

# Using the Pregnancy Perception of Risk Questionnaire to Assess Health Care Literacy Gaps in Maternal Perception of Prenatal Risk

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In order to make appropriate decisions, patients must be able to understand and use the context-specific health information with which they have been provided, and health providers must be able to convey information to patients who possess varying degrees of health literacy.

Adherence to medical recommendations often depends on patient perception of their medical risks and the importance they attach to those risks. In obstetrics, maternity patients are generally identified as high risk or non-high risk (routine). Conferring the designation of "high risk" may confer additional benefits in educational efforts, literacy evaluation, and relief of educational barriers to care that are reflected in high-risk patients' higher assessments of their risks.

In this study, medically identified risk factors were reviewed for patients in the high-risk and routine obstetrical clinics. Patients labeled as "routine" might still possess significant numbers and types of medically identified risk factors (MIFs) due to patients' socioeconomic status and health risks. If prenatal risk is a spectrum, adaptation of obstetrical health care materials and culturally appropriate counseling may mitigate gaps between patient understanding of their MIF number and type and patient risk perception in order to reach the goal of universally improved patient adherence to medical recommendations.

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## INTRODUCTION

**H**ealth literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" and

remains a focus of health policy research.<sup>1,2</sup> Although attaining a high level of health literacy demands that patients be able to access health information, understand instructions, compute medication dosages, and negotiate complex health delivery systems, not all patients are able to achieve that goal.<sup>2</sup> Individuals with low educational attainment, for whom English is a second language, or who are elderly, ethnic minority, or disabled may be unable to reach high health literacy goals.<sup>2,3</sup>

Far from being an isolated problem, the National Adult Literacy Survey determined that 21% to 23% of Americans are functionally illiterate.<sup>4,5</sup> Generally, Medicaid enrollees read at approximately 5th-grade level but health information may be at the 10th-grade level or higher.<sup>5-7</sup>

In order to make appropriate health-related decisions, patients must be able to understand and use the context-specific health information with which they have been provided. But health providers must be aware of patients' abilities to process health information in order to optimize patient outcomes and also be able to convey information to patients who possess varying degrees of health literacy.<sup>8-10</sup>

Health literacy becomes increasingly important in understanding of prenatal perception of risk by maternity patients. Maternal understanding of and perception of risk may have an impact on patients' willingness to follow antenatal recommendations. But if patients remain unaware of or minimize medically identified risk factors (MIFs), little can be expected for patients to either remediate correctable health risks or adhere to antenatal recommendations.

Although numerical scores based on statistical associations can be used to define risk, it remains a subjective judgment.<sup>11</sup> Although numerous studies have investigated harmful health behaviors, substances, and environmental health risks that may affect pregnant patients and the unborn, relatively little is known about how mothers process, internalize, and act upon their own perceptions of prenatal risks.<sup>11,12</sup>

There are at least 2 views of risk elements incorporating objective and perceptual properties. For objective properties, risk can be assessed using the type of event,

adversity, stated time period, and probability of occurrence.<sup>13,14</sup> Perceptually, patients may place risk in categories, assign value, or place a time frame or expectation to the risk exposure. *Risk* has been defined “as the probability that a particular adverse event occurs during a stated time period or results from a particular challenge.”<sup>14</sup> Regardless of risk counseling, “health care professionals who communicate about health risk need to understand the perspectives of those who [*sic*] they advise and to appreciate the influence of personal values, orientation towards the future, and culture upon risk appraisal—lay or scientific.”<sup>14</sup>

In this study, respondents were queried about their perception of prenatal risk using a visual analogue scale (VAS) called the Pregnancy Perception of Risk questionnaire (PPRQ).<sup>11,12</sup> The questionnaire was selected because prior work demonstrated the PPRQ to have evidence of construct validity, convergent validity, and high internal consistency and reliability in assessing maternity patients’ perception of their risks during pregnancy.<sup>11,12</sup> The VAS may overcome health literacy obstacles since respondents are “(not required) to relate specific numbers or words” for VAS completion.<sup>15</sup> Also, VAS attributes include simplicity and ease of administration, reproducibility, validity, and sensitivity.<sup>16,17</sup> Traditionally, “a VAS score is determined by measuring the distance from the end indicating 0 on a straight line to the mark placed by the respondent.”<sup>16</sup> Use of either micrometers or rulers is employed to measure VAS lines.<sup>15-17</sup>

Similarly, using the PPRQ, respondents are asked to place a vertical mark along a line that demonstrates their perception of a stated risk. In order to score items, the distance is measured from the vertical mark placed by the participant to the start of the 100-mm line, and scores are obtained by adding the scores for each of the 9 items and dividing the score by 9 to obtain an overall score out of 100 (Dr Maureen Heaman, personal communication; May 22, 2007). Rather than being identified as an absolute value (eg, high, medium, or low), scores are evaluated in the context of the studied population (Dr Maureen Heaman, personal communication; May 27, 2007).

Patient responses to the 9-item PPRQ are scored on the 100-mm line between the choices of “no risk at all” and “extremely high risk.” Questions included:<sup>11,12</sup>

- The risk for myself during this pregnancy is?
- The risk for my unborn baby during this pregnancy is?
- My risk of hemorrhaging (losing too much blood) during this pregnancy is?
- My risk of having a cesarean section is?
- My risk of dying during this pregnancy is?
- My baby’s risk of being born prematurely is?
- My baby’s risk of having a birth defect is?
- My baby’s risk of having to go to the neonatal intensive care unit is?
- My baby’s risk of dying during this pregnancy is?

## METHODS

Jersey Shore University Medical Center (JSUMC) institutional review board approval was granted for the study. During a 12-month period (July 9, 2006-July 9, 2007) pregnant patients registered in the JSUMC high-risk and routine obstetrical clinics were asked to participate in the study. Once HIPAA consent was obtained, participants were asked to complete the 9-item PPRQ. One hundred thirty-three patients agreed to participate in the study. PPRQ forms were scored and demographic information was also obtained from all study participants. Instructions for completion of the PPRQ VAS were provided in English and Spanish.

Demographic information from patients’ charts were collected and included pregnancy estimated date of confinement (EDC), estimated gestational age (EGA), registration in either high-risk or routine obstetrical clinics, date of birth, address, gravidity, parity, MIF type, past medical history, patient and partner habits (eg, smoking, alcohol, substance abuse), impairments/barriers to prenatal care, and planned or unplanned pregnancy status. MIFs, defined as risk factors that the patient demonstrated during the index pregnancy (or the pregnancy of the patient at time of PPRQ form completion), were identified by the obstetrical medical team as potentially having an adverse effect upon antenatal/perinatal patient and/or fetal outcomes, including increased risks for intrauterine fetal demise, maternal/fetal morbidities, intrauterine growth restriction, and other adverse reproductive outcomes. MIFs were noted in each patients’ chart and included patient obesity, hypertension, substance abuse, hepatitis, advanced maternal age, diabetes (gestational or pregestational), late/insufficient prenatal care, bleeding episodes during pregnancy, history of preeclampsia/eclampsia, and other medical and psychosocial risk factors.

Pregnancy EGA data were recorded on the day that each patient completed the study and was based on EDC confirmed by the date of patients’ last menstrual periods and ultrasound assessments. Each chart indicated patients’ physician-identified EDCs. Those EDCs had already been assessed by clinic physicians using standard American College of Obstetrics and Gynecology protocols, and no EDC changes were made by any of the researchers involved with this study. EGA on date(s) of PPRQ form completion were calculated for each patient using a standard obstetrical dating calculation systems.

Paired samples correlations logistic regression analysis and analysis of variance/ $\chi^2$  testing (significance  $p < .05$ ) were used to assess whether patients’ PPRQ results correlated with risk factors and demographic variables.

## RESULTS

One hundred thirty-three patients were enrolled. Box 1 itemizes demographic variables obtained on the date of PPRQ form completion which included patients’

EDC/EGA, high or routine clinic enrollment, ethnicity, date of birth, gravidity and parity, and medical information. The index pregnancy was defined as the patient's pregnancy, psychosocial, and medical information at the time of PPRQ form completion (Box 1).

MIFs were defined as information that the medical team had assembled from the patient, patient examination, antenatal testing results, and/or from social services regarding patients' medical, psychosocial, and/or substance abuse histories. MIFs included whether patients' were obese or had hypertension, history of heroin use, hepatitis, advanced maternal age, pregestational/gestational diabetes, vaginal bleeding during pregnancy, positive or negative tuberculosis purified protein derivative (PPD) status, history of preeclampsia, teen pregnancies, language barriers to care, varicella/rubella immune or nonimmune status, and other variables (Box 2).

If the patient had a prior history of cesarean section, subcategories included whether those sections were repeat elective or primary cesarean section due to nonre-

assuring fetal heart rate or other complications.

MIF habit information included whether the patient was a smoker or had alcohol, cocaine, or other substance abuse prior to and/or during the index pregnancy. Information was also obtained regarding partner habits (eg, cigarette smoking, marijuana, methadone, and/or cocaine abuse).

MIF partner-related stressors were defined as conditions/situations caused directly or indirectly by patients' partners that patients had identified as stress inducing, including whether the partner was a smoker, substance abuser, instigator of domestic violence, and/or had been involved in criminal activity. Other patient stressors were financial/difficulty with essential purchases (eg, food purchases); domestic violence; inadequate personal transportation; family member(s)' demise; job loss; partner conflict with and/or separation from partner; involvement in the criminal justice system; homeless/shelter concerns; or having physically, intellectually, and/or emotionally challenged family member(s).

MIF patient impairments included whether the

#### Box 1. Demographic Variables

Date of Pregnancy Perception of Risk questionnaire form completion	Date of birth
Estimated date of confinement/estimated gestational age	Gravidity/parity
High-risk or routine clinic enrollment	History of substance abuse
Ethnicity (Latina, non-Latina black, non-Latina white, Asian)	Past surgeries
Unplanned/planned pregnancy	Impairments/barriers to care
	Stressors (eg, financial)

#### Box 2. Medically Identified Patient Risk Factors

Obesity	History of previous cesarean section(s)	Anemia
Hypertension	Abnormal antenatal first- or second-trimester genetic screening (eg, Down's syndrome)	History of STD (eg, chlamydia, trichomonas, gonorrhea, HIV)
Antenatal or prepregnancy history of heroin/marijuana/alcohol and/or cocaine abuse and/or cigarette smoking	History of previous incarceration	History of a previous child with or family history of genetic defect(s)
Hepatitis	History of domestic violence	Rh negative status
Advanced maternal age	Asthma	History of preeclampsia/eclampsia
Pregestational or gestational diabetes	Psychiatric disorder(s)	Teen pregnancy
Late/insufficient prenatal care	Group B streptococci positive	Language barrier—Spanish
First-, second, and/or third-trimester bleeding during the index pregnancy	Prior molar pregnancy	Language barrier—other language
Tuberculosis purified protein derivative—positive/negative status	Antenatal noncompliance	Varicella immune/nonimmune status
History of intrauterine fetal demise	Maternal protein abnormality (not otherwise specified)	Maternal sickle cell or hemoglobin SC trait
Maternal hypothyroidism	Frequent urinary tract infections	
	Prior preterm birth	

patient had learning, language, and/or visual impairments. MIF psychiatric impairments were whether patients had been diagnosed with depression, or had history of suicide attempt(s), suicidal ideation(s), and/or postpartum depression.

Language barriers included whether the patient was predominantly and/or native speaker of Spanish or another language. Care barriers were whether the patient had childcare and/or transportation issues that affected patients' abilities to obtain recommended clinic care and/or attend scheduled visits.

Within the study, 30.4% were enrolled in the high-risk and 67.4% in the routine obstetrical clinics. Patient ethnicities were defined as Latina (63.5%), non-Latina black (18.9%), non-Latina white (16.2%), and Asian (1.4%) (Table 1).

For gravidity (including the index pregnancy), 22.5% of respondents had 1 pregnancy; 28.2%, 2 pregnancies; 21.1%, 3 pregnancies; 14.1%, 4 pregnancies; 7.0%, 5 pregnancies; 5.6%, 6 pregnancies; and 1.4%, 8 pregnancies (Table 1). For MIF numbers, 1.5% of respondents had no risk factors; 10.4%, 2 risk factors, 32.8%, 3 risk factors; 23.9% 4 risk factors; 3.0%, 5 risk factors, 4.5%, 6 risk factors; and 1.5%, 7 risk factors (Table 2).

In this study, paired samples correlations were calculated for age, patients' type of clinic (high-risk or routine) registration, ethnicity (Latina, non-Latina black, non-Latina white, Asian), gravidity, and psychiatric fac-

tors. PPRQ scores were associated with whether patients were enrolled in the high-risk clinic ( $p = .023$ ). However, there was no association between PPRQ scores and patients' gravidity ( $p = .756$ ), age ( $p = .326$ ), ethnicity ( $p = .723$ ), or psychiatric factors ( $p = .987$ ). Paired samples correlations demonstrated  $-0.93$  (age and PPRQ score),  $-0.337$  (type of clinic registration and PPRQ score),  $0.42$  (ethnicity and PPRQ score),  $-0.038$  (gravidity and PPRQ score),  $-0.002$  (psychiatric factors and PPRQ score), and  $0.163$  (risk factors and PPRQ score).

## DISCUSSION

Patients in the high-risk clinic demonstrated higher PPRQ scores, suggesting increased concerns regarding potential pregnancy complications/outcomes. However, correlation between patients PPRQ scores and MIFs was not demonstrated. One concern is that patients who are not identified as high risk may minimize or not fully understand that significant risks also exist for their pregnancies even though they have not been registered in the high-risk clinic.

Rather than implying pregnancy risk as an all (high risk)-or-none (routine) phenomenon, this study suggests that more patient education and improvements in patients' antenatal health literacy are needed. In order to facilitate patient understanding, some health literacy advocates have encouraged "the use of short, written materials that use everyday language and culturally sensitive graphics to encourage the desired behavior."<sup>24</sup>

Significant resources are spent each year to improve adverse reproductive outcomes for at-risk patients. This study indicates that more work is needed to educate, to the same degree, all pregnant patients about their MIFs regardless of whether those patients have been assigned to routine or high-risk clinics. MIFs' lack of awareness or minimization by patients is unlikely to lead to patient adherence to medical recommendations for amelioration of those risks. Efforts and resources should be devoted to improving the health literacy of patients and eliminating health literacy gaps between MIFs and patients' perceptions of those risks. Although more investigation is needed, being considered a high-risk obstetrical patient may confer additional benefits in patient education, literacy evaluation, and relief of educational barriers to care that are reflected in high-risk patients' higher assessments of their prenatal risks.

Adaptation of obstetrical health care materials and culturally appropriate counseling may mitigate gaps between MIFs and patient perception. Patient understanding of their MIF number and type may be more important than their categorization into high-risk or routine antenatal clinics. If pregnancy risk is a continuum, then reconsideration of that risk as being an all (high-risk)-or-none (routine) concept should be a goal of further research.

**Table 1.** Demographic Data

Patient Ethnicity	Clinic Study Participant Percentage
Latina	63.5%
Non-Latina black	18.9%
Non-Latina white	16.2%
Asian	1.4%

**Percentage of Respondents**

Percentage of Respondents	Gravidity
22.5	1
28.2	2
21.1	3
14.1	4
7.0	5
5.6	6
1.4	8

**Table 2.** Medically Identified Risk Factors Number and Participant Percentages

Medically Identified Risk Factors No.	Clinic Study Participant Percentage
0	1.5%
2	10.4%
3	32.8%
4	23.9%
5	3.0%
6	4.5%

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