

Preeclampsia: The Patient Perspective

By Eleni Zuras Tsigas

President, Preeclampsia Foundation

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ABSTRACT

Preeclampsia remains a leading cause of maternal and fetal mortality and morbidity while research in this important area of reproductive disease remains sporadic and grossly underfunded. Thus, practice guidelines often lack concrete evidence, and management controversies abound. The Preeclampsia Foundation, eager to see cutting edge research applied to all aspects of preeclampsia, is currently stressing the need for more translational research in areas such as prediction, prevention and especially successful treatments, ideally rendering the Foundation unnecessary. In the meantime, our mission is to address the most egregious challenges we see every day – to stop preventable mortality and morbidity by eliminating delays in diagnosis and medical errors, ensuring better and more consistent management practices, educating both patient and care givers of the potential for long term health issues, and helping women and their families through the impact of preeclampsia. Thus, we will achieve healthier outcomes for mothers and babies. Our experiences at the Foundation show that outcomes could be substantially improved if health care providers practiced that which is *already known consistently* and effectively – and if patients were deliberately and repeatedly *educated* about signs, symptoms and the need for timely reporting. To accomplish these goals, we need improved doctor/patient communication, better patient and provider education, and more stringent health services standards, as well as the appropriate research to support these initiatives.

BACKGROUND

The Preeclampsia Foundation represents the more than 200,000 American women to suffer from preeclampsia *yearly* (a number equal to those affected by breast cancer; about one in 12 pregnancies, increasing to one in five for high risk patients). Incorporated in 2000 as a 501(c)(3) nonprofit organization, we are the only patient advocacy organization focusing on the whole spectrum of hypertensive disorders of pregnancy in the United States, made all the more credible by our top-notch medical board. We have a very robust online community, with over 4,000 registered members, three to five million website hits per month, and an online forum that has emerged as the best source of peer-to-peer education and support, with over 150,000 posts since its inception three years ago. Now, we've expanded from the internet to local communities with several groups forming around the U.S. and Canada to actively participate in fundraising, patient education and outreach, and local support programs.

The scope of preeclampsia's impact goes beyond the clinical manifestations that physicians and nurses deal with as illustrated by this recent cry for help on our Forum:

"I am terrified of getting PE/HELLP again. My husband is more scared than me. He doesn't want to lose me. Is it possible, that if I get PE again that I could die? What are the chances after having it with your 1st preg? I'm 30 yrs old. To make a long, sad story short, I was at the clinic yesterday to have my pregnancy terminated...I am SO angry & I feel deep down I have no choice. The disease has made the choice. I'm scared and really want a second child, but I'm still undecided. I'd like to hear some good advice from some of you experienced in a second preg. Sorry if I sound completely lost.... I am at this point."
~ "Issa" (PF Forum member)

With a limited budget and an all-volunteer staff, the Preeclampsia Foundation supports several initiatives in the areas of patient education and support, professional education, public outreach and awareness, research, and fundraising. We have in the past and are beginning again to fund new research initiatives, especially young investigators. We are now poised to accelerate and multiply our programs and services through professional staff and greater financial resources.

THE CHALLENGES

Historically, the state of preeclampsia research has been dreadful, particularly when considered against the high prevalence of this perplexing disorder. In 2002, the World Health Organizationⁱ even used the phrase “an appalling example of neglect” when describing the attention paid by the clinical research community, government granting agencies and the pharmaceutical industry to this significant health problem affecting up to 10% of all pregnant women and newborns each year. While this country endures a national crisis on health care research in general, it is clear that pregnant women and their babies ride at the back of that bus. At the National Institutes of Health, for instance, funding for preeclampsia ranks near the bottom. Preeclampsia is a leading cause of preterm delivery, and we are currently learning of the long-term cardiovascular and metabolic consequences of premature birth. Thus, preeclampsia also carries an enormous economic burden, another factor that those allocating funds for research need to take into account.

One of the downsides of the “disease of theories” is that clinical diagnosis and care can be confusing, inconsistent and inadequate, resulting in unnecessary death or disability for hundreds of mothers and thousands of viable babies. In the United States, a country where maternal mortality rates have not diminished in 20 years and racial disparity in pregnancy-related mortality continues unchecked, we must “diligently search for the reasons...for these devastating events and apply what is learned to the care of all pregnant women.”ⁱⁱ The annual number of pregnancy-related deaths is small, so mortality statistics alone are not an adequate indicator of the state of maternal healthcare. We need to do a better job reviewing serious morbidity – near-miss events – as indicators of possible lapses in maternal healthcare, and methodically evaluate the role of patient education, professional education, and actual clinical practices more stringently than we have done so far. **Research on how to improve health services is lacking and needs to be prioritized.**

Preeclampsia often gets swept aside not only because pregnancy research is a legal minefield, but also because **it has been erroneously considered a transient condition** – once a pregnant woman has delivered, “she’s fine.” But the truth is, often, she’s not. Among the several thousand members of the Preeclampsia Foundation, there are countless stories of long-term health issues suffered by survivors, and there is now strong research evidence that links preeclampsia and cardiovascular disease.ⁱⁱⁱ The NIH, American Heart Association, and Women Heart – all organizations driving women’s cardiovascular disease (CVD) education and awareness campaigns – do not mention

preeclampsia as a “risk marker.” Further, our contact with them shows that many of their leaders have limited to no idea that preeclampsia has a connection to CVD. The profound long-term impact on babies born too soon, evidence of post-traumatic stress syndrome, and increased risk of preeclampsia for women who were themselves born pre-term, all clearly support the long-lasting – *not* transitory – impact of preeclampsia.

Patient ignorance is dangerous. We see many situations where detection and treatment were delayed or mortality would likely have been averted had patients been informed and thus proactive in reporting relevant symptoms. In many cases, the patients did not know what symptoms warranted health care provider intervention or did not trust themselves enough to seek more qualified care. A woman’s risk of having preeclampsia is 8-100x that of having a baby with Down syndrome^{iv}, which she frequently knows more about. Today’s patients often do not have all their health care needs addressed in one place or by one provider so they (or family members) have to advocate effectively for themselves. Given the early onset and progression of some severe preeclampsia – and the infrequency of prenatal visits prior to 28 weeks – it is most likely that the patient will be first at the scene for possible intervention. Uninformed patients don’t know what warrants provider intervention. They may present late for care or be non-compliant with keeping prenatal appointments and taking prescribed medications. They may not immediately report signs and symptoms, a family or personal history of preeclampsia and other related health issues. Women often don’t trust themselves enough to seek more qualified care, when necessary.

Frequently at the root of this gap is the “poor communication” model of doctor/patient relationships, where communication is typically non-existent, extremely limited or – worse yet – patronizing. Being more “health-aware” and getting good prenatal care is every woman’s right and responsibility; a patronizing or protective approach is counterproductive. Health care providers overly concerned with “scaring” their patients are forgetting that being “scared” never killed or maimed a woman or her unborn baby.

No matter how informed a patient might be, she should never be met with dismissive, uninformed or inadequately prepared health care providers. Because of the masquerading nature of preeclampsia, we have too many cases of women who were diagnosed with the flu, gall bladder problems, dehydration, exhaustion, or headaches which were treated with Tylenol 3[®] because nobody took the time to thoroughly examine them, order appropriate lab work, and generate a differential diagnosis that just might have led them to discover it was preeclampsia.

*“When you hear hoofbeats, don't assume it's a horse. It might be a zebra.”
~ Medical school adage*

Many maternal and fetal deaths or “near-misses” from preeclampsia are associated with substandard care. Poor management includes failure to identify and act on established risk factors (including primigravida) at initial booking or to recognize and act on signs and symptoms consistent with preeclampsia, reported by the patient either over the phone or at a prenatal appointment.^v Other lapses in health care include the accuracy of the information communicated by providers to their patients (e.g., preeclampsia does not just occur in first pregnancies, nor does the problem immediately go away with delivery). While we recognize that our membership’s experiences skew to the worst case scenarios and that the majority of caregivers probably engage in appropriate health care practices, the number of those not doing so are too many to ignore.

Good research does not necessarily translate to clinical practice. For instance, the NIH Working Group Report^{vi} (also adapted in various ACOG publications) and Cochrane Reviews are not uniformly used as guidelines for clinical practice. Basic screening methods such as blood pressure or proteinuria measurement are not consistently or accurately practiced (e.g., adhering to the American Heart Association's guidelines for BP measurement^{vii}). Outpatient treatment guidelines for those who manage mild disease at home are clearly lacking, and we even hear too frequently of patients sent home with clear indicators of severe disease. Early pregnancy predictive tests for preeclampsia will be a welcome step forward, but only if they are accompanied by a clear and consistent standard of care that is widely practiced. Finally, post-partum patient education and health care provider response to reported symptoms is nearly non-existent. For example, many cases of post-partum eclampsia might have been avoided if women were properly educated at discharge and if emergency room caregivers were educated about the potential complications when these women present there.

SOME SOLUTIONS

Some solutions are noted below, along with a plea that research findings provide the evidence-based support for widespread implementation.

Implement routine patient education programs in all health care settings, addressing cultural and aptitude diversity via brochures, posters, and nurse instruction. As with proactive breast cancer education (monthly self-exams, yearly mammograms), patient education can be accomplished with a calm, informative approach that is not overly alarmist, but clearly intent on educating and reinforcing a woman's responsibility for her prenatal well-being. Our experience with actual cases demonstrates that prenatal patient education and ongoing preeclampsia support for those diagnosed (e.g., support groups, credible online resources) reduce patient anxiety, improve patient compliance and especially improve health outcomes.

Improving standard professional education practices is an important and complementary intervention. Our experiences suggest a need to provide additional avenues and incentives to educate providers and hospitals about preeclampsia health services, patient safety and preventable medical errors. This training should begin in medical and nursing schools and be reinforced through CME/CEU courses, and integrated into hospital quality assurance programs, in-services and grand rounds. Medical associations (ACOG, AAFP) and federal (CDC) and state public health offices should work together to improve compliance with existing guidelines, and pave the way for the development of more sophisticated guidelines. An online confidential forum, restricted to physician access, could provide expert guidance by medical experts in preeclampsia. There is evidence that specific medical education programs and hospital management practices can improve outcomes.^{viii} However, this is not just a call for the intra-hospital analysis that is widely practiced or the mortality reviews that some states' public health offices dictate, but a call for a national review of all preeclamptic women with serious complications to understand and respond to preventable medical errors.

We recommend the development of a community guideline, similar to the United Kingdom's PRECOG^{ix}, which could provide an evidence-based risk assessment, a list of factors suitable for early referral and a specific tiered schedule of assessment and step-up referral for signs and symptoms of preeclampsia, all intended to improve screening and eliminate unnecessary delay in diagnosis. This would most likely be a practical extension of the NIH's Working Group Report as

well as ACOG's Technical and Practice Bulletins. **Secondly, evidenced-based guidelines – and the mostly non-existent research upon which they must be built – should be developed to address management practices – expectant management and decision points for delivery.** Right now, conclusive information does not exist beyond the relatively low standard of “Expert Opinion.”

Finally, cardiovascular communities should take note of the long-term health impact confirmed by recent research. Health care providers and women's heart health campaigns should emphasize a woman's preeclampsia history for the significant risk factor that it is (equivalent to smoking according to some studies) and educating survivors to be even more vigilant about their cardiovascular health. Internists and family doctors, among others, should be identifying preeclampsia in their patients' health history. Just as we should be looking to other research communities for out-of-the-box thinking, progress made in preeclampsia research should be shared with other disciplines such as cardiology to promote systems biology investigations and collaborative research.

SUGGESTED RESEARCH AREAS

This NICHD meeting (Sept. 21-22, 2006) will no doubt review and focus on the needs of bench science, but below are some research initiatives with practical application suggested by the experience of the Preeclampsia Foundation. The Foundation is prepared to provide funding and to participate in some of these areas, and we look forward to expert collaboration to refine these goals.

1. *Impact of patient education and communication*
 - Evaluate amount and impact of patient communications on anxiety, reporting, compliance and health outcomes
 - Evaluate source(s) of information (e.g., books, internet, nurses) and relative value of each
 - Assess socio-economic issues that may impact patient compliance (e.g., spouse support, finances, HMOs)
2. *State of health care providers' preeclampsia IQ*
 - What do health care providers actually know about preeclampsia and how do they screen and manage their patients?
 - How should these findings impact the delivery of health services, including education of and resources for physicians, nurses, midwives and other health care providers?
3. *Develop and implement best practices for screening and management*
 - Evidence-based guidelines for screening and detection (see UK's PRECOG)
 - Evidence-based “best practices” for expectant management, including conducting prerequisite research on clinical management of preeclampsia
 - Improvements in health services/clinical practice – impact on health outcomes
 - National confidential review of preeclampsia-related maternal mortality
 - Improving hospital management of preeclampsia screening (e.g., extend research piloted at Women & Infants Hospital of Rhode Island^x)
 - ID earlier signs & symptoms to tease out leading indicators
 - Evaluate quantity and quality of fetal surveillance against impact on fetal health outcomes

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