To Pap or When to Pap--Clinical Pearls in Health Care Maintenance in Women with Developmental Disabilities

Charlotte Clark–Neitzel, MD
Family and Developmental Medicine, PLLC
Olympia, Washington
clarkneitzel@comcast.net

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DISCLAIMERS

I have no financial incentives.

I will generally not cover recommendations from different organizations but will use USPSTF recommendations as a base because–

I want focus on IMPLEMENTING a set of basic guidelines in CLINICAL ENCOUNTERS with women with I/DD in a PRACTICAL manner using case presentations and clinical pearls.

I want to leave time for discussion.
Outline

Screening for Cervical Cancer (Negotiation)

Screening for Chlamydia and Gonorrhea (Taking a Sexual History)

Screening for Breast Cancer (Mammograms and Physical Accessibility) (CBE and the Role of Physicals/Well Visits)
USPSTF Recommendation on Screening for Cervical Cancer (March 2012)

*These recommendations apply to women who have a cervix, regardless of sexual history. These recommendations do not apply to women who have received a diagnosis of a high-grade precancerous cervical lesion or cervical cancer, women with in utero exposure to DES or women who are immunocompromised (i.e. HIV positive).*

The USPSTF recommends screening for cervical cancer in women ages **21 to 65 years** with cytology (Pap smear) **every 3 years**. (A Recommendation)
Reasoning most pertinent to women with developmental disabilities

Virtually all cervical cancer cases occur in women who have not had Pap smears ever or for many years. Some of these were occurring in women thought to be “never sexually active.”
Continued USPSTF Recommendation on Screening for Cervical Cancer (March 2012)

The USPSTF recommends screening for cervical cancer in women ages 21 to 65 years with cytology (Pap smear) every 3 years or for women ages **30 to 65 years** who want to lengthen the screening interval, screening with a combination of cytology and human papillomavirus (HPV) testing every **5 years**. (A Recommendation)

The USPSTF recommends **against** screening for cervical cancer in women **younger than age 21 years**. (D Recommendation)

The USPSTF recommends **against** screening for cervical cancer in women **older than age 65 years** who have had adequate prior screening and are not otherwise at high risk for cervical cancer. The USPSTF recommends **against** screening for cervical cancer in women who have had a **hysterectomy** with removal of the cervix and who do not have a history of a high-grade precancerous lesion (i.e.[CIN] grade 2 or 3) or cervical cancer. (D Recommendations)
Implementing these Recommendations: Start with where the patient and her caregivers are at–

Patient comments–
“Yucky, yucky, yucky.”
“Okay if I get the fuzzy feet.”

Caregiver/relative comments–
“She’s never had sex. No way does she need that.”
“DDD (Department of Developmental Disabilities) says she has to have a Pap every year.”

Start with where you are at–

Explain the recommendations on screening with Pap and what a Pap smear is. Ask for permission but also negotiate.

“Who else are you going to bring into the ..(exam room).. but yourself.” Parker Palmer
Case Presentation 1

25 year old with Down syndrome who lives with parents. Mother requested Pap. Mother’s gynecologist tried to do Pap but “got no where.” Patient smiles and says “okay” as she does to most requests until she sees the stirrups.

First Exam: Would not allow stirrups initially. Did external genital exam on table (will explain position next). Liked the “warm” light. Then got into stirrups and let external exam be repeated easily. Then sits up suddenly, smiling, “good job.”

What would you do now?
External Genital Exam Pearls

For first exam make external genital exam your focus.

External genital exam (and blind cytobrush Pap technique and vaginal swabs) can be done on table with “frog legs” (flex legs at knees and hips then relax/open into hip abduction).

Document details of external/vaginal exam and behavior techniques for obtaining. Helps to make decisions how to approach for next time.
External Genital Exam

To get the above views, gently spread the labia with one hand while at same time with a finger of other hand put light pressure to upper perineum.
External Genital Exam Pearls

For speculum or bimanual exam to be non-traumatic you need at least finger width (>cm) hymen opening and no labial adhesions.

If discharge and a lot of irritation – do wet mount and treat first.
Case Presentation 1

25 year old with Down syndrome who lives with parents. Mother requests Pap. Mother’s gynecologist tried to do Pap but “got no where.” Patient smiles as you explain and says “okay” as she does to most requests until she sees stirrups.

First Exam: Would not allow stirrups initially. Did external genital exam on table (will explain positions next). Liked the “warm” light. Then got into stirrups and let external exam be repeated easily. Then sits up suddenly, smiling, “good job.”

Stopped exam here. Will come back to later.
Case Presentation 2

22 year old with Cornelia de Lange’s syndrome

- New patient, “needs a physical today and DDD says a Pap has to be part of it”

- Nonverbal with some signs, aggressive behaviors particularly hair pulling and pinching, severe aerophagia/abdominal distension causing obvious discomfort at visit. Over past year placed on multiple GI medications combined with multiple psychoactive medications with GI side effects

- Was removed from a previous placement early teens for “abuse” then went to several group homes who “couldn’t handle her”

- Records show no Paps/pelvic exams but over past year has had several general anesthesia procedures for EGD, ENT and dental work.

What would you do now?
Case Presentation 2 Continued

Letter given for state DDD agency at that visit then had multiple visits with improvement of medical-psychiatric conditions. At 23 year old had following exam: 
FEMALE–GENITOURINARY: Likes to undress naked and get on exam table. Then needed caregiver maximal physical support: External genitalia show general inspection is normal and no lesions present. **Inner labia narrow opening.** **Hymen with minimal residual irregular tissue with at least 2cm long open though narrow.** Vaginal inspection discovers no discharge. Wet mount negative. **Very narrow and short.** Cervical inspection detects normal appearance and without lesions or discharge. **Barely visualized upper lip of cervix.** Despite open hymen, with the narrow, short vagina had to use pediatric speculum. **Uterus bimanual exam demonstrates** without tenderness, masses, or enlargement. **Adnexa palpation** discovers non-tender and without enlargement, masses or nodularity.

Pap normal but no endocervical cells present. GC/chlamydia negative.
Pearls on Speculum Techniques

Rarely need to use a speculum larger than small disposable or Pederson regular in primip.

Have a metal Huffman and pediatric speculum available (see on display).

Can do speculum exam even if patient will not move to end of exam table if tilt metal speculum at 30o (but less comfortable).

Bimanual much less important than Pap. But sometimes single finger bimanual gives you idea of anatomy/location of cervix.
Have cytobrushes that match the smaller speculums (see on display).
Case Presentation 1

25 year old with Down syndrome who lives with parents.

First Exam: Would not allow stirrups initially. Did external genital exam on table. Liked the “warm” light. Then got into stirrups and let external exam be repeated easily. Then sits up suddenly, smiling, “good job.”

Blind Cytobrush Technique

Liquid preparation technology has made possible.

Option if not able to do speculum.

May be better in certain congenital vaginal anatomy.
Comparison of Techniques

Liquid prep with standard speculum technique 80% endocervical yield.

Liquid prep with blind techniques produced 44% endocervical cell yield.

The Endocervical Dilemma

Recent Guidelines from USPSTF and United Kingdom recommend testing every three years but make no mention of what to do should results not include endocervical cells.

Australian guidelines (which recommend Pap smears every 2 years) state that the quality of a smear is not determined by the presence or absence of endocervical cells and need not change screening interval.

The American Cancer Society recommends annual repeat screening for women whose Pap smears show no endocervical cells.

Canadian Task Force on Preventive Health Care states that the evidence is contradictory and no recommendation can be made (receives a C grade, meaning that ).
The Endocervical Dilemma

“The majority of recent, rigorous and validated studies support the view that the presence of endocervical cells is not necessary for a Pap smear result to be valid and may possibly be a risk factor for cervical abnormality.”

Case Presentation 2

Revisit the case of woman with Cornelia de Lange syndrome who is now 26 years old

Able to do blind liquid cytobrush technique 2–3 years later with much less physical support.

Pap with this technique had endocervical cells present versus the speculum Pap a year earlier without endocervical cells.
Unknowns

Prevalence and risk of cervical cancer in I/DD population.

Prevalence and risk of sexual activity and abuse in I/DD population. (Next section of this presentation will give some information on assessing individual risk. Next presentation to cover disparities and prevalence literature. Sexual abuse at least as prevalent as general population.)

Role of Pap with HPV and 5 year screening interval if cannot visualize completely cervix for sampling or if no endocervicals present.

Role of HPV vaginal swab if cannot obtain Pap.
Screening for Chlamydial Infection (June 2007) and GC Infection (May 2004)

The U.S. Preventive Services Task Force (USPSTF) recommends screening for chlamydial infection for all sexually active young women aged 24 and younger and for older non-pregnant women who are at increased risk. (Grade: A Recommendation) (Separate recommendation for screening for chlamydia and GC infections for all pregnant women).

The U.S. Preventive Services Task Force (USPSTF) recommends that clinicians screen all sexually active women, including those who are pregnant, for gonorrhea infection if they are at increased risk for infection (that is, if they are under age 25 or have other individual or population risk factors.) (Grade: A Recommendation)
Case Presentation 3 A/B

24 yo and 26 yo “sisters” both with Down syndrome recently removed from same “foster home” due to “abuse” present as new patients for “need physicals and Depo”

Patient A – Non verbal, very cooperative/passive with physical including pelvic exam. Pap and chlamydia/GC were sent. Placed on q6month continuous cycle BCP.

Patient B – Very combative for any exam initially.

What would you do next?
Taking a Sexual History From Caregivers

Questions used in our clinic annually by MA to the caregivers with the following EMR toggle prompts:

History of abnormal Pap___. History of STD ___. Known to be or ever been sexually active ___. Any questions of abuse in previous living situations ___. Multiple unknown living situation___.

Studies vary widely on sexual abuse rates in this population. At least as high as general population.
Recommended Tests

Nucleic acid amplification tests (NAAT) recommended for CT/GC in men & women

Optimal specimen types are first catch urine in men and vaginal swabs in women

Vaginal swabs are simple and can be done by anyone/patient themselves.
Case Presentation 3 A/B

24yo/26 yo “sisters” both with Down syndrome removed from same “foster home” due to “abuse” present as new patients for “need physicals and Depo”

Patient A– Non verbal, very cooperative/passive with physical including pelvic. Pap and GC were negative. Chlamydia was positive. (On SSRI began smiling, talking, a little more difficult to perform pelvic exam.)

Patient B – Very combative for any exam initially. When got sister’s result then scheduled patient back. Second visit a week later allowed in bathroom on toilet to do vaginal NAAT’s– negative. Pap attempted a few months later. Tried with triazolam– even worse agitation. Home visit where allowed Pap in bed after using bathroom with “frog leg” position and blind cytobrush techniques. (HIV/RPR/hepB screening neg for both also).
Pearls

You can get a lot done in the bathroom!

Triazolam— Worth trying but rarely find useful for gynecologic exams, particularly if probable history of abuse. (May help with long transport to office.)

Some patients with developmental disabilities need home visits.
Taking a Sexual History

Take primary history directly in patients with mild intellectual disabilities but use simple, direct questions.

1. Are you sexually active?
   Direct- *Have you ever had sex?*
   (If no– Do you know what sex is?)
   –Are you having sex now?

CDC booklet– *A Guide to Taking a Sexual History*
http://www.cdc.gov/std/treatment/SexualHistory.pdf
Taking a Sexual History

1. Are you sexually active?
   Direct – **Have you ever had sex?**
   – Are you having sex?

2. Are your sex partners women, men or both? How many sexual partner have you had the past year?
   Direct – **Who did you have sex with?**
   – Have you had sex with a man (boyfriend/boy) or with a woman (girlfriend/girl)?
   – Have you had sex with more than one man (boyfriend/boy)? (adjust question to above responses)

3. What kind of sexual contact have you had? Genital? Oral? Anal?
   Direct – **What did you do when you had sex?**
   – Was there a penis in your vagina? Your mouth on a penis? Your mouth on vagina?

4. Are your sexual partners high risk?
   Direct – **Are you hurt (or worried or afraid) because of this sex?**
3. What kind of sexual contact have you had? Genital? Oral? Anal?

Direct—What did you do when you had sex?
- Was there a penis in your vagina? Your mouth on a penis? Your mouth on a vagina?

If the answer to 1 is yes but no to all of 3 then ask further and realize sometimes persons with I/DD will consider, for example, a kiss on the cheek as “having sex.”
Case Presentation 4

28 yo G1P1 with encephalopathy from prematurity complications with mild ID and CP, ho genital warts, for “Pap and birth control refills”. Co of vaginal itching ? discharge. Sexually active with “boyfriend” for 2 years. Physical and Pap done. Wet mount + hyphae treated fluconazole. Refilled BCP’s,

Would you do anything else?
Case Presentation 4

28 yo G1P1 with encephalopathy from prematurity complications with mild ID and CP, ho genital warts, for “Pap and birth control refills”. Co of vaginal itching ?discharge. Sexually active with “boyfriend” for 2 years. Physical and Pap done. Wet mount +hyphae treated fluconazole. Refilled BCP’s.

3 weeks later she returns because “boyfriend has gonorrhea.” She had been afraid he was having sex with others. They had genital and oral sex(“made me”, “didn’t like”, “yelled at me a lot”). ?Domestic violence– no longer contact with this “boyfriend.” GC culture/exam oral and vaginal. Ceftriaxone and doxycycline. HIV/RPR/hepB/Chlamydia screenings.

1–2 months later returns with caregiver co new behavioral problems, patient co nightmares and insomnia. Diagnosed and treated PTSD from domestic violence.
Taking a Sexual History

4. Are your sexual partners high risk?  
   (There are a number questions that could go here.)

Direct – Are you hurt (or worried or afraid) because of this sex?  
- Do you want STD tests (with explanation what STD testing is)?
Screening for Breast Cancer

The USPSTF recommends biennial screening mammography for women aged 50 to 74 years. (Grade B)

The decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms. (Grade C)
Mammograms

Physical accessibility for mammograms has improved the past few years as the switch to digital technology necessitated new machines which were built more accessible.

Very brief overview issues from sources below (easy download for further details)–

U.S. Department of Justice: “Access To Medical Care For Individuals With Mobility Disabilities” (May 2010)

1. Adjusts to multiple heights and pivot angles
2. Allows side and front approaches
3. Adequate clearance beneath camera (and plate).
Positioning Chairs
Positioning Chairs

Adjustable Height
Removable Footrests and Armrests
Adjustable Seat Length (Knees to Hips)
Seat Belt
Adjustable Back/Reclines
Screening for Breast Cancer 2

The USPSTF concludes that the current evidence is insufficient to assess the additional benefits and harms of clinical breast examination (CBE) beyond screening mammography in women 40 years or older. (Grade I)
What is the role of physical including CBE–
– in health care maintenance in general?
– in health care maintenance in patient who cannot give reliable history for targeted exam?

What is the role and frequency of well/HCM visits–
– in general?
– in patient who cannot give reliable history for targeted exam?
Case Presentation 5

51 year old with mild intellectual disability and schizophrenia presents as new patient for “overdue for physical” and seeming more “tired” to caregiver.

Several years since seen by medical provider because couldn’t find “one I trusted.” She explained this meant one who would listen when she said she did not want something.

She stated she was fine with most of physical but would not take off shirt/bra and did not want breast exam.

What would you do?
Case Presentation 5 (continued)

Did rest of physical. Liked stethoscope. I asked if could repeat chest exam but this time touching chest and breast through clothes. She agreed if I used the stethoscope throughout.

3x4 cm hard, fixed right breast mass.

(Stage IV breast cancer treated chemo/radiation through 2008 – last whole body PET scan Negative 2012)
What we do in our clinic

We offer/recommend every 2 year well/HCM visit to all patients with physical (targeted for some parts).

For all patients who may not be able to give a good history to target an exam:

– every year visit with full physical in long appointment slot.

– every other year with a focus on health care maintenance and GU history/exam.

– every other year with a focus on a functional assessment and update of neurodevelopmental profile.
Subjective:

CHIEF COMPLAINT(S): Requesting address GU problems with health care maintenance/ physical visit as well as other problems below.

WELL HISTORY/HC: SYMPTOMS/RELATED: Reports symptoms of Health Care Maintenance/Well Visit History was taken from flowsheets as below.

FEMALE GU: PP: SYMPTOMS/RELATED: Reports symptoms of as follows:
incontinence___

menstrual issues___

Menopause/perimenopause issues___
birth control needs___
counseling sexuality/STD___

GU abnormality with DD diagnosis___

LOCATION: Reports area of involvement as GU

QUALITY/COURSE: Reports condition is
++++++ unchanged | worsening | improving |

DURATION: Reports the general length of symptoms to be years.

++++++ hours I days | weeks | months |

INTENSITY/SEVERITY: Reports measurement (or degree) as mild.
++++++ moderate | severe |

MODIFIERS/SEVERITY: Has tried as follows below

Incontinence supplies | Birth control pills | Other medication | None___

CONTEXT/WHEN: Reports usually associated with developmental disability and as follows below.

Last Menstrual Period___

Able to do PAP smears in office previously___

History of abnormal Pap___ History of STD___

Known to be or ever been sexually active___

Questions of abuse in previous living situations___

Multiple/unknown living situation___

Dr. Clark’s well woman___
Subjective

CHIEF COMPLAINT(S): Limited function or disability (n). Requesting DDD comprehensive evaluation and physical needed to assess current level of functioning and ADL's for...

HPI: SYMPTOMS/RELATED: Reports symptoms of learning problems, Requesting DDD comprehensive evaluation and physical needed to assess current level of functioning and ADL's for...

Independent:

Dependent:

LOCATION: Reports area of involvement as generalized, CNS

QUALITY/COURSE: Reports condition is

+++++ improving | worsening | unchanged |

DURATION: Reports the general length of symptoms to be years.

+++++ hours | days | weeks | months |

INTENSITY/SEVERITY: Reports measurement (or degree) as moderate.

+++++ severity

ONSET/TIMING: Reports occurrence as chronic, since early childhood

MODIFIERS/TREATMENTS: Has tried supported living activity.

CONTEXT/WHEN: Reports usually associated with neurotransmitter profile and other functional activity as below:

Genetic Diagnosis/Etiology:

Cognition (include Communication/Vocational):

Neuromuscular:

Seizure:

Sensory:

Behavioral/Mental Health:

ROS: GEN- Constitutional: Denies symptoms such as

Reports symptoms of weight loss.

+++++ fatigue (malaise or lethargy) | fever |

RECT: Denies symptoms such as vision problems/glasses

Reports symptoms of...
What is the role of physical including CBE—
- in health care maintenance in general?
- in patient who cannot give reliable history for targeted exam?

What is the role and frequency of well/HCM visits—
- in general?
- in patient who cannot give reliable history for targeted exam?

Personalized preventative care— How to do?
The decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms. (Grade C)

-----DISCUSSION-----
Thank You

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Olympia, Washington

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