A Prospective Evaluation of the Value of Intensive Previsit Counseling in Patients with Neuroendocrine Tumors

Neuroendocrine tumors (NETs) are rare tumors with an incidence of two to five cases per 100,000 persons and recent data show an upward trend in their incidence and prevalence.1 A key feature of NETs is that they often overproduce various peptides or amines. Detection of these biomarkers in plasma or urine can aid in their diagnosis. However, most primary care physicians encounter NETs so infrequently that the preferred, most up-to-date testing paradigms for the work-up of these patients are unfamiliar. The New Orleans Louisiana Neuroendocrine Tumor Specialists (NOLANETS) is a multispecialty group that specializes in the diagnosis and subsequent management of patients with these rare tumors.

Many patients with NETs often travel great distances to visit a center specializing the care of NETs. This travel can be very costly, stressful, and time-consuming. This stress can be compounded if patients present to the specialized center without key medical records. Without this information, the diagnosis or formulation of a treatment plan is often delayed, which can lead to patient frustration. The literature suggests that a patient's main desire is for information and identification of a patient's agenda is an important component of patient satisfaction.2 Interaction between a trained nurse at the specialty center and the referral source (physician and/or patient) before the patient's first visit should help to ensure that patients have all of the necessary medical records and test reports available on their presentation to the referral center. In turn, this should lead to a more comprehensive and efficient visit, resulting in optimal patient care.

The NOLANETS group has been developing and refining a previsit counseling protocol since 2005 designed to help ensure that critical information is at our clinic before the patient's first visit. By 2008, this protocol was standard for all new patients. The previsit counseling consisted of a 30- to 45-minute telephone conversation with each new patient by a highly trained new patient intake nurse that is knowledgeable about the necessary urinary and plasma biomarker determinations, the proper pathologic or immunohistochemical tissue evaluation, and the critical radiologic and nuclear medicine studies. During this counseling session, the nurse explained the rationale for each specific laboratory test and the timetable for obtaining this material so the patients would understand the necessity of having these data before their first consultation. The object of this study was to determine if previsit counseling, using a predetermined list of tests, would result in patients having the majority of the data needed for the most efficient evaluation and treatment planning at their initial visit.

The minimum data set of tests that we deemed critical was created based on the reviews of currently available international consensus statements and our own practical clinical and laboratory experiences at the NOLANETS clinic. Although the specific diagnostic paradigm for each NET is tumor-dependent, we included those tests that we felt were necessary to optimize a patient's first visit. Included in our data set were: 1) critical hospital reports: operative notes and pathology reports; 2) plasma and urinary biochemical markers: pancreastatin, chromogranin A, serotonin, neurokinin A, and 24-hour urine collection for 5-hydroxyindoleacetic acid (5-HIAA). These provide valuable information regarding tumor volume, prognosis, and functionality; 3) radiological examinations: triple-phase computed tomography (CT) scans of the chest and/or abdomen, and/or pelvis or magnetic resonance images (MRIs) and Octreoscans®. These allow for the localization of the tumor; and 4) immunohistochemical stains and histologic evaluations: Ki-67, chromogranin A, and synaptophysin (quantitative and qualitative stains). These tests allow us to determine the tumor's proliferative rate, degree of tumor differentiation,
and degree of tumor neovascularization. The greater the percent of cells that stain positive, the better differentiated the tumor is and the better the patient’s prognosis.

The medical records of 288 patients with NETs seen between January 2008 and July 2009 were collected and prospectively reviewed. These patients traveled to the NOLANETS clinic from 36 U.S. states and one Canadian province. All patients included in the study were counseled for 30 to 45 minutes. We reviewed the charts of each patient to determine the date of pathology diagnosis, the date of their first NOLANETS visit, the state where the patient resided, and if the tests requested were available at the time of the patient’s initial visit. The data were then expressed as percentages and subcategorized by individual test.

Two hundred twenty-seven patients (227 of 288 [79%]) had previous surgical procedures relating to their NET. Eighty-nine percent of patients had their operative reports, and 93 percent had their pathology reports.

Of the total patient group, 82 percent were able to obtain serum chromogranin A, 56 percent serotonin, 61 percent neurokinin A, 64 percent pancreastatin, and 72 percent urinary 5-HIAA before their initial visit with our group.

Ninety-four percent had CT/MRI scan results and 76 percent had Octreoscans® available.

In total, Ki-67 was available in 34 percent of the patients. Chromogranin A stains and quantitative chromogranin A were available in 68 and 14 percent of patients, respectively. Synaptophysin stains and quantitative synaptophysin were available in 60 and 11 percent of patients, respectively.

It is important to note that there were exceptions made on a patient-by-patient basis that affected the percentage of test results available. Some of the reasons for this included the patient’s physical presentation, the urgency of need for a visit, and/or the patient’s travel preferences or restrictions.

According to our data, the biomarkers for pancreastatin and neurokinin A were some of the most difficult tests to obtain. This could be the result of the need for special preservative-containing tubes for specimen collection, the limited reference laboratories that perform these tests, or time constraints. Similarly, quantitative stains for Ki-67, chromogranin A, and synaptophysin were also difficult to obtain. This could be the result of the lack of remaining tissue, the lack of compensation for performing the stains, the inability to get the slides or blocks released, or misunderstanding on the part of the patient regarding the process for obtaining the slides or blocks. However, these tests should not be overlooked because they have significant predictive value and are critical to formulating an optimal treatment plan.

This study demonstrates that intensive previsit counseling results in those patients having the majority of the requested test results available at the time of their first clinic visit. We believe that this improves patient satisfaction and results in more timely and comprehensive recommendations and treatment plans.

Jarret Brashear, M.D.
Louisiana State University Health Sciences Center
New Orleans, Louisiana

Pamela Ryan, B.S.N., R.N.
Ochsner Kenner Neuroendocrine Tumor Clinic
Kenner, Louisiana

Yi-Zarn Wang, M.D.
Lowell B. Anthony, M.D.
J. Philip Boudreaux, M.D.
Saju Joseph, M.D.
Richard Campeau, M.D.
Eugene A. Woltering, M.D.
Louisiana State University Health Sciences Center
New Orleans, Louisiana

REFERENCES