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EDITORIAL

The ITP Practice Guideline: What, Why, and for Whom?

By Alan Lichtin

IN THIS ISSUE of *Blood,* the first practice guideline written by ASH members for ASH members can be found. It is appropriate to discuss why this has come to be.

What are practice guidelines? Why have they become such a hot topic? Practice guidelines are official statements issued by government agencies or professional organizations that specify how to care for medical conditions or perform specific procedures. Nearly 5,000 practice guidelines have been developed in recent years by federal and state governments, medical specialty societies, managed care organizations, hospitals, utilization review and quality assurance entities, private vendors, and advocacy groups. Practice guidelines have the common goal of improving the quality of care but are also being used to control health care costs, reduce practice variation, improve efficiency, and address malpractice. Practice guidelines differ from other documents in their emphasis on determining whether clinical practices are based on scientific evidence or expert opinion.

In an effort to determine accurate assessments of diagnostic and treatment strategies, randomized controlled clinical trials are conducted. However, initial results are often subjected to intense criticism about methods and interpretation. Doctors' practice begins to change only when repeated trials produce consistent data. Practice guidelines have come to exist because of a fundamental, noneconomic desire for improving the quality of care, making our practice decisions more consistent with the evidence rather than with our "beliefs" about what works best.

These days, being sick is very expensive. Society thinks too much money is spent on health care. Society, whether it be represented by politicians, insurance companies, or the judicial system, no longer can tolerate the health care system as it exists. Society wants clearer declarations of truth about what doctors should do. Today, payers' concerns are driven by their perception, supported by some evidence, that a sizeable portion of what physicians do is unnecessary or inappropriate. Now, large employers, managed care organizations, and HCFA which have a direct financial interest in ensuring that their enormous health care expenditures are going toward health care services of proven effectiveness, seek practice guidelines to guide payment decisions.

Because we physicians spent years in training, learning to "do the right thing" for our patients, we hate being told by nondoctors that what we are doing is not the right thing. So, doctors have gotten together and asked ourselves, can we regulate ourselves? Can we find ways to "do the right thing" better, in a way that we as doctors are more uniform in caring for our patients? Can we convince payers that we are seeking the best care for our patients, while at the same time doing it at a low cost? Can we convince payers that their money is being spent on necessary and appropriate care? Ideally, practice guidelines can make care for an illness more uniform and help payers feel certain their dollars go to appropriate and necessary care.

Practice guidelines also are, by definition, from the Institute of Medicine, "systematically developed strategies to assist practitioners and patients in making decisions about appropriate health care for specific clinical circumstances."[1] Since the mid 1980s, practice guidelines have become a big movement in medicine. In 1993, "Practice Guidelines" became a heading of its own in Index Medicus. Excellent guidelines reflect what the best literature says, using the most valid and reliable data accumulated from the best studies, written by the smartest, most unbiased doctors, who have the greatest wealth of experience. Guidelines would also be best when they are succinct, easily readable, disseminated and updated.

In 1991, Jeff Wasser, a practicing hematologist in Connecticut, became interested in this groundswell of the practice guideline movement. In 1993, with more and more guidelines being written in other fields and with the turbulent upheavals in health care, Jeff and Dan Rosenblum, chairman of the Committee on Practice, appealed to the ASH Executive Committee for ASH to write a guideline. $100,000 was appropriated for ASH to sponsor a guideline on a disease believed to be principally hematologic, and one for which many therapeutic and economic questions existed.

Idiopathic thrombocytopenic purpura (ITP) was chosen. Jim George, Chief of Hematology/Oncology at the University of Oklahoma, was asked by then ASH President Art Nienhuis in January 1994 to organize a committee to write the guideline. University-based physicians and clinicians

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from the Committee on Practice were assembled over the next 2 years. We were aided by Steven Woolf, a guideline methodology expert, who served as our consultant. From Jim George's institution, we were also helped by a clinical epidemiologist well versed in guideline development, Gary Raskob. A complete literature search was conducted and each article was reviewed with specific criteria to assess its validity. Case series without control patients were distinguished from randomized controlled trials which provided firm data. Together, we established a system for voting on over 2,000 questions regarding the diagnosis and treatment of ITP.

A reader of the guideline may have several troubling thoughts. When the guideline states something is inappropriate (the result of a vote, based on our methodology), it must be understood that this only represents the viewpoints of a handful of people on the panel. Some outside reviewers of the ITP practice guideline who have seen the document before publication have voiced this concern. For example, there is a more conservative pediatric approach to ITP than what the guideline states. Thus, both our sample size and methodologic limitations need to be kept in mind. Also, recommendations in the guideline are not intended to be standards, ie, hematologists are not necessarily practicing bad medicine if they act differently from what the guideline recommends.

Jim George is to be congratulated for his effort as main writer for this ITP guideline. He deftly and diplomatically steered us through our meetings, convincing the doubters among us that we could actually contribute to the care of patients with ITP by defining what is known and not known. The Committee missed the deadline of completing the document in 1 year, but after 2 years, it is now in this issue of *Blood*. We did stay within our budget. Nationally, guidelines generally cost three to five times what ours did, because typically much more of the work is delegated to paid consultants.

So, what have we accomplished? This present ITP guideline should be viewed as just a starting point. During the 2 years we worked on this guideline, our eyes were opened to the fact that most of what we do with ITP patients is based on case series of selected patients whose course cannot be evaluated in the absence of a control group, and whose outcomes were only evaluated by platelet counts. There is a lack of knowledge of the natural history of untreated ITP and of the effect of treatment on clinical outcomes of major bleeding and death. This guideline raises many important questions for future studies.

At the Seattle meeting, the ASH Executive Committee formed an Ad Hoc Committee on Practice Guidelines of which I have been appointed chairman. Part of the charge of this Ad Hoc Committee is to educate the ASH leadership and membership on the history[2] and significance[3] of the guideline movement, how insurers view guidelines,[4] how other specialties use guidelines to establish standards of care,[5] and how to measure whether writing guidelines translates into better physician decision making.[6] Ultimately, ways to measure (1) patient outcomes and (2) the impact of the guideline on improving patient outcomes need to be determined.

This guideline will need to be updated. Mechanisms for monitoring the literature and incorporating new findings and updates on the ITP guideline are being established. Some professional societies have an open forum on new guidelines—an opportunity for members of the society to exchange ideas publicly on the topic before it is published. At the upcoming Orlando ASH meeting, our Forum on Practice will focus on practice guidelines. We also plan to discuss the impact of guidelines on our practice behaviors and patient outcomes, as well as to discuss the science behind the guideline movement. Obviously, we will also discuss this ITP guideline.

I encourage the ASH membership and those physicians in other specialties who deal with ITP patients (obstetricians and primary care physicians, for example) to read the ITP guideline carefully. The ranges of opinion, presented by our scoring code of numbers and letters, can make difficult reading. But this sometimes surprisingly wide range of opinion should not be interpreted as indecisiveness of the panel. On the contrary, it represents the inevitable divergent decisiveness that occurs when no firm data are available. Hopefully, future updates of the ITP guideline will gradually replace opinion with evidence-based recommendations.

Finally, in a managed care setting, when a hematologist is being second-guessed by a care regulator, he or she can point to the guideline and state, "This is what my professional society says I can and/or should do for my patient." Hopefully, the guideline will assist us in putting the patients' interests above all else.

Please send comments on the guideline to Jim George or me so that we may use your thoughts in upcoming updates to the ITP guideline.

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