

# "Your Test is Abnormal"

## Applying Shared Decision Making to Difficult Conversations

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# Disclosures Cason

Merck Gardasil

Speaker's Bureau  
Advisory board



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# Disclosures Policar

Nothing to disclose



# Shared Decision Making

“...clinicians provide patients with information about all the options and help them to identify their preferences in the context of their values.”

Fried, T. R. (2016). *N Engl J Med*

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# Counseling Tips

First rule: ask probing questions

- Questions that are specific to HER
- What does she “know”
- About HER concerns, her questions, her feelings



# Pitfalls/Common Barriers to Good Communication

- Launching into your agenda first without negotiating the focus of the interview.
- Offering reassurance prematurely.

Medical oncology communication skills  
training **learning modules** 3 (2002)  
Fallowfield, L., (2002). *Lancet*



# Pitfalls/Common Barriers to Good Communication

- Giving pathophysiology lectures.
- Ignoring the context of the communication encounter.
- Not finding out the patient's information needs.

Medical oncology communication skills training **learning modules** 3 (2002)  
Fallowfield, L., (2002). *Lancet*



# Counseling Pearls

- Build rapport
- Point out accurate information she knows
- Active listening
- Empathy with neutral words
- Information sandwich
- Rephrasing
- “On the one hand”





Sara 26 Year Old G<sub>0</sub>P<sub>0</sub>

- Student a local college
- Seen at Student Health Center for well woman visit; cytology report: ASCUS, reflex HPV positive
- Sexual debut at 17; five lifetime partners
- Non-smoker
- Using OCs for the past 5 years



# Sara 26 Year Old G<sub>0</sub>P<sub>0</sub>

- Prior to colpo she appears anxious
- What are her concerns?
- How can you help?



# Neutral Words



Use neutral words to transmit empathy rather than labeling feelings like “You seem anxious”

“I can certainly understand that \_\_\_\_ is concerning to you”

“Wow, \_\_\_\_ is hard to deal with”



Sara 26 year old G<sub>0</sub>P<sub>0</sub>

“I can see that this is hard for you, can you tell me what is most concerning for you about this?”



# ASC-US and LSIL

Borderline cytology is associated with considerable excess anxiety in the period of 6-24 months after the original test



Korfage, I. J. (2010) *Eur J Cancer*

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# Psychosocial Effects of Abnormal Pap Smear Questionnaire (PEAPS-Q)

14 Questions on a 5-point Likert scale re:

- Patient's feeling and beliefs
- Concerns about and experience of the procedure
- Distress regarding the outcome and cancer
- Concerns regarding sexual and relationship issues



# PEAPS-Q

- Uncertainty regarding need for procedure
- Fear of cancer
- Fear of dying
- Fear of infertility



# PEAPS-Q

- Concerns regarding:
  - Sexual function
  - Physical discomfort
- Logistical difficulties (babysitter, money, insurance, transportation, job conflicts)
- Similar trends in each study but some differences in various populations studied





# Interventions

- Often women don't volunteer concerns
- Pay attention to her emotional response
- Understanding her concerns and addressing them reduces anxiety and allows her to assist in management.



Valdini, A., (2004). *J Low Genit Tract Dis*

Stinnett, B. A. (2000). *J Low Genit Tract Dis*

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# Interventions

- Counseling and education reduce anxiety
- Pre-visit intervention may improve adherence and reduce anxiety associated with colposcopy



Valdini, A., (2004). *J Low Genit Tract Dis*

Stinnett, B. A. (2000). *J Low Genit Tract Dis*

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# Associated with Increased Anxiety

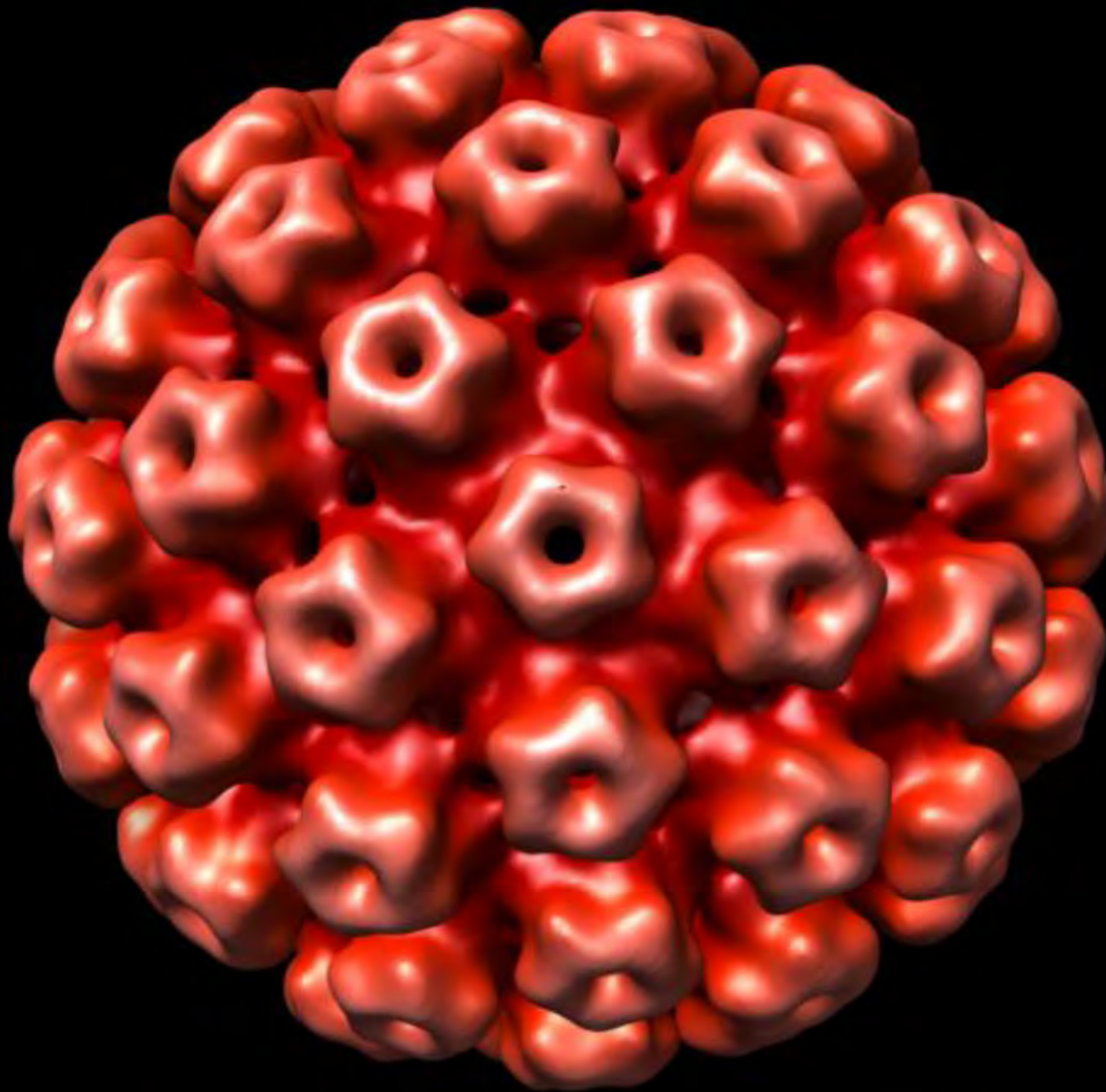
- The wording of the referral letter for colposcopy
- Women who received a letter stating 'some changes' were at a five-fold increased risk for high levels of anxiety than those who received a letter stating 'light changes'.



# Associated with Increased Anxiety

Women with high depression scores had a nine-fold risk for higher levels of anxiety and did not respond with lower anxiety levels after information and examination.





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Sara 26 Year Old G<sub>0</sub>P<sub>0</sub>

As she is crying Sara says:

“I’m sorry I’m so emotional! I just can’t believe my boyfriend cheated on me and gave me HPV. Now I’ll have HPV for the rest of my life!!”



# Reaction To a Positive HPV Test

- Shame
- Embarrassment
- Stigma
- Self blame
- Anxiety
- Regret





# Reactions

- Confusion
- Fear
- Powerlessness
- Anger

Promotion of the HPV vaccine has not *yet* increased awareness or “normalization” of HPV infection





# Sexual Relationships

1/3 of HPV + women reported feeling worse about **past and future** sexual relationships compared with <2% of HPV- women



# Determine *Her* Questions and Concerns

- Cancer -overriding concern
- Worry about horizontal transmission
- Fomites
- Sexuality
- Pregnancy
- Children



# Patient Education Tips

- Develop “scripts” that work for you
- Utilize written materials
- Teach back
- Utilize staff educators to introduce topic and save time



# Try NOT to Disagree



- Whenever possible, find something in what she says to agree with and ***then add*** your scientific or medical information
- “Yes! .... and...”
- Instead of “no” or “but”



# Response to Sara

- **“You’re absolutely right** that HPV is passed from person to person by skin to skin contact”
- “And interestingly\_\_\_\_\_”



# Information Sandwich

- Sandwich the information you want to give her between questions
- Education requires knowing what the learner already knows and building on that knowledge



# What Does Sara “Know”?

Women learn about HPV...

- On-line
- From social media
- From TV and movies
- Through friends
- Lastly, from medical providers



# Teach Back



- “To make sure we are on the same page, can you tell me what your understanding of your results are?”
- “What have you read (or heard or what do you know) about HPV?”





# I Will Always Have HPV, Right?

- “Your immune system clears most viruses that you get. With time, your immune system is very likely to clear the HPV.”



# I Will Always Have HPV, Right?

- “Almost everyone clears the virus to undetectable levels before it does any harm to the cells on the cervix.”
- “Most women clear the HPV within 2-3 years-- on average after 8 months.”



# It's Not An STD *In The Usual Sense*

“HPV is a risk marker for pre-cancer and cancer”

- We don't test men
- We don't treat HPV
- We don't treat or test partners
- It goes away on it's own the vast majority of the time



# Does This Mean My Partner Slept With Someone Else?

“Having an HPV infection is not a marker for sexual behaviors or infidelity”



HSIL

HSIL

CIN 3

Severe  
dysplasia

Carcinoma  
in-situ

## High Risk Vs. Low Risk



“Unfortunately, it’s confusing because the name HPV is used to describe two types of viruses. One type causes warts but can’t cause cancer. The other type can cause cancer and doesn’t cause warts.”



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# What Is HPV Infection?

- “HPV infection is a marker for risk, not a sign of disease”
- This term is very helpful:

## A risk marker

- “Most everyone gets HPV but most of the time we don’t know it’s there, it doesn’t cause any harm and goes away by itself.”



# Who Has HPV Infection?

- HPV infection is very common
- “Most women will acquire HPV infection shortly after they begin having sex, unless they have been vaccinated”.



# How Did I Get It?

- “Skin to skin contact”
- “Usually through intimate genital contact”
- “Perhaps fingers, mouth, sex toys”





# When Did I Get It... and Who Gave It To Me?

- “A positive HPV test doesn’t tell us when you got the HPV infection, or how long you have had it.
- It could have been any time after you started having sex and from any prior or current partner.”



# Will I Get Genital Warts?

- “Remember that the wart virus is different than the HPV we test for with the pap.”
- “We do not test for the wart virus and it is not recommended.”
- “If you do, we can treat them.”



# Will It Affect My Pregnancy?

- “The type of HPV that can cause pre-cancer doesn’t hurt a pregnancy.”
- “The type of HPV that causes warts can RAREY pass warts to the baby during birth and large warts can get in the way on the vulva.”

Erickson, B. K.,. (2013) *Am J Obstet Gynecol*

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# Will I Get Cervical Cancer?

- Highly unlikely
- Follow up as advised by the health care provider!!
- Cervical cancer is preventable
- Cervical cancer should be thought of as a very rare complication of a very common virus



# How Are Men Tested?

- No HPV test is accurate nor approved for men
- No national organization (like the CDC) recommends HPV screening or testing for men because it doesn't change how they are managed
- Men don't need be examined unless they see genital warts on themselves



# How Can I Prevent HPV Infection?

- Vaccine
- Avoid exposure to other STDs
- Condoms
- Each new partner increases risk

Silins, I., (2005). *Int J Cancer*

Lehtinen, M., (2011). *Sex Transm Infect*



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# Systematic Review

- 4/8 longitudinal studies showed a protective effect of condoms in prevention of HPV infections and cervical neoplasia
  - In the remaining 4 studies, a protective effect was observed, but not statistically significant
- This means that consistent condom users had a
  - Lower risk of becoming infected with HPV
  - Higher chance to clear the existing infections
  - Higher chance of high-grade CIN regression without surgical intervention

Lam. (2014). *J Med Screen*

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# Protection with Condoms

- Consistent condom use appears to offer relatively good protection from HPV infections and associated CIN.
- Advice to use condoms might be prevent unnecessary colposcopies, treatments, and reduce the risk of cervical cancer.

Lam. (2014). *J Med Screen*

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# Incidence of Genital HPV Infection in Condom Users

- 37.8 per 100 patient-years among women whose partners used condoms for all instances of intercourse during the eight months before testing
- 89.3 per 100 patient-years at risk in women whose partners used condoms less than 5 percent of the time

Winer, R. L. (2006). *N Engl J Med*,

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# HR HPV in Males by Condom Use in 3 Countries

- Always using condoms was significantly associated with the lowest proportion of HPV detection for any HPV type, any oncogenic type, and multiple types.
- HPV+ samples was lowest for men who always used condoms

Repp, K. K., (2012). *J Infect Dis*

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# Underestimation of Protection?

- Condoms are a nearly impermeable barrier for transmission of small viruses like HPV
- HPV is transmitted by skin-to-skin contact; found in male genital areas not covered by a condom.
- Breakage, slippage, and late application are common
- Research errors such as recall bias and social desirability bias



# How Do I Get Rid of It?

- Condom use
- Having a strong immune system
  - Stop smoking
  - Eat healthily: whole fruits, vegetables, fish and nuts (increased riboflavin, thiamine, vitamin B12, and folate)
  - Get enough sleep
  - Exercise

Chih, H. J (2013). *Nutr Cancer*  
Erickson, B. K. (2013). *Am J Obstet Gynecol*,



# Intervention for Co-infected Couples

- “Calmly and without alarm” gave information to both partners about the possible effects and risk factors of HPV infection.
- Partners were advised to
  - Pay particular attention to the hygiene of both the reproductive tract and their hands
  - Use personal underwear and towels only
  - Avoid oral and anal sex
  - Reduce or eliminate smoking
  - Have only (condom) protected intercourse
  - If HPV-related lesions, to treat them

Garolla, A., (2014). *J Sex Med*

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## Group A

24 infected couples

*Non-counseled*

## Group B

25 infected couples

*Counseled*



Garolla, A., (2014). *J Sex Med*

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Janet: 59 Year Old G<sub>5</sub>P<sub>2</sub>TAB<sub>3</sub>

- HSIL cytology 6 months ago
- Has no-showed for 2 prior colposcopy appointments
- Smoker
- History of cryotherapy for unknown reasons 25 years ago
- Seen for colposcopy today



# Colposcopy



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# Colposcopy

- Associated with high levels of anxiety
  - Higher than with surgery
  - Similar to the anxiety levels in women following an abnormal screening test for fetal abnormalities.
- Can have psychological consequences including pain, discomfort, and failure to return for follow-up.



# Pain Perception with Colposcopy

- Greater pain expectancy prior to colposcopy resulted in higher self-reported pain ratings
- Anxiety following colposcopy was due to experienced pain and pain unpleasantness

Kola, S. (2012)..*Eur J Pain*,

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# To Reduce Anxiety

- Playing music
- Viewing the procedure on a monitor (video colposcopy)

Galaal, K., (2011) *Cochrane Database Syst Rev*

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# Individualize the Patient Interaction

Tailoring information to suit individual coping style may maximize the apparent efficacy of interventions aimed at reducing stress

Kola, S., (2013). *J Behav Med*

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# Lower Anxiety

- Satisfaction with the HCP is associated with decreased anxiety with colposcopy
- A HCP being a “confidant” when communicating cytology results decreases anxiety
- The grade of the referral cytology has more influence on anxiety than “information”

HCP: health care provider  
de Bie, R. P., (2011). *Bjog*



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# Janet 59 Year Old G<sub>5</sub>P<sub>2</sub>TAB<sub>3</sub>

- The front desk staff person has told you about Janet's two "no shows" and was clearly irritated.
- Janet appears detached, distracted and to be in a bit of a hurry.
- She asks how long this will take?



# Janet 59 Year Old G<sub>5</sub>P<sub>2</sub>TAB<sub>3</sub>

- What questions would you like to ask Janet?
- Does it seem important to manage your own annoyance?
- What might be going on for Janet?
- Indirect signs of barriers are cognitive dissonance, unexpected resistance, and unexpected emotional discomfort on the part of the clinician.

Quill, T. E. (1989) *Ann Intern Med*,



# Re-phrasing



- “So I hear you saying ...(\_\_\_\_) do I have that right?”
- “It sounds like....(\_\_\_\_) is that what you mean?”





# Alternates



- “Many of my patients say that they ...(\_\_\_) that what you mean?”
- “So you feel pretty strong about ...(\_\_\_) is that accurate?”



# Sexual Impact

- 6 months post colposcopy decreased:
  - Spontaneous interest in sex
  - Frequency of intercourse
  - Sexual arousal

Hellsten, C., (2008).. *Bjog*,

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# Fear: Two Years Later

- Almost one-third of the women still had a fear of cancer
- A subgroup of depressed women, had high anxiety depression scores at 2-years post colposcopy

Hellsten, C., (2008) *Bjog*

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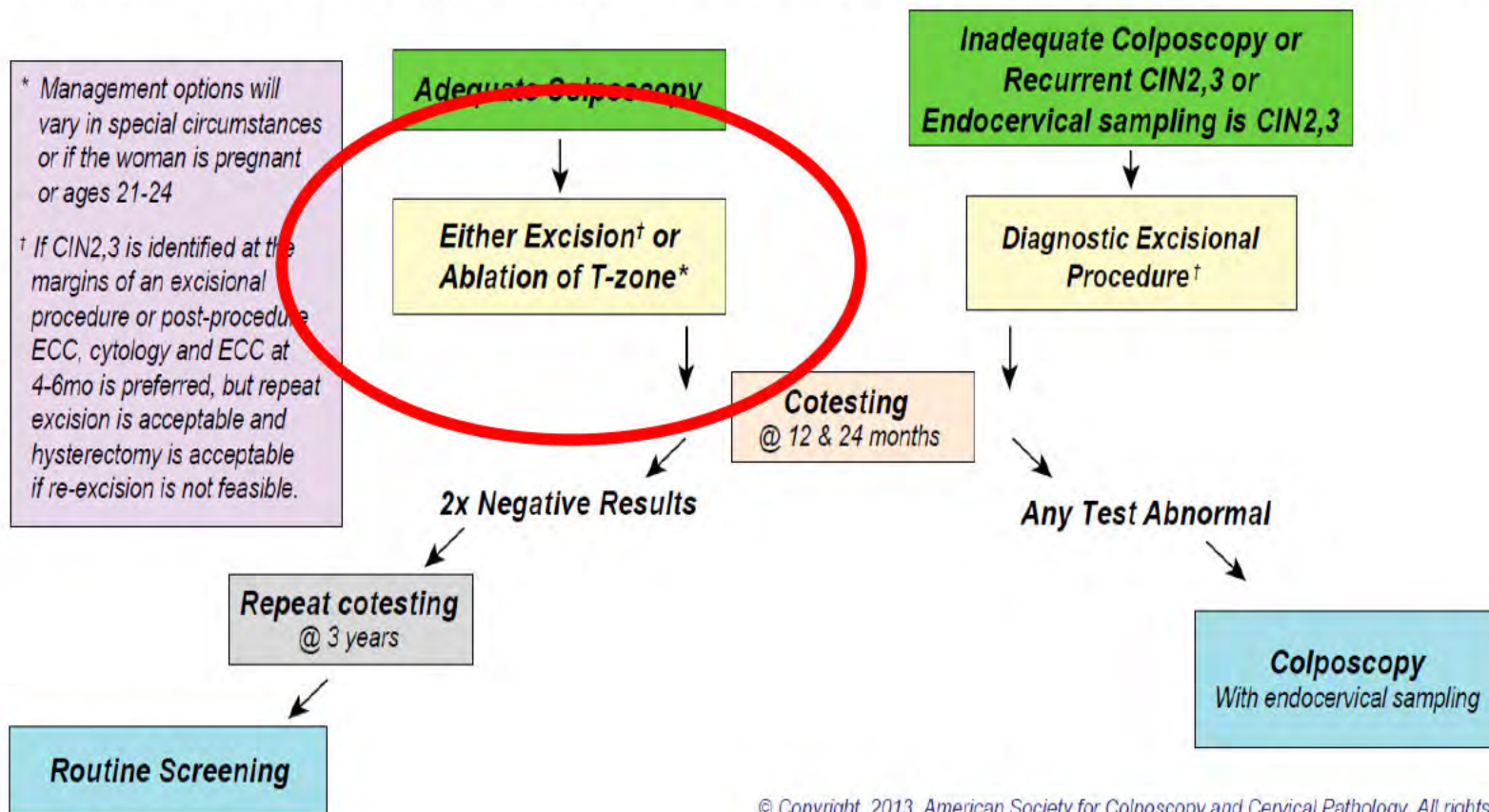
Sandra 38 year old G<sub>2</sub>P<sub>2</sub>

- LSIL on cervical cytology 6 weeks ago
- Colposcopy 2 weeks ago was satisfactory
- Two quadrant lesion
- CIN 2 on biopsy
- Undecided whether she has completed childbearing



# Management of Biopsy-confirmed CIN2,3

## Management of Women with Biopsy-confirmed Cervical Intraepithelial Neoplasia — Grade 2 and 3 (CIN2,3)\*



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Sandra

## Directive Counseling

- You have the option of a LEEP or a cryotherapy
- I advise you to undergo a LEEP because it has the highest cure rate (or the lowest failure rate)
- It will take 15 minutes and I can do it here in the office
- Do you have any questions?





# Sandra

Is Sandra a “young woman” as  
defined by the ASCCP 2012  
Consensus Guidelines?



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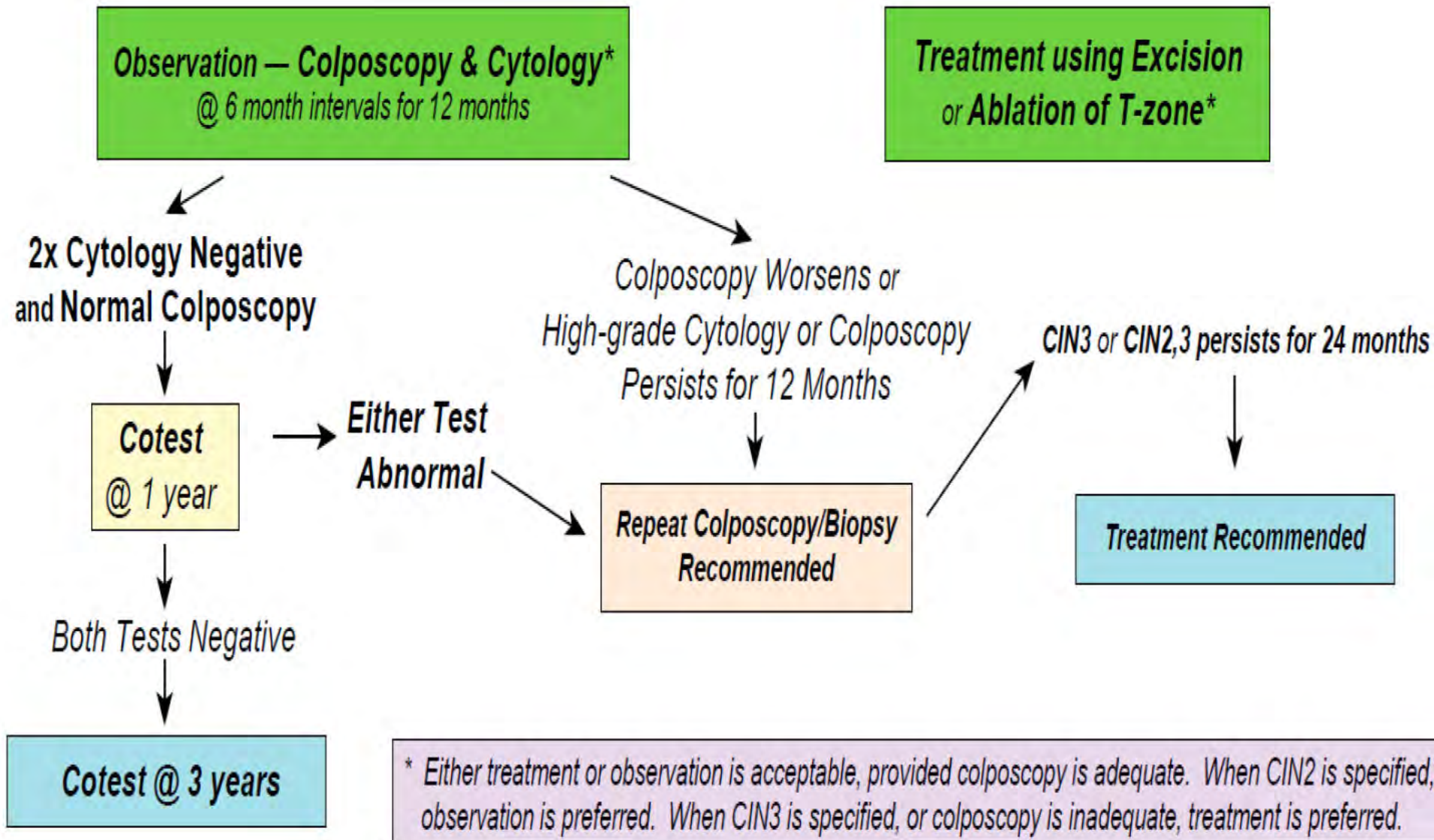
# Sandra

- The term “young women” indicates those who after counseling by their clinicians consider risk to future pregnancies from treating cervical abnormalities to outweigh risk for cancer during observation of those abnormalities.
- No specific age threshold is intended.





# Management of **Young Women** with Biopsy-confirmed Cervical Intraepithelial Neoplasia — Grade 2,3 (CIN2,3) in Special Circumstances\*



# CIN 2 Regression: 18-24 yr olds

- 2-year regression rate for CIN2  $\geq 60\%$
- 1 year progression rate 15-16% mostly CIN 3; no cancers
- No association between rates of regression and patient age

Munro, A.. (2016). *Acta Obstet Gynecol Scand*,  
Moscicki, A. B (2010) *Obstet Gynecol*  
Ho, G. Y., (2011) *J Low Genit Tract Dis*



Sandra:

“Ask-Tell-Ask” Rephrase



## SDM counseling

“Do you think you'd like to have more kids?”

“It sounds like you might be interested in having one more child but your husband isn't so sure, do I have that right?”



# “Ask-Tell-Ask”



- Use straightforward language to communicate the treatment options, bad news, or other information.
- Information should be provided in short, digestible chunks.
- Rule of thumb no more than 1-3 pieces of information



# “Ask-Tell-Ask”



- Use natural frequencies rather than percentages
- **Not** a long lecture or a lot of detail.
- Use fifth-ninth grade English in communicating.
- Avoid medical-ese.





Sandra:  
“Ask-Tell-Ask”

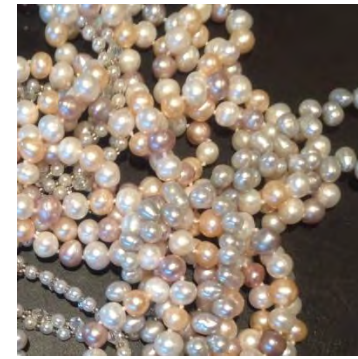


1. “You have a choice between treatment or we can follow you for up to 2 years, as it will go away on it’s own about half the time”



# Sandra

## “Ask-Tell-Ask”



2. “In research studies there is some evidence that women who have had a LEEP might have a slightly higher risk of preterm labor. This doesn’t mean you *will* have early labor if you have a LEEP, it just means there could be a higher chance.”



Sandra

“Ask-Tell-Ask”



3. “If you choose to wait, we would need to watch you very closely to be sure nothing got more severe in the meantime.”





# Sandra

## “Ask-Tell-Ask”



4. “For women of your age with CIN 2, the failure rate of LEEP is 4 out of hundred and the failure rate for cryo is 13 out of a hundred women.
5. “If you have a recurrence (failure), it usually can be treated with a second office procedure”

JNCI (2009)

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Sandra

“Ask- -Ask”



Respond with open ended, probing questions that are relevant to what Sandra has said:

“How would it be for you if the first treatment failed and you had to undergo re-treatment?”

**Then rephrase again**



Sandra

“Ask- -Ask”



“If you choose to watch and wait,  
how would it be for you to come back  
in 6 and 12 months for repeat  
colposcopies and cytology tests?”

“How concerned are you right now?”



# Treatment vs. Expectant Management

- Recommendation of treatment as opposed to expectant management has a stronger association with complete adherence.
- Treatment procedures may be viewed as more serious by the patient and, therefore, foster better adherence.

Alston, M. J.,(2016). J Low Genit Tract Dis,

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# Severity of CIN

- Women with CIN 3 may be more likely to adhere to follow-up colposcopy.
- Women with <CIN 3 may need more targeted follow-up

Kola, S., (2012). *Psychooncology*

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# Factors Associated With Adherence to Advised Management

The recommendation of any kind of treatment as opposed to expectant management is associated with complete follow-up

Alston, M. J.(2016).. J Low Genit Tract Dis,

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Molly 22 year old  $G_1P_0TAB_1$

- Cytology report: ASC-H
- Colposcopy was satisfactory
- No lesions seen
- Biopsies negative
- ECC benign



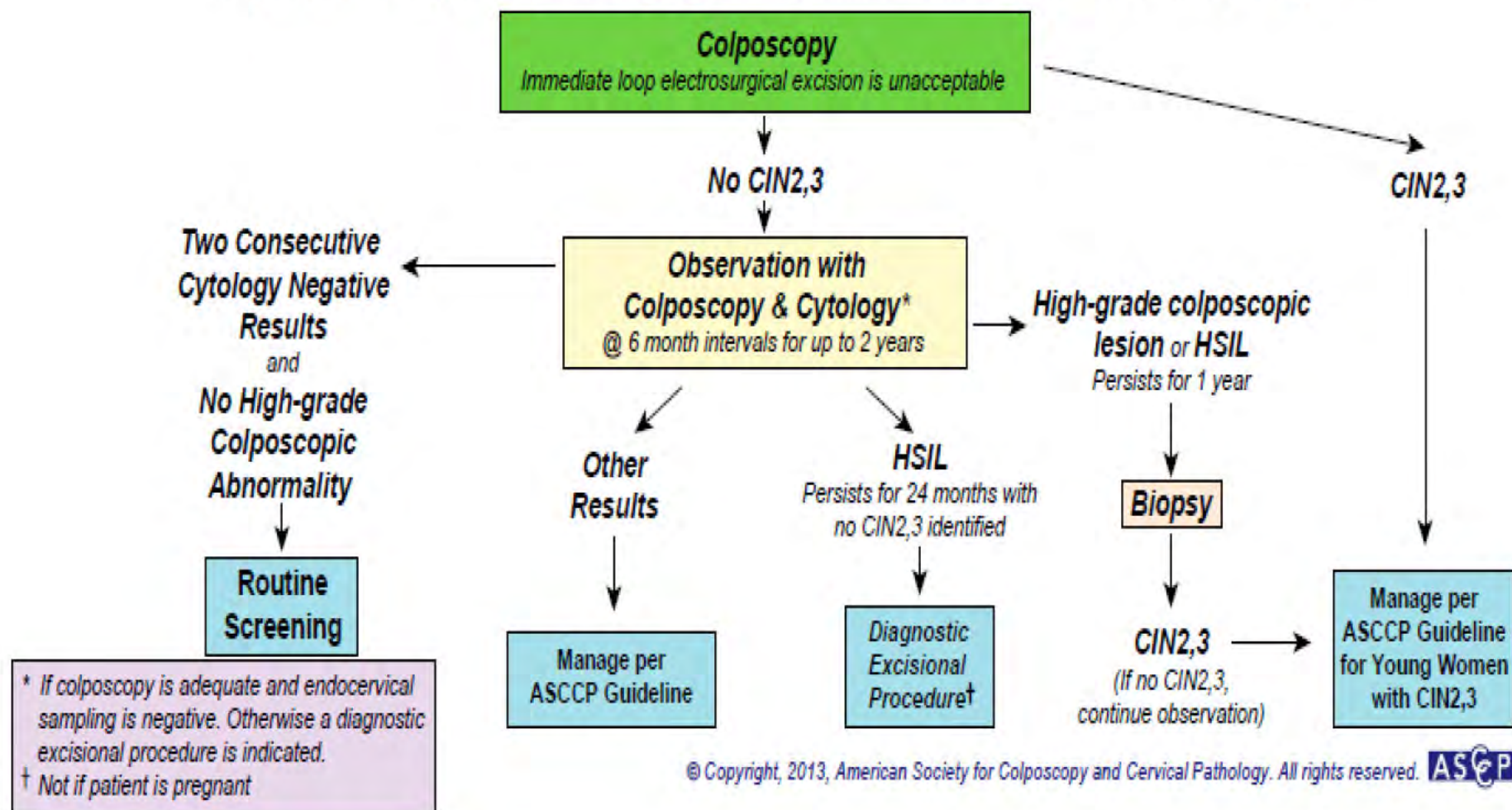
Molly 22 year old  $G_1P_0TAB_1$

- The patient was told that she should return in 6 months for cytology and colposcopy and have this repeated a total of four times.





## Management of Women Ages 21-24 yrs with Atypical Squamous Cells, Cannot Rule Out High Grade SIL (ASC-H) and High-grade Squamous Intraepithelial Lesion (HSIL)



# Repeat Colposcopies

Women are more vulnerable psychologically at follow-up for repeat colposcopies than women having a first colposcopy

Valdini, A., (2004). *J Low Genit Tract Dis*  
Stinnett, B. A. (2000).. *J Low Genit Tract Dis*



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# Psychosocial Impact of Repeat Cytology vs. Colposcopy

There was no difference in the longer-term psychosocial impact of management policies based on cytological surveillance or initial colposcopy

Sharp, L., (2013). *PLoS One*,

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Molly now 23 year old  $G_1P_0TAB_1$

Molly is back 1 year later for her second repeat colposcopy and asks:

“Can I just get this treated and be done with it, this is awful!”

"I can certainly understand how you would feel that way. I think it's a very normal reaction."



# Chanise 46 Year Old G<sub>4</sub>P<sub>3</sub>TAB<sub>1</sub>

- HSIL on cytology
- Inadequate colposcopy
- Pathology results
  - HSIL on ECC
  - Squamous epithelium on random biopsy



# Chanise

- Advised to have diagnostic excisional procedure
- Declines treatment





# CIN 3 Natural History

- 31%- 50% developed cancer within 30 years
- The risk of cancer of the cervix or vaginal vault for women treated conventionally was 0.7% after 30 years

McCredie, M. R., (2008). *Lancet Oncol*,

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# Chanise

## Directive Counseling

- “It’s critical that you have this procedure done or you could develop cervical cancer and die from it!”
- “There are really no other treatment alternatives because of where the lesion is located.”





# Chanise

## Directive Counseling

“If you choose not to have this treatment, I will have no choice but to discharge you from my practice because I have nothing else to offer you.”



# Chanise

- Open ended, probing questions to get to the root of the issue
- What might be going on for Chanise?
  - A different belief system?
  - Tired of coming in?
  - Alienated?

Quill, T. E. (1989). *Ann Intern Med*,



# Obstacles to Adherence

Fear of:

- Pain
- Cancer
- Negative impact on fertility
- Mutilation

Percac-Lima, S (2010). *J Gen Intern Med*,

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# Adherence Related to Pain or Anxiety?

Women who did not attend for follow-up treatment reported significantly greater anxiety and pain unpleasantness following colposcopy than women who did attend.

Kola, S., (2012). *Psychooncology*

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# Inadequate Communication

Including lack of explanation  
regarding diagnosis, procedure and  
results

Percac-Lima, S (2010). *J Gen Intern Med*,

ASCCP2016



# Obstacles to Adherence

## Logistical constraints

- Cost, lack of insurance
- Wait times
- Work schedule/clinic schedule
- Language barrier
- Transportation
- Childcare

Hui, S. K.,(2014). *J Prim Care Community Health*

Percac-Lima, S (2010). *J Gen Intern Med,*



# Obstacles to Adherence

- CIN has no symptoms
- Perception of risk is not fully rational and is based on past life experience



# Adherence Associated with Care Coordination

We attribute our high rate of adherence to:

- Extensive outreach
- Patient care coordination in an integrated health care system
- Two full-time RNs are responsible for all follow-up and patient care coordination

Alston, M. J.,(2016). J Low Genit Tract Dis,

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# Questions for Chanice

## SDM counseling:

"I wonder what your ideas are about why this is happening to you."

"I sense you are unhappy with the my recommendation that you have a LEEP, but I am not sure why. Perhaps you could help me understand what is going on."



# “Tell Me More”



- “Could you tell me more about what information you need at this point?”
- “Could you say something about how you are feeling about what we have discussed?”
- “Could you tell me what this means for you and your life?”



# Questions for Chanice

ould you like us to discuss this with a family member or friend in the room?”

- “Can I offer you some time with one of our counselors (e.g., a social worker or navigator)?”
- “What questions do you have for me?”



# Many Of My Patients Say...



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# Fill in with your “best guess”

- They will have complications or side effects from the LEEP
- The treatment will change them sexually
- They will lose their job if they take time off

“I wonder if that might be concerning you?”



On the one hand...On the other hand

“So it sounds like on one hand  
... and yet on the other hand  
... Do I have that right?”

Pause for a reply



“By effectively uncovering and addressing barriers, the clinician can turn roadblocks to effective communication into means for enhancing the therapeutic relationship.”

Quill, T. E. (1989). *Ann Intern Med*

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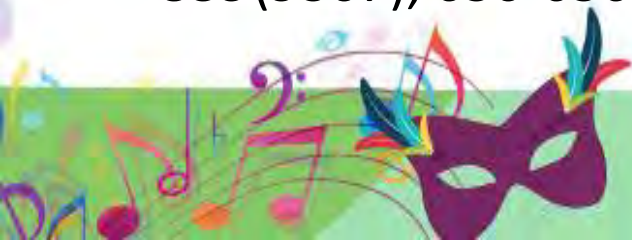
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