



American Academy of Developmental Medicine and Dentistry

Developmental Medicine and Dentistry Reviews & Reports



Message from the Editor: In this issue of the “Reviews and Reports”, Dr. Shobin discusses the risk/benefit analysis that should be applied to the decision of whether annual PAP and pelvic exams are appropriate for all individuals with intellectual disabilities. This is a difficult topic as contending issues of discomfort and trauma of the exam must be balanced against general population recommendations and personalized care and, frequently, an unreliable sexual history. The most difficult patient with whom one would want this dialogue is often the patient who has the most severe cognitive deficit and doesn't

understand the benefits but clearly perceives the invasion and discomfort. In the past, these issues have been used as excuses to not perform a necessary exam, but this is clearly not optimal medical care. Using the recommendations of the American College of Obstetrics and Gynecology and assessing for risk factors is a good place to start. Dr. Shobin provides an experienced clinician's perspective on this difficult task and distinguishes the approach based on whether the exam is for cancer screening or is problem-oriented.

—Steven G. Zelenski, D.O., Ph.D. Co-Editor, R&R

The Role of the Gynecologic Exam in the Care of Women with Intellectual Disabilities

BY DAVID SHOBIN, M.D., FACOG

In the issue of gynecologic examinations for female patients with special needs, confusion abounds around the timing and indication for such exams. Under the best of circumstances and in the best of hands, a GYN exam in this population has the potential to be physically and emotionally traumatic, and consequently, the exam should be reserved for those patients who truly need it. Nonetheless, many patients are routinely referred for an “annual pap” or a “yearly exam” under the misconception that good medicine requires an annual pap smear on all adult females or even that such exams are mandated by state law. But in fact, no such laws or requirements exist other than that people with intellectual disabilities should be treated the same as the rest of the non-impaired population. This becomes a diagnostic balancing act in which the need for good preventive care must be weighed against the provider's admoni-

tion to above all, do no harm. With that in mind, whether or not to conduct a gynecological exam on a patient with special needs should not be a complicated decision if the health care professional follows certain basic indications.

First, regarding the law: state laws generally require that females with special needs aren't given second-class medical status because of their disability but, instead, should be managed like their non-handicapped peers. For example, a non-impaired thirty-year-old, asymptomatic, virginal female does not require an annual GYN exam and pap smear. For all such patients, the yearly check-up is a myth. Rather, the decision to undergo a gynecologic exam should be made jointly by the physician and patient (and/or guardian), should consider the relative risks and benefits of the procedure, and should be individualized for that patient.

Second, be sure to examine patients who have physical complaints and/or

symptoms not simply because an arbitrary period of time has elapsed. On the surface, this suggestion appears to contradict current standards regarding cancer screening and preventive care, yet such recommendations were formulated for the normal population, not in connections with those for whom exams might prove traumatic and for whom the physical and emotional risk outweighs the benefit. This raises the question of the unique demands posed by pap smear testing – an accurate, inexpensive cancer-screening test – and its role in this population.

And third, the data supporting the decision to perform a pap smear at a particular interval is based on an accurate history of sexual intercourse. Both the American College of Obstetricians and Gynecologists and the U.S. Preventive Services Task Force (1,2) suggest pap screening only after the initiation of sexual intercourse. Thus, a woman who we

can be sure is not, and never has been, sexually active does not require a pap smear. (3) Why not?

Traditional pap smears – smearing a cervical or vaginal cellular sample onto a slide, which is then examined by a cytologist – are rarely performed these days, having been replaced by collecting the cells in a liquid medium. But whatever they're called, the pap is a screening test for cervical cancer. Cervical cancer and its precursors are caused by high-risk strains of HPV, the human papilloma virus. HPV affecting the female cervix is a sexually transmitted disease (STD) spread through sexual intercourse. Cervical cancer does not occur in the absence of this viral infection; and therefore, patients who have never been sexually active do not require cytologic (pap) screening. This is especially true of virginal patients with intact hymens at any age. If forced to perform an "annual pap" on such a patient, inserting a vaginal speculum to visualize the cervix can cause significant trauma and pain, and instead, the examiner usually opts for performing a "Q-Tip" exam – inserting a cotton swab past the hymen into the lower vagina, swirling it around to collect cells, and then submitting the collection as a "vaginal pap." But not only can this, too, be a traumatic exam and one woefully inadequate for cervical cancer detection, it isn't necessary.

How then should the health care

examiner proceed when confronted by such a patient and a demanding staff? First, the professional should take a thorough history, including a sexual history. This is followed by a breast examination. Then, if the history definitely indicates pregnancies, including miscarriages and/or abortions, the examiner may conclude that the patient is no longer virginal and may proceed with a narrow speculum exam and pap. However, if the history is uncertain or virginity is alleged, the most significant part of the pelvic exam, after initial visual inspection, is to ascertain whether or not a hymen is intact. In cooperative patients, or in patients whose thighs can be held apart, this can often be visually determined. In difficult cases, gentle palpation of the hymen's presence with a lubricated, gloved index finger will suffice. There is never a need, in routine virginal cases, for vaginal penetration by finger or speculum. If the hymen is present, forget about performing an unnecessary pap test. If it is absent, one may infer prior vaginal penetration and proceed with the narrow speculum exam and pap.

Assume for a moment that the patient has been found to be virginal and the pap attempt is abandoned. How should the remainder of the exam then proceed? In asymptomatic patients, a gentle single-finger rectal exam will usually suffice to determine the presence of abnormal

pelvic masses and, in patients over forty, to collect stool for occult blood testing. Occasionally, the patient won't cooperate for a rectal exam. Here, a trans-abdominal pelvic sonogram should be adequate to rule in or out the presence of abnormal masses. If all is deemed normal, the virginal asymptomatic patient needs to be examined rectally or sonographically every two-to-three years, without a pap, unless sexual activity or specific gynecologic symptoms intervene. Another way of dealing with patients known to be combative or uncooperative is by oral anxiolytics, e.g., lorazepam 2 mg by mouth, one-half hour before the exam. If the patient becomes sufficiently relaxed, a rectal exam might be accomplished.

As mentioned earlier, those patients who truly require a GYN exam are those who are symptomatic. Symptoms are the same as in normal females: abnormal vaginal bleeding, unusual discharge, itching, etc.; and in the non-virginal patient, they can be evaluated and treated similarly. However, patients with intact hymens pose a slight problem, but it is usually not insurmountable. Vulvovaginitis, for example, occasionally with an accompanying discharge, can often be diagnosed by simple vulvar inspection and by obtaining a vaginal swab of the accompanying secretions, using a microscope to check for the presence of yeast, trichomonas, bacterial

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INSTRUCTIONS

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Upon completion of the reading of this article, the learner will be able to:

1. Appreciate the importance of tailoring gynecologic care of a person with a profound neurodevelopmental/intellectual disability to their specific needs.

2. Describe the challenges that continue to interfere with gynecologic care for people with neurodevelopmental/intel-

lectual disability, creating a significant health care disparity.

3. Describe key factors in a risk assessment analysis that will help the patient and care team decide whether performing a gynecologic exam is appropriate at a particular point in time.

4. Describe key aspects of a gynecologic exam and how it may have to be modified in a patient with severe cognitive impairment.

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vaginosis, or other conditions. Irregular and/or troublesome bleeding in the reproductive-age patient (with or without emotional overlay) who has a normal rectal exam or sonogram will most likely have a hormonal etiology and will be called “dysfunctional uterine bleeding.” This is often treated with hormonal contraceptive agents, either oral or injectable, without the need for a penetrating vaginal exam. However, in postmenopausal patients, or if the bleeding is profuse to the point of anemia or faintness or for those patients who don’t respond to hormonal therapies, consideration must be given to a thorough vaginal exam under anesthesia and including the obtaining of a sample of endometrium, the uterine lining tissue. Likewise, any surgical procedures, however minor, require anesthesia.

Dr. Papanicolau’s trademark smear was

a groundbreaking medical advance, and this brief overview is not intended to disparage his accomplishment. This overview merely suggests that everything has a place. And that place requires judgment on the part of the examiner, where the need for accurate, early diagnosis must be balanced against the difficulties posed by the exam. In the case of patients with special needs, that place occurs not nearly as frequently as the requested “yearly GYN exam and pap” would suggest. The concerned layperson or family member, however, should not misinterpret the above to imply that gynecologic examinations should be dispensed with. Rather, by following common sense guidelines, focusing on good history-taking, and adhering to expert recommendations, unnecessary exams in this population can be dispensed with and appropriate examinations made more acceptable.

REFERENCES

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