Clinical Guidelines That Can Improve Your Care
A Guideline for Common Breast Problems
By Caryl Heaton, DO, UMDNJ-New Jersey Medical School, and Amy Locke, MD, University of Michigan

This is a guideline that comes from my alma mater, the University of Michigan. I had seen this group of guidelines, but avoided them, not wanting to show any favoritism over the Ohio State guidelines, but there aren’t any! So let’s give credit to the Office of Continuing Medical Education at the University of Michigan, who have developed about 30 self-study modules for primary care physicians. Most of these provide an evidence-based guideline and also provide free American Medical Association (AMA) continuing medical education (CME) credits.

Breast complaints are common to every practice; one estimate is that 16% of women over 40 will present with a symptom related to the breast. Anyone in practice knows that breast symptoms come with an increased level of anxiety in patients, most of whom are aware that breast cancer is the most frequent malignancy in American women and the second most common cause of cancer-related death.

This guideline covers four categories: (1) palpable mass or asymmetry, (2) breast pain with a negative exam, (3) nipple discharge without abnormal exam findings, and (4) assessment of women with high risk for breast cancer. For the first time, we have put the whole guideline on the Family Medicine Digital Resources Library (FMDRL) Web site (www.fmdrl.org) at www.fmdrl.org/1450. This guideline is created to provide clinicians with concrete suggestions, so not every recommendation is equally based on the evidence. They do, however, identify the level of evidence for the major recommendations (A through D). The other assumptions for this guideline are that the women are over the age of 18 and that appropriate mammographic screening has taken place. “Diagnostic Breast Imaging,” for the purposes of this guideline, is diagnostic mammogram and/or ultrasound, based on the age and the radiologist’s judgment.

A palpable mass or asymmetry must be classified as having a low, intermediate, or high index of suspicion, based on the clinical exam. The low suspicion physical exam shows

Information Technology and Teaching in the Office
Interpreting the Medical Literature—How Do We Train Learners (and Remind Ourselves) About the Role of Statistics
By Thomas Agresta, MD, University of Connecticut

You have a student who is seeing Mrs Smith, a 28-year-old woman recently diagnosed with polycystic ovary disease who desires to have children and has been trying to conceive for more than a year. She is also concerned about diabetes risk. The resident working with the student pulls up an article and immediately tells you that you should refer to an infertility specialist for treatment with Clomiphene since that is the best treatment with a difference that is statistically significant.1

You congratulate the pair of learners for rapidly searching out answers from the literature and remind them that you need to review this information with Mrs Smith to ensure that it is relevant to her.

You now probe a little deeper regarding the article, trying to get a grasp on the learners’ understanding of the content of the article as well as their ability to interpret literature effectively.

(continued on page 2)
A Guideline for Common Breast Problems

does not resolve completely with aspiration, or if the cyst is recurrent in the same location. Masses not reported as definitive fibroadenomas or cysts on FNA should be evaluated by a breast specialist, and close follow-up of any masses that have been aspirated is important.

Breast pain with a negative exam requires mammography and a check for contributing causes (Table 2). Curiously, the guideline fails to mention abscess or cellulitis as a common cause of breast pain, so warmth, induration, and erythema don’t make it into this algorithm. It still seems reasonable to check for these, even in a non-breast-feeding woman. If infection is ruled out clinically and imaging is negative, the likely diagnosis is benign cyclic or noncyclic mastalgia. It is reasonable to reassure the patient, and there is good evidence for a trial of evening primrose oil (1,000 mg twice a day for 3–6 months, or its active ingredient, gamma linoleic acid, 160 mg twice a day. Topical diclofenac gel and/or a well-fitted bra may be helpful. Persistent pain that is unresponsive after 2–3 months should be cause for a referral to a breast specialist.

The management of a breast discharge without an abnormal breast exam begins with analysis of whether the fluid is serous or sanguinous or if other high risk factors are present, such as discharge spontaneous or from a single duct. These findings require referral. If the discharge is galactorrhea (milky or yellow or sticky), and is bilateral, a medical workup (pregnancy test, TSH, and prolactin level) is appropriate, and referral is not recommended, although the evidence on this is not strong, based on expert panel only. The most common cause of galactorrhea is medications, including phenothiazines, other antipsychotics, metaclopamide, domperidone, methldopa, reserpine, verapamil, and oral contraceptives.

Table 1

<table>
<thead>
<tr>
<th>Palpable Breast Mass or Asymmetry: Diagnosis and Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low index of suspicion</strong> (nodularity with no discrete mass, no risk factors, with up-to-date screening)</td>
</tr>
<tr>
<td>Follow up exam in 2-3 months</td>
</tr>
<tr>
<td>If no mass: routine follow up</td>
</tr>
<tr>
<td>If nodularity persists: treat as intermediate risk</td>
</tr>
<tr>
<td>Bi-RADS® category 1-3: re-examine in 1-2 months</td>
</tr>
<tr>
<td>If low clinical index of suspicion: routine follow up</td>
</tr>
<tr>
<td>If now intermediate or high index of suspicion: refer to specialist</td>
</tr>
<tr>
<td>BreastsMass (characteristics on physical exam: no discrete mass, no risk factors, with up-to-date screening)</td>
</tr>
<tr>
<td>Intermediate index of suspicion</td>
</tr>
<tr>
<td>If age &lt; 30, ultrasound + mammography</td>
</tr>
<tr>
<td>If age ≥ 30: breast imaging</td>
</tr>
<tr>
<td>Non-visualized: re-examine in 1-2 months</td>
</tr>
<tr>
<td>If low clinical index of suspicion: routine follow up</td>
</tr>
<tr>
<td>If now intermediate or high index of suspicion: refer to specialist</td>
</tr>
<tr>
<td>Cyst</td>
</tr>
<tr>
<td>Asymptomatic simple cyst: routine follow up</td>
</tr>
<tr>
<td>Symptomatic or complex cyst: refer to specialist for aspiration or excision</td>
</tr>
<tr>
<td>Breast imaging and referral to breast specialist</td>
</tr>
<tr>
<td>Complex cyst: refer to specialist for aspiration or excision</td>
</tr>
<tr>
<td>If mass resolved, follow up physical exam in 2-3 months</td>
</tr>
<tr>
<td>If mass not resolved: refer to specialist</td>
</tr>
</tbody>
</table>

January 2008
An intermediate risk level is the non-spontaneous multiduct discharge that is yellow to gray-green or black (that's how they describe it). Avoiding nipple stimulation, mammogram (if over 12 months) and a reexamination in 3–4 months is called for. If the patient requests symptomatic treatment, a referral should be made.

Finally, the guideline offers some tools for primary care physicians in the assessment of women with high risk for breast cancer. We know that there are women who are truly at high risk who would benefit from early monitoring and perhaps genetic counseling. There are also women who are anxious about breast cancer but have no statistically increased risk. A woman is at high risk if her calculated 5-year risk of breast cancer is > 1.7%. They recommend using the National Cancer Institute (NCI) calculator (based on the Gail Model) that can be found at www.cancer.gov/bcrisktool (or a woman can call 1-800-4-cancer). The NCI calculator will underestimate the risk in a woman who has a strong family history of breast cancer or suspected genetic mutations. (These women have aunts, great aunts, and cousins with breast cancer and the tool just asks about first-degree relatives). A personal history of thoracic radiation or prior lobular carcinoma in situ will also substantially increase a woman's risk for breast cancer. These factors should be taken into account when counseling our patients. Screening recommendations for high risk women are listed in Table 3 and are based on both the National Comprehensive Cancer Network Breast Cancer Screening and Diagnosis Guidelines (http://nccn.org) and the American Cancer Society Guidelines for breast screening with MRI as an adjunct to mammography.

Women at high risk should be offered referral to a breast specialist and should be offered therapy to reduce their risk, such as Tamoxifen or Raloxifene. Tamoxifen has adverse effects, such as an incidence of endometrial cancer, deep venous thrombosis, cataract formation, hot flashes, and increased liver enzymes. But there is evidence that it can reduce the incidence of breast cancer by 49% in high-risk women. Recent evidence suggests that Raloxifene is as effective as Tamoxifen in decreasing the risk of breast cancer in high-risk women.

### Table 2
**Breast Pain Diagnosis and Treatment**

<table>
<thead>
<tr>
<th>Contributing Factors to Breast Pain</th>
<th>Screen for contributing factors: medications, medical conditions</th>
<th>Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• birth control pill</td>
<td>Memmogram if &lt;40 and 21 year since last mammography</td>
<td>If negative, offer evening primrose oil, NSAIDS, advise bra-fitting</td>
</tr>
<tr>
<td>• progestrone</td>
<td>If positive screen, eliminate cause if possible</td>
<td>If no improvement, refer to specialist</td>
</tr>
<tr>
<td>• poorly fitting bra</td>
<td>Follow breast mass algorithm</td>
<td>NSAIDS, evening primrose oil, or both. If no improvement, refer to specialist</td>
</tr>
<tr>
<td>• spironolactone</td>
<td>Refer for breast imaging</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Positive mass on exam</td>
<td></td>
</tr>
<tr>
<td>Breast pain</td>
<td>Negative exam</td>
<td></td>
</tr>
</tbody>
</table>

Table 3

**Scanning Recommendations for High-risk Women**

<table>
<thead>
<tr>
<th>High Risk Category</th>
<th>Age to Begin Screening</th>
<th>Screening Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 year risk of invasive cancer ≥1.7% based on NCI Breast Cancer Risk Assessment Tool (see Table 3)</td>
<td>Age 35</td>
<td>Annual mammogram + clinical breast exam (CBE) every 6–12 months, periodic breast self exam encouraged</td>
</tr>
<tr>
<td>LCIS/typical hyperplasia</td>
<td>After diagnosis of LCIS/hyperplasia</td>
<td>As above</td>
</tr>
<tr>
<td>Prior thoracic radiation therapy</td>
<td>8–10 years after thoracic radiation therapy or age 40, whichever is earlier</td>
<td>As above, with MRI controversial**</td>
</tr>
<tr>
<td>Strong family history or genetic predisposition</td>
<td>5–10 years prior to age of diagnosis of earliest index case</td>
<td>Annual mammogram + clinical breast exam (CBE) every 6–12 months, periodic breast self exam encouraged. Consider annual MRI for women with 20%–25% or greater lifetime risk.</td>
</tr>
<tr>
<td>Known or suspected hereditary breast and ovarian cancer</td>
<td>Age 25</td>
<td>As above.</td>
</tr>
</tbody>
</table>


** For prior thoracic radiation therapy, ACS guidelines include MRI and NCCN guidelines do not.

LCIS—lobular carcinoma in-situ
women with a lower risk of endometrial carcinoma.

The guideline provides some details for counseling women at high risk and includes prescribing recommendations for Raloxifene or Tamoxifen for women who cannot or will not see a breast specialist. The woman at higher risk (or her clinician) may be referred to the National Comprehensive Cancer Network (NCCN) Guidelines for Breast Cancer Risk Reduction (www.nccn.gov).

This guideline from the University of Michigan has practical algorithms and clearly written, succinct text that gives realistic recommendations of what to do. Not every recommendation has strong evidence behind it, but unfortunately that is our world as primary care physicians. Like every guideline of this type, maintenance and updating will be critical. This set of self study modules can be found at http://cme.med.umich.edu/iCME. The list is quite extensive, and time will tell how well they keep it updated. It’s definitely worth taking a look.

Caryl Heaton, DO, UMDNJ-New Jersey Medical School, Editor
Diana Heiman, MD, University of Connecticut, Coeditor
(Continued from page 1)
Interpreting the Medical Literature

Asking the simple question—does this study apply to Mrs Smith?—brings out the fact that the article is focused on patients already in infertility treatment, perhaps not all comers in a primary care office, but your learners are confident that it is appropriate. Since Polycystic Ovary Syndrome and infertility are relatively common in a primary care practice, you decide that all members of the team could benefit from a more thorough review of the topic. The resident also has a journal club that she is responsible for in 3 weeks and decides to use this article to review. You encourage the student to help in this since they were involved in the original patient encounter that began this practice-based learning experience.

You realize that this is an article on treatment and therefore direct the learners to the online site of Users Guides to the Medical Literature from JAMA to have them begin to prepare for their presentation. A week later the resident returns with several questions regarding the statistics used to analyze the data. The first question that they ask you is about the power of the study. It seems they readjusted the numbers partially through the study because they had lower than expected live births in all the groups and therefore were able to have the same 80% power with fewer patients. You refer the learners to the Rice Virtual Online Statistics text and tools to review power analysis and sample size requirements. They are able to use the tools to actually predict needed sample sizes for various levels of \( \alpha \) and \( \beta \) error (also reviewed) and graphically display what happens when you vary these numbers. The learners then realize they can actually use these tools live—during the journal club to demonstrate these principles to remind all about these common statistical principles.

The next series of questions they have revolve around the actual statistical tests used in the article. These go something like “What is a Fischer’s exact test or a Wilcoxon rank-sum test?” You yourself are a bit rusty on these concepts (or never learned them as many clinicians would likely respond). So you decide to look together at these terms in the online texts and under what circumstances they should be used. It becomes clear that you can find many of the actual statistical calculators on the Web and with a little guidance and reading you can use them to help teach learners about how to interpret articles. This now becomes part of your standard toolkit for residents and students when they are faced with formal analysis of the literature.

It should be noted, however, that for most of our students’ and residents’ work, it is not important to be able to use these tools, but it is important to understand and trust the principles behind their use in research articles. By using these resources in a structured manner with specific articles or clinical questions in mind, we encourage critical thinking among our learners. It is important to instill in them the background needed to understand the difference between the types of research articles and how to think about them critically. It is just as important to help them realize when not to do primary literature review and use the tools of information mastery instead. So, try out some of these sites for your own learning and think how you might incorporate them into your curriculum to support an active learning environment.

### REFERENCE


### Internet Tools for Understanding Statistics

<table>
<thead>
<tr>
<th>Title</th>
<th>URL</th>
<th>Comments</th>
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<td>Users Guide to Medical Literature</td>
<td><a href="http://www.cche.net/usersguides/main.asp">www.cche.net/usersguides/main.asp</a></td>
<td>JAMA articles—good overview useful for longitudinal curriculum and one-time reviews</td>
</tr>
<tr>
<td>Rice Virtual Lab in Statistics</td>
<td><a href="http://onlinestatbook.com/rvls/index.html">http://onlinestatbook.com/rvls/index.html</a></td>
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<td>Java simulations demo concepts</td>
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<td>VasserStats</td>
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<td>SticiGui</td>
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Richard Usatine, MD, University of Texas Health Science Center at San Antonio, Editor

Thomas Agresta, MD, University of Connecticut, Coeditor
Evidence-based Answer
Evidence exists to support the safe use of selective serotonin reuptake inhibitors (SSRIs) for the treatment of anxiety disorders in lactating women. Paroxetine may be the best tolerated. (SOR B, based on a meta-analysis of primarily low-quality studies.) Clomipramine and select benzodiazepines in single doses may also be reasonable. (SOR C, based on expert opinion.)

A 2005 meta-analysis identified 36 studies and case reports on breast-feeding women taking SSRIs. A total of 267 infants were described. All SSRIs studied were found to be excreted in breast milk to varying degrees. A small number of reversible pediatric adverse effects were reported for all SSRIs studied except paroxetine (Table 1). All of the studies were of small sample size. Only one study provided follow-up data to 12 months of age, and no studies provided follow-up data on possible adverse effects beyond 12 months of age. Additionally, some but not all of the infants studied were also exposed to maternal SSRIs in utero. No data were reported on escitalopram.

A review of the Micro Medex Web site by individual drug names reveals a Thomson Lactation Rating of “infant risk is minimal” for sertraline and paroxetine. All other SSRIs, benzodiazepines, bupropion, buspirone, clomipramine, and tra-zodone are rated as “infant risk has been demonstrated” or “infant risk cannot be ruled out.”

The American Academy of Pediatrics committee on drugs currently classifies all SSRIs and benzodiazepines as drugs whose effects are unknown but may be of concern during lactation. In its 2002 Model List of Essential Drugs, the World Health organization classified clomipramine as compatible with breastfeeding and the use of oxazepam, clonazepam, lorazepam, or diazepam as compatible with breastfeeding in single doses only. Long-term use of benzodiazepines can result in hypotonia and lethargy in the breast-fed infant.

REFERENCES

LOE—level of evidence

Table 1
Summary of Studies and Case Reports on SSRIs During Breast-feeding

<table>
<thead>
<tr>
<th>Drug</th>
<th>n (Infants)</th>
<th>Adverse Effects Reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citalopram</td>
<td>23</td>
<td>One case of disturbed sleep</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>69</td>
<td>One case of irritability, two cases of colic, two cases of withdrawal symptoms, one possible case of seizure-like activity</td>
</tr>
<tr>
<td>Fluvoxamine</td>
<td>12</td>
<td>One case of icterus</td>
</tr>
<tr>
<td>Paroxetine</td>
<td>77</td>
<td>None</td>
</tr>
<tr>
<td>Sertraline</td>
<td>76</td>
<td>One case of disturbed sleep</td>
</tr>
</tbody>
</table>

SSRIs—selective serotonin reuptake inhibitors

Jon O. Neher, MD, University of Washington, Editor

HelpDesk Answers are provided by Evidence-Based Practice, a monthly publication of the FPIN Consortium (www.ebponline.net)
POEMs for the Teaching Physician

Metformin Does Not Harm Patients With HF and Diabetes

Clinical Question: Do oral hypoglycemics cause harm in patients with diabetes and heart failure?

Setting: Outpatient (any)

Study Design: Meta-analysis (other)

Funding: Government

Synopsis: Up to 40% of adults with diabetes will have heart failure. Diabetes worsens the outcomes from heart failure, and tight control of blood glucose is associated with worse outcomes in patients with heart failure. To investigate the role of antidiabetic agents in patients with heart failure, these Canadian researchers searched several databases for randomized controlled trials or cohort studies that evaluated the association between hypoglycemic agents and clinical outcomes in patients with diabetes and heart failure. Two authors independently selected the studies for inclusion and abstracted the data. Research results for insulin and metformin were not homogeneous and were not formally combined. Three studies found an increased mortality associated with insulin therapy; the fourth and largest study did not find an associated increase in mortality (but did not find a decrease, either). Thiazolidinedione treatment was associated with reduced all-cause mortality (odds ratio [OR]=.83, 95% CI=0.71–0.97) but an increase in hospitalization for heart failure. Metformin as single therapy was associated with decreased mortality as compared with sulfonylureas (OR=.70; 95% CI=0.54–0.91) or insulin (OR=.86; 95% CI=0.78–0.97) after 2.5 years of treatment, as was combination therapy with metformin and a sulfonylurea. Sulfonylureas were not independently studied but were used in comparison groups for several studies of other hypoglycemic drugs. In these studies, there was no increased mortality with sulfonylureas. Most of the studies were of good quality.

Bottom Line: Metformin may decrease mortality in patients with heart failure. Insulin is associated with increased mortality. The thiazolidinediones decreased mortality but increased hospitalization for heart failure. (LOE=2a)


Clinical Rule to Diagnose PCOS More Accurately

Clinical Question: What are the key signs and symptoms for the diagnosis of polycystic ovarian syndrome?

Setting: Outpatient (specialty)

Study Design: Decision rule (validation)

Funding: Self-funded or unfunded

Synopsis: These authors recruited patients referred to an endocrinology clinic for evaluation. This is a limitation of the study, since these patients have already been filtered by their primary care physicians who made the referral. Patients completed a detailed questionnaire and then were evaluated by an endocrinologist who was masked to the questionnaire results and who made the final diagnosis of polycystic ovarian syndrome (PCOS) using standard National Institutes of Health (NIH) criteria. Fifty patients had PCOS; 50 did not. The best predictors of PCOS were identified, and the survey was then applied prospectively to a second group of 117 patients, 41 of whom had PCOS using the NIH criteria. The four best predictors were

-- (1) average duration of menstrual cycle greater than 34 days or totally variable,
-- (2) three or more sites of dark, coarse hair,
-- (3) obesity between the ages of 16 years and 40 years, and
-- (4) no history of galactorrhea outside of pregnancy or recent childbirth. In the validation cohort, patients with two or more factors were likely to have PCOS (positive likelihood ratio=13), while those with fewer than two of these factors were unlikely to have the syndrome (negative likelihood ratio=0.16).

Bottom Line: A simple questionnaire completed by patients before they see the physician can assist in the diagnosis of PCOS. It is limited by the fact that it has only been validated in a referral setting. (LOE=1a)


URI: Patients Want Explanation, Not Prescription

Clinical Question: Do patients expect antibiotics when they see a doctor for a respiratory infection?

Setting: Emergency department

Study Design: Cohort (prospective)

Funding: Government

Synopsis: Approximately 70% of patients visiting family physicians or pediatricians will receive an antibiotic for the treatment of a respiratory tract infection. Their physicians usually assume that they will not be satisfied without a prescription. To test this hypothesis, these researchers enrolled 272 patients treated at 10 emergency departments for upper respiratory symptoms not related to chronic respiratory diseases, sinusitis, otitis media, or pneumonia. The researchers used a validated questionnaire to record patients’ expectations of care before the visit. Immediately following the visit they were asked if they received...
an antibiotic prescription, if they had a better understanding of their symptoms, and to rank their level of satisfaction on a 5-point scale. Nearly half the patients stated before the visit that they expected an antibiotic prescription. Thirty percent of patients received an antibiotic prescription, and 51% received a non-antibiotic prescription. Physicians correctly identified 27% of patients who expected an antibiotic. Satisfaction was similar whether or not patients received an antibiotic prescription, with 87% of patients receiving antibiotics feeling satisfied and 89% of patients not receiving antibiotics feeling satisfied. Receipt of an antibiotic prescription was associated with physicians’ perception of the patients’ expectations but not with patients’ actual expectation of antibiotics. However, an understanding of their illness had a larger effect on satisfaction: 92% of patients reporting a better understanding of their illness were satisfied, compared with 72% who reported no better understanding (odds ratio=4.4, 95% CI=2.0–8.4).

**Bottom Line:** Approximately half of all patients with an acute respiratory illness expect to receive an antibiotic prescription, although satisfaction with the visit is not related to its receipt. Physicians are not adept at determining which patients expect an antibiotic. Patients who felt they gained a better understanding of their symptoms were more likely to be satisfied than patients who didn’t get any explanation. (LOE=2b)


LOE—level of evidence. This is on a scale from 1a (best) to 5 (worst). 1b for an article about treatment is a well-designed randomized controlled trial with a narrow confidence interval.

Mark Ebell, MD, MS, Michigan State University, Editor

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Excerpted from “For the Office-based Teacher of Family Medicine”

Teaching Learners to Care for Children and Youth With Special Health Care Needs

By Sweety Jain, MD, Lehigh Valley Hospital Family Medicine Residency Program, Allentown, Pa
(Fam Med 2007;39(2):85-7.)

Children and youth with special health care needs (CYSHCN) “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount beyond that required by children and youth generally.” A recent report estimated that 9.3 million children and youth in the United States (approximately 13% of the population of this age group) have a special health care need. To care for children and youth with special health care needs, the American Academy of Pediatrics recommends providing a medical home, which is “not a building, house, or hospital, . . . but rather an approach to providing comprehensive primary care . . . that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.” In a medical home, a physician partners with the patient and his/her family to assure that all of the medical and nonmedical needs of the patient are met.

Most family physicians are skilled in offering compassionate and coordinated care to patients and serving as their medical home but may not be as familiar in caring for children and youth with special health care needs. As the care of children and youth with special health care needs transitions from the offices of their pediatricians to those of family physicians, it is becoming increasingly important for office-based teachers of family medicine to familiarize themselves with the care of these patients. Until a well-structured curriculum in caring for patients with special needs is designed, the office-based teachers of family medicine should take the initiative to educate medical students and residents on how to care for these patients and serve as their medical home. The following case example brings out pertinent issues of children and youth with special health care needs and may help family medicine preceptors design their own curricular outline for teaching in this area.

J.S. is a 17-year-old white male with a diagnosis of Pervasive Developmental Disorder, not otherwise specified (PDD-NOS). In this disorder, some features of autism or another pervasive developmental disorder are present, but the patient does not meet all of the diagnostic criteria of any specific disorder. He is a junior at a large urban high school where he attends regular classes with support. He lives with his parents and his 11-year-old brother. J.S. was diagnosed with the disorder at the age of 27 months. The family then began its journey into the world of evaluations and interventions, including mental health services; occupational and speech therapy; psychiatric, psychological, and behavior therapies; and consultations with developmental pediatricians,audiologists, and early intervention providers. The mother relates that in some offices, the front desk personnel as well as health care professionals understood and met his needs so that J.S. experienced comfort and acceptance. In contrast, at other offices that were not as attentive to his needs, she was always more worried that J.S. would have difficulty controlling his anxiety.

As J.S.’s parents look ahead to their son’s transition to adult care, they have several questions for his future medical professionals. These should serve as an outline of an office curriculum on handling children and youth with special health care needs for teachers of family medicine. The mother asks if those who care for J.S. will have the following attributes:

(1) “Will they be knowledgeable about his disability? Will they be sensitive to his particular needs? Will they understand him and the unique way he communicates?”

Teaching Point: Medical students and residents will be pleasantly surprised at how much they can learn from the parents and caregivers about the condition and available resources for its management and for coping with it (Web sites, organizations, support groups, etc). The parents/caregivers can also help the physicians and learners understand the patient’s specific needs and means of communication such as the use of signing with fingers or by head nodding.

(2) “Will they treat him with the respect and dignity that they give to their other patients? Treat him in an age-appropriate manner? Speak to him directly, not through me?”

Teaching Point: All conversation should be directed to the patient and not to the accompanying caregiver or parent. Direct eye-to-eye contact between the physician or learner and the patient must be made. When talking to a patient in a wheelchair, the physician or learner should sit down to accomplish eye contact with the patient. Spending time with learners reviewing video recordings of their encounters and giving feedback can be of great benefit in training them to provide patient-centered care to this special population of patients.

(3) “Will they have patience and empathy? Spend enough time to get to know him?”

Teaching Point: Getting to know patients with disabilities requires patience and time on the part of the physician and the learner. Since occasional brief visits make it more difficult for physicians and learners to get to know their patients, an extended initial visit or regular brief visits at the beginning of the relationship may be useful in getting to know the patient.
(4) “Will the office be disability friendly? Will he be welcomed and understood by all the staff?”

Teaching Point: It is important that the office structure and layout accommodate the physical needs of children and youth with special health care needs. However, it is even more important that the physicians, learners, front office staff, and nurses make effort to welcome each patient with a special need and work together as a team to give the care that the patient needs.

(5) “Will the physician use the time with him as a teaching opportunity, to help him understand his physical status and his care needs? Provide him with information in a format that he can understand?”

Teaching Point: Patient education should be an integral part of the visit, since patients with special health care needs may require more education than other patients. Physicians and learners should develop skills at tailoring the education to suit the needs and the abilities of these patients and teach them about all relevant issues, including growth, development, and sexuality, using health education resources in the most suitable format. For example, patients with auditory deficits may find written material most useful, while patients with blindness may benefit from audio material on CDs or cassettes.

(6) “Will they be able to answer questions about medical insurance and help with applying for Supplemental Security Income (SSI) or Medical Assistance (MA)?”

Teaching Point: While learners may need to rely on the expertise of the social worker or the billing/insurance coordinator for answers to questions on these issues, familiarizing themselves with the details of different programs will help them be better advocates for their patients with disabilities.

(7) “Will they take a holistic approach to his health care? Will they address other important elements of a healthy, productive lifestyle like recreation and socialization and having a support network within the community?”

Teaching Point: Holistic medicine is “the art and science that addresses the whole person . . . to prevent and treat disease.” A holistic approach should be applied in patients with disabilities as in any other patient. In an ideal medical home for children and youth with special health care needs, physicians and learners must not just take care of the medical needs but also address the social and other aspects that make the individual an integral part of the community in which he or she resides.

(8) “Lastly, will there be any service coordination? Will the physician and/or his/her office staff know what resources are available to them? It would be ideal if they could serve as a single point of entry for these matters.”

Teaching Point: Residents and medical students should be made aware of the importance of physician-directed care coordination. The medical home physician should work with the patient and family to create a plan of care that can be shared with other providers and specialists. The medical home office can maintain a central record or database containing all pertinent medical information, including hospitalizations and specialty care. Further, through care coordination, families can be linked to support and advocacy groups, parent-to-parent groups, and other family resources.

In summary, through the above questions, the parent of this adolescent asks his future family physicians if they would be able to provide a medical home to her son and to other children or youth with special health care needs.

As for the teachers of family medicine, the questions now are:

• Are we ready to serve all of J.S.'s needs and give J.S. the kind of care he requires?
• Are we able to provide medical homes for children and youth with special health care needs in our offices as we do for our other patients?
• Are our students and residents equipped with the knowledge required for creating a medical home for children and youth with special health care needs transitioning to our practices?
• If not, what needs to be done and what are the barriers stopping us from getting there?

Family physicians’ offices/practices are best suited to serve as medical homes for children and youth with special health care needs since they are accustomed to providing compassionate and coordinated care for all of their patients. To learn more about caring for this group of patients and to prepare to teach learners on this topic, family physicians may seek help at their local or state academies and also from corresponding local or state pediatric organizations. To educate the medical students and residents, case presentations and conferences with invited speakers may be used in conjunction with lectures and office precepting. The American Academy of Pediatrics Medical Home Web site has extensive training material to help office based teachers of family medicine equip themselves for educating students and residents.

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