as the Institute for

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To learn more please contact Roger Samuel, Vice President, MSA Executive Search, roger.samuel@ihstrategies.com. Health and Society cultivates researchers and leaders dedicated in partnership to the discovery and application of knowledge that promotes health and reduces disparities.

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