“Your Results Are Abnormal" Applying Shared Decision Making to Difficult Conversations

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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*

Counseling Tips

First rule: ask probing questions

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

How to Kill the Conversation

Don’t ask about the patient’s information needs.

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

How to Kill the Conversation

Offer reassurance prematurely.

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

How to Kill the Conversation

Ignore the context of the communication encounter.

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

How to Kill the Conversation

Launch into your agenda first without negotiating the focus of the interview.

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

Clinical Pearls

Counseling Pearls

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

- Student; 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 years old
G_0P_0

Sara appears anxious prior to her colpo.

- What are her concerns?
- How can you help?

Sara, 26 years old
G_0P_0

Clinical Pearls

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”

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

Sara, 26 years old
G_0P_0

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*

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

14 Questions on a 5-point Likert scale

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

Stinett, B. A., (1999) *Low Genit Tract Dis*

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*

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*

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’.

Hellsten, (2007). *Bjog*

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.

Hellsten, (2007). *Bjog*

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.

Sara, 26 years old
G_0P_0

Reaction To a Positive HPV Test

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

O'Connor, M., (2014). *Bjog*

Reactions

- Confusion
- Fear
- Powerlessness
- Anger

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

Daley, E. M (2010). *J Health Psychol*

Sexual Relationships

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

McCaffery, K., (2004). *Bjog*

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

Clinical Pearls

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"

You're **absolutely right** that HPV is passed from person to person by skin to skin contact, **and interestingly…**

Sara, 26 years old
G_0P_0

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

Clinical Pearls

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."

"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."

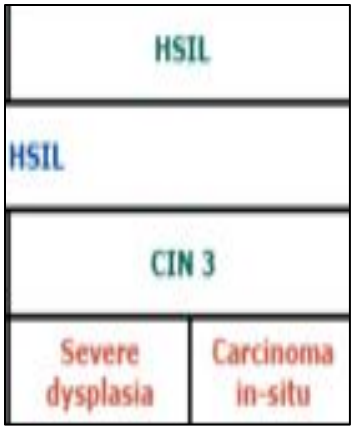
- We don't test men
- We don't treat HPV
- We don't treat or test partners
- It goes away on it's own the vast majority of the time

Does This Mean My Partner Slept With Someone Else?

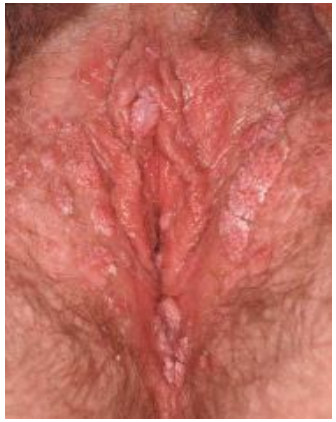
"Having an HPV infection is not a marker for sexual behaviors or infidelity."

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."



Vs.



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 that 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 on the vulva can get in the way."

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

Will I Get Cervical Cancer?

"Highly unlikely"
"Follow up as advised"
"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*

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*

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*

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*

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.

# of HPV+ samples was lowest for men who always used condoms.

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

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

Lam. (2014). *J Med Screen*

How Do I Get Rid of It?

Condom use

Strengthen immune system

- Stop smoking
- Eat healthily: whole fruits, vegetables, fish and nuts (increased riboflavin, thiamine, vitamin B12, and folate)
- Get enough sleep
- Exercise

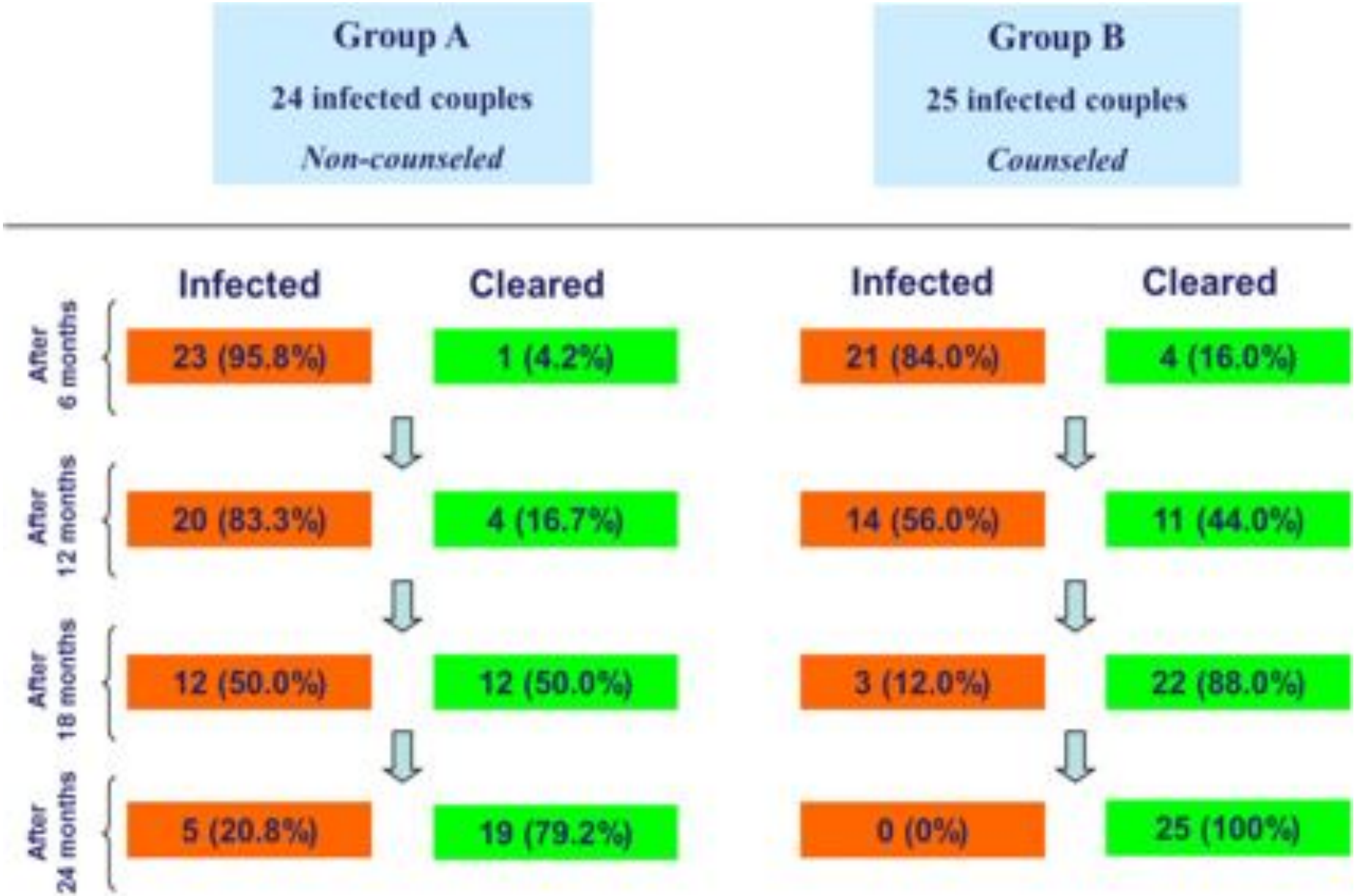
Chih, H. J (2013). *Nutr Cancer*
Erickson, B. K. (2013).*Am J Obstet Gynecol*

Intervention for Co-infected Couples

"Calmly and without alarm" gave information to both partners about the possible effects and risk factors of HPV infection.

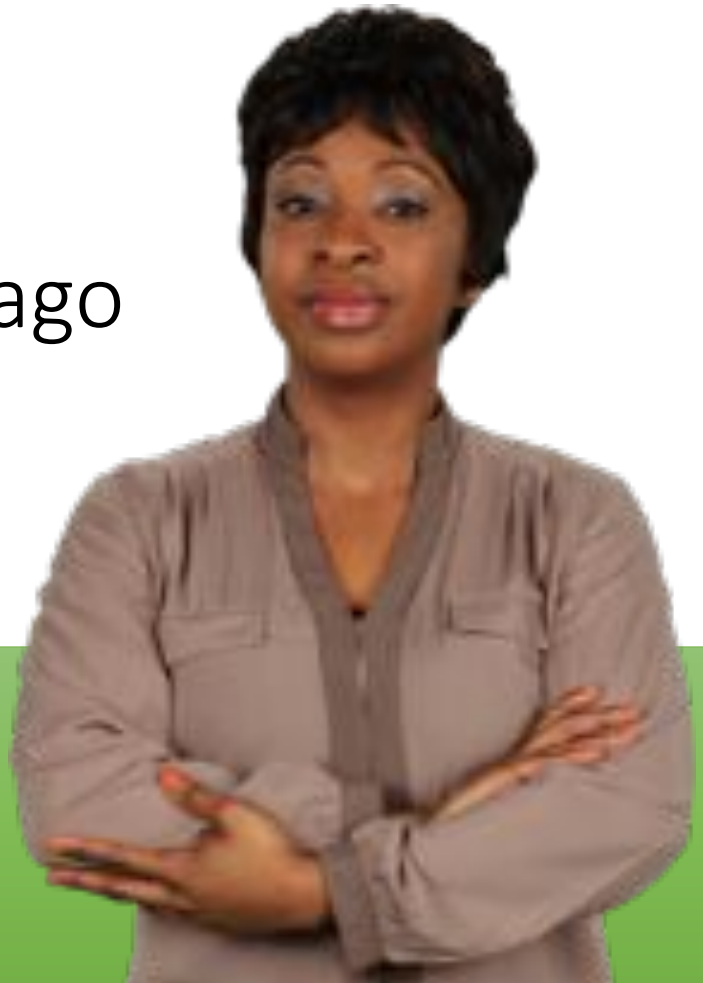
- Pay particular attention to the hygiene of both the reproductive tract and their hands
- Use personal underwear and towels only
- Avoid oral and anal sex
- Reduce or eliminate smoking
- Have only (condom) protected intercourse
- If HPV-related lesions, to treat them

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



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

- 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



Janet, 59 years old

$G_5P_2TAB_3$

Colposcopy

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.

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

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). *Er J Pain*

To Reduce Anxiety

Play music

View the procedure on a monitor (video colposcopy)

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

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*

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*

- 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.

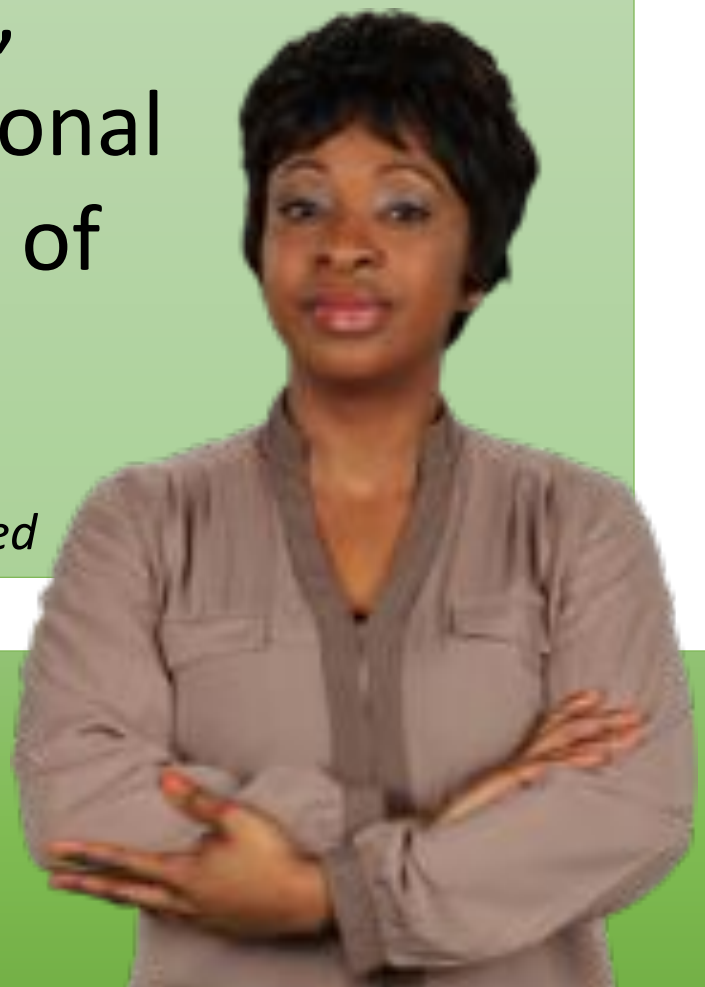
Janet, 59 years old
$G_5P_2TAB_3$

- What questions would you like to ask Janet?
- Does it seem important to manage your own annoyance?
- What might be going on for Janet?

Janet, 59 years old
$G_5P_2TAB_3$

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*



Janet, 59 years old
$G_5P_2TAB_3$

Clinical Pearls

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… (___), is 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*

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

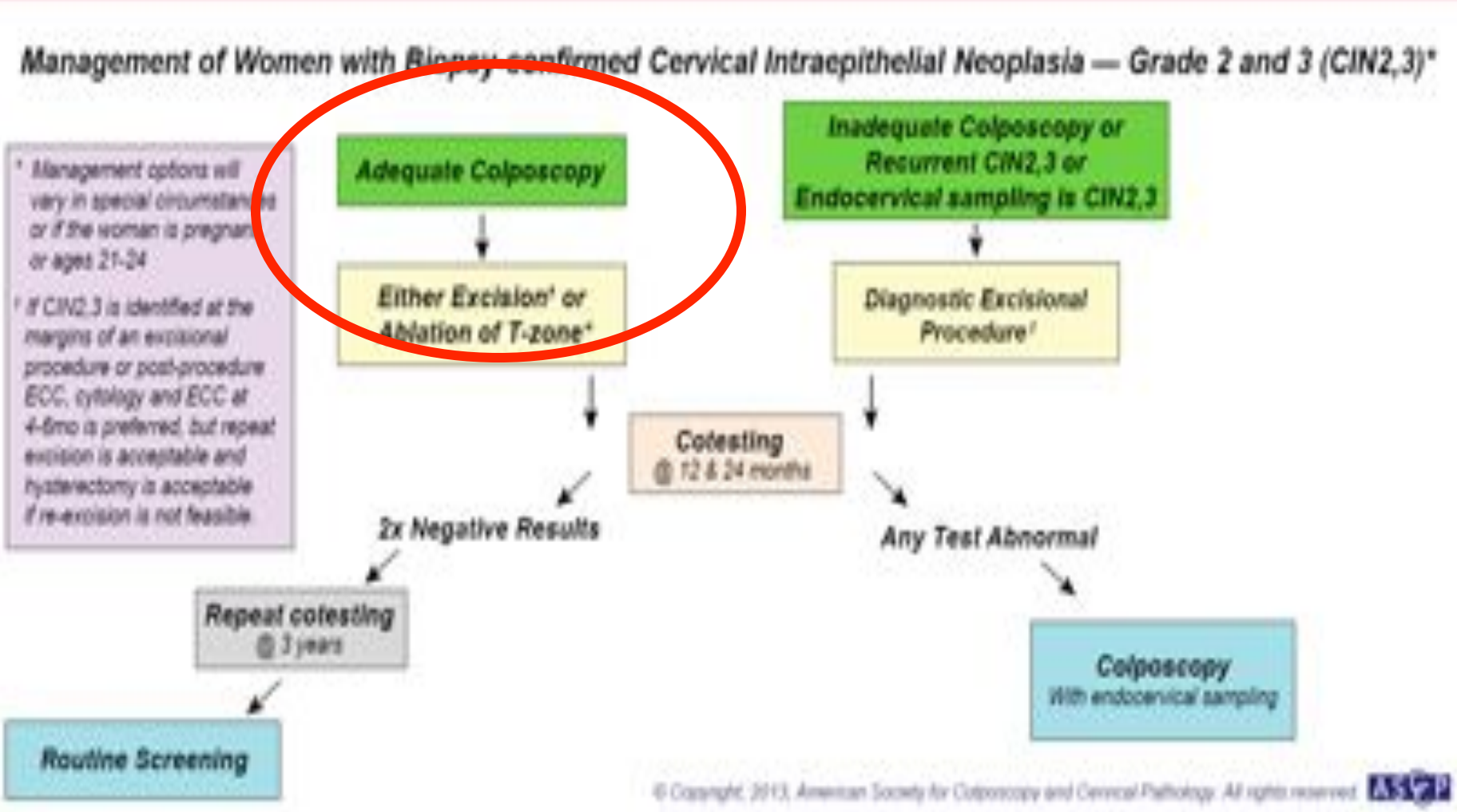
Hellsten, C., (2008) *Bjog*

- 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

Sandra, 38 years old

G_2P_2

Management of Biopsy Confirmed CIN 2,3



Directive Counseling for Sandra

"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?"

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

Sandra, 38 years old
G_2P_2

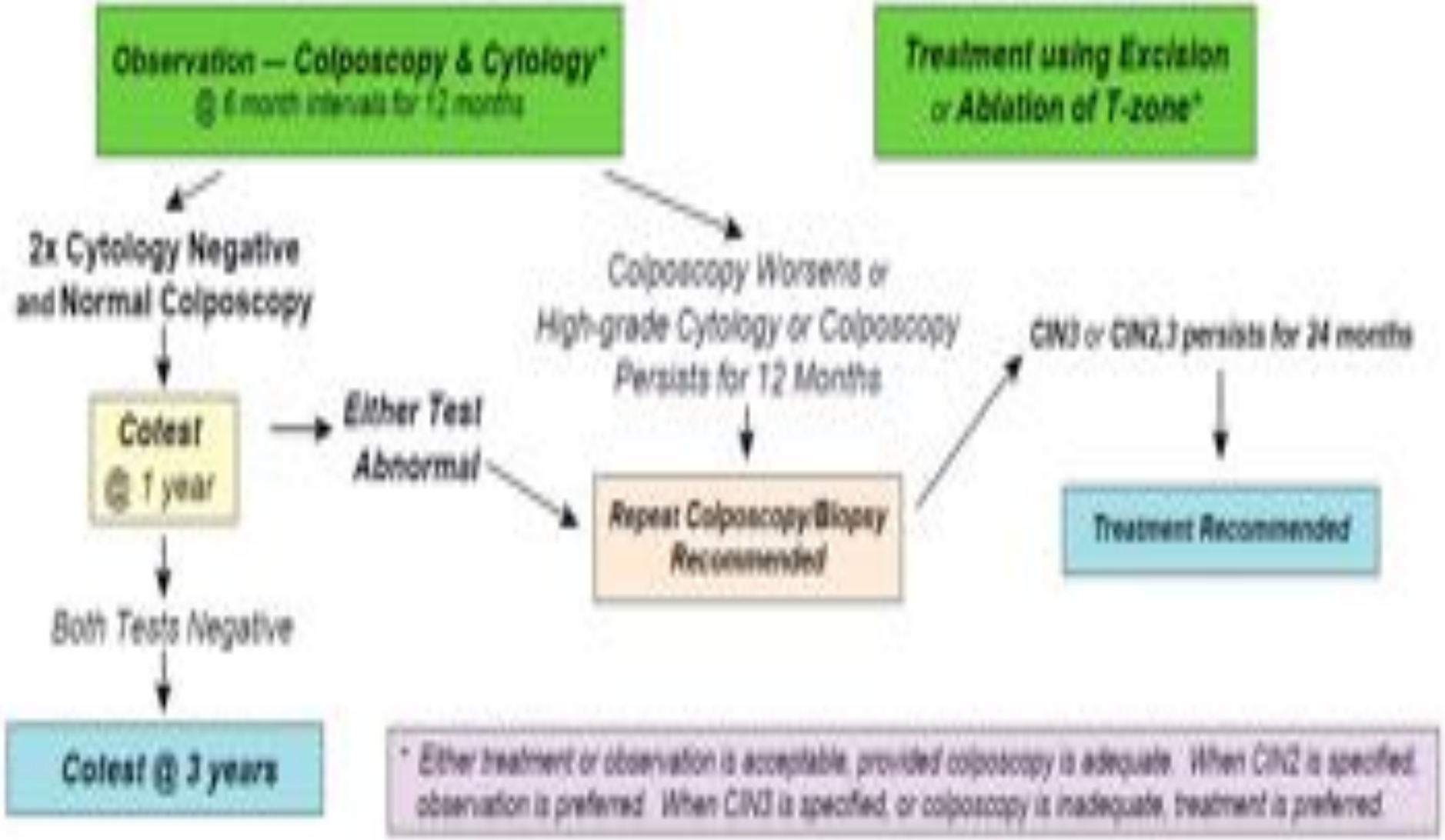
The term ‘‘young women’’ indicates those who after counseling by their clinicians consider risk to future pregnancies from treating cervical abnormalities to outweigh risk for cancer during observation of those abnormalities.

No specific age threshold intended.

Sandra, 38 years old

G_2P_2

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 ≥60%
- 1 year progression rate 15-16% mostly CIN 3; no cancers
- No association between rates of regression and patient age

Moscicki, A. B (2010) *Obstet Gynecol*

Clinical Pearls

“Ask-Tell-Ask” Rephrase

Shared Decision Making Model

“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

“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.”

"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."

“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."

"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.

JNCI 2009

“Ask-Tell-Ask”

5. “If you have a recurrence (failure), it usually can be treated with a second office procedure”

"Ask-Tell-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

“Ask-Tell-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 Mgmt

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

Factors Associated With Adherence to Advised Mgmt

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

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

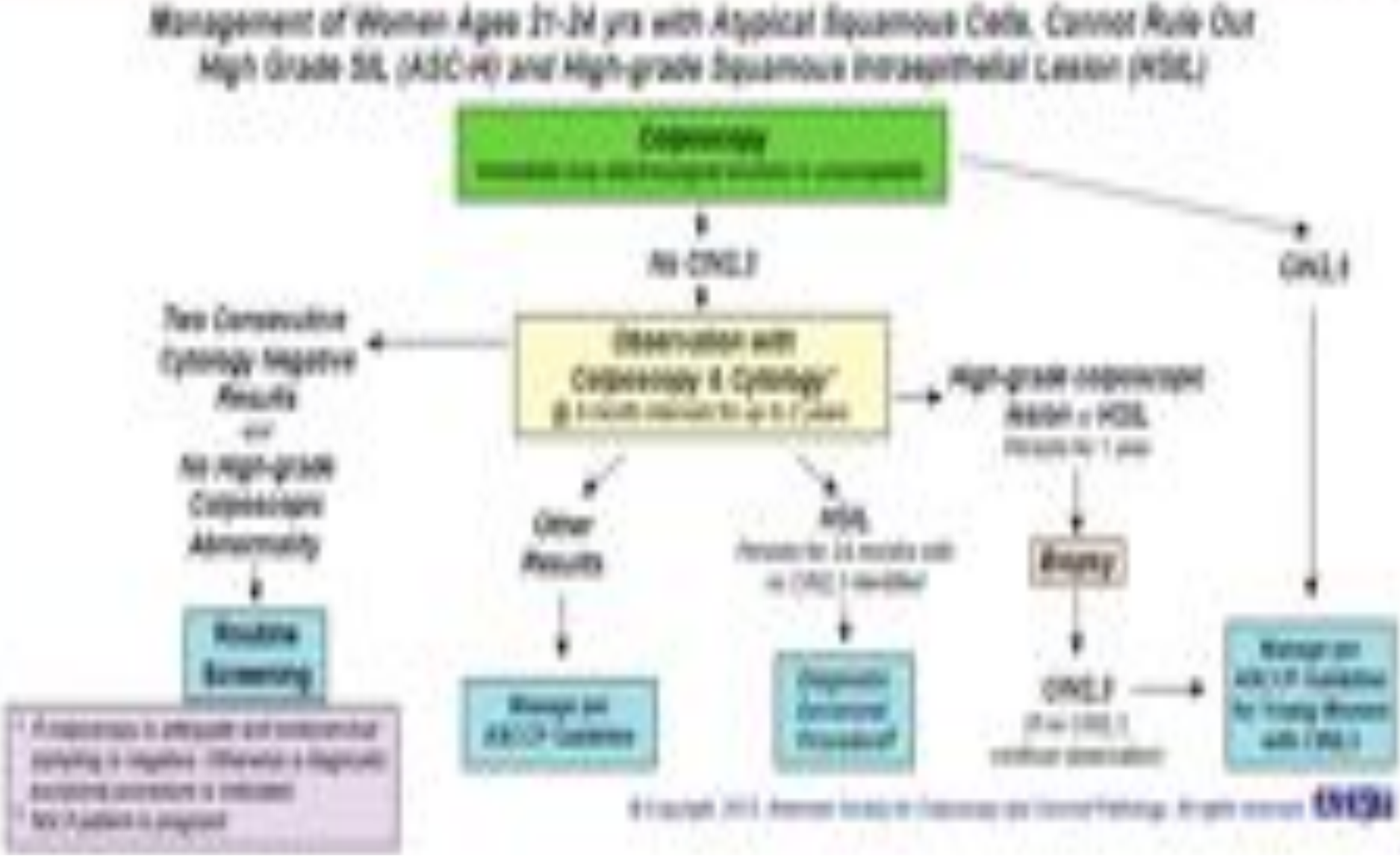
Kola, S., (2012). *Psycho-oncology*

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

Molly, 22 years old
$G_1P_0TAB_1$

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

Molly, 22 years old
$G_1P_0TAB_1$


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)
Colposcopy
No CIN2,3
CIN2,3
Observation with Colposcopy & Cytology*
Two Consecutive Cytology Negative Results
or
No High-grade Colposcopic Abnormality
Other Results
HSIL
High-grade cytology except HSIL
Biopsy
Routine Screening
CIN2,3

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*

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*

Molly is back one year later for her second repeat colposcopy.

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

Molly, 23 years old
$G_1P_0TAB_1$

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

Chanise, 46 years old
$G_4P_3TAB_1$

Chanise is advised to have a diagnostic excisional procedure, but she declines treatment.

Chanise, 46 years old
$G_4P_3TAB_1$

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,*

Directive Counseling for Chanise

"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."

"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."

SDM Counseling for 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*

Adherence Related to Pain or Anxiety?

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

Kola, S., (2012). *Psycho-oncology*

Inadequate Communication

Including lack of explanation regarding diagnosis, procedure and results

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

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

Shared Decision Making Questions

I sense you are unhappy with the recommendation that you have a LEEP, but I'm not sure why. Can you help me understand what is going on?

Chanise, 46 years old

$G_4P_3TAB_1$

Shared Decision Making Questions

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

Chanise, 46 years old
$G_4P_3TAB_1$

Clinical Pearls

“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

“Would 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?”

Clinical Pearls

Many Of My Patients Say…

"I'd like to understand what concerns you about getting a LEEP."

"Many of my patients say that they are concerned that…"

Fill in with your “best guess”

“Many of my patients say that they are concerned that…

- 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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