IPC 3 Standardized Patient Exam Shared Decision Making

INFORMATION FOR STANDARDIZED PATIENTS:

BACKGROUND:

You are Annie Green, a 27 year old female who is following up in clinic for ulcerative colitis, a chronic bowel problem. You are doing OK, but are running out of medications (Asacol), and you need a refill.

You were diagnosed at the age of 7 after having extensive problems with diarrhea, and stomach pain. At that time you had insurance under Medicaid. Growing up, you and your family had limited financial resources, but with your Medicaid coverage, your parents were able to make sure you were followed regularly by your primary care doctor and that you were seen by your specialists.

Once you reached age 18, you were no longer eligible for Medicaid and in the last 4-5 years it has become somewhat difficult to make ends meet. You got married at the age of 23. Your financial situation is tight, but you are managing to stay afloat. Both you and your husband work, and he has a second job as well. None of the jobs provide health benefits. You are saving a little money (a very high priority for you), and are able to set aside about \$100 - 150 a month. You have about \$1500 set aside currently.

You are on Asacol, but are not particularly happy about the almost 60 dollars per month it takes to buy even the generic form of this medication. Most of the time this medicine works OK, but you are still getting some mild flares with diarrhea and cramping (not bad, but quite annoying, occurs about once every month or so). It is also is difficult to afford regular visits to your doctor, which cost about 180 dollars per visit for your primary care doctor and even more for the specialists. You are usually able to afford the medicine for ulcerative colitis, but have run out of medication several times in the past, usually when another financial problem received higher priority, or when you couldn't afford the cash for a doctor's visit. However, when you miss your medication for very long, it can cause a serious flare in your illness, leading to at least a couple of ER visits you wouldn't have otherwise had to have (as well as the resultant expense – you are still paying off those bills).

You and your husband do not have children, but hope to have children at some point. In your current state of health, you realize that would not be a good thing. None of your friends have a chronic medical condition and you are frustrated that no one seems to understand how stressful this can be. You are tired of all the medicine you have to take all of the time.

Your grandmother died from colon cancer last year. You were close to her, and she had a long and complicated battle with her cancer. This has led you to be concerned about colon cancer, as you heard once that you might be at increased risk for it, but you know little more than that about your risk.

SPECIAL INSTRUCTIONS:

When asked, you are open about revealing the following information:

- You are not pleased at the thought of being on a medication for the rest of your life at such a young age. Your friends are young and do not have to be on medications so why should you?
- You and your husband have thought about children, but financially and medically, you know that you cannot afford to do this at this time. This frustrates you somewhat, and you are starting to wonder about your 'biologic clock' running out.
- You have a small nest egg, which has taken you and your husband a lot of work to save, and you are putting it toward an important priority for the two of you. (You pick: Start community college, buying a second car, so that one of you doesn't have to walk to work, down payment on a house, etc.) You do not want to give it up.
- You have a GED, and want to get further education. Although your literacy level is at par with your education, your health literacy is lower, and you know relatively little about medical conditions, treatment, etc. If asked, you may acknowledge that you don't know very much about medical problems.
- As patients often do, do not hesitate to show frustration or sadness as you are led through this discussion as these topics can be most frustrating and tiring to patients who have been dealing with them chronically.
- The student will discuss screening colonoscopy with you. You should make a decision based on the facts above. Regardless of whether the student does a good job in helping with your decision, do not feel compelled to accept the colonoscopy (although you may accept it).
- You had a colonoscopy when you were diagnosed at the age of 7. You don't recall anything about it, other than you know that a doctor but a tube 'up your butt'.
- You know a little about ulcerative colitis. You know that it is inflammation in your rectum. Nobody knows why you have it. You get pain and diarrhea if you miss your medicines for more than a couple of weeks sometimes it can get bad enough you have to go to the hospital. It can maybe cause cancer. It (and the medicines you take to control it) can mess with pregnancy. You aren't sure if it is possible, but you hope it will go away permanently someday.
- You are concerned about colon cancer. You have strong memories about your grandmother, and you still feel the loss.
- Am I eligible for Obamacare?

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Background for M1s:

You are seeing 27 year old Annie Green in your clinic. She is following up for medication refill on her mesalamine for her ulcerative colitis. She was first diagnosed when she was just 7; she had a pancolitis, with diffuse diarrhea and bloody stools. From what you know, Annie has done fairly well recently; she hasn't had an ED visit for about a year.

As you review her chart, you realize she has not had a colonoscopy since diagnosis. The American College of Gastroenterology recommend that annual screening colonoscopies (with multiple biopsies) should be done in patients 8-10 years after a diagnosis of UC with pancolitis. (Other GI societies make similar recommendations). In patients with pancolitis, the risk of colon cancer is 5-10% after 20 years, and 12-20 after 30 yrs.

The cost of a colonoscopy with biopsies for an uninsured patient is approximately \$2,500. (this is AFTER the discount given to self pay patients.) Patients are asked to pay half of this at the time of service, but this is negotiable if pt is unable to afford. An absolute minimum of \$50 is required at the time of service. The remaining amount could be paid off by a payment plan which extends the payments over a one year period (would require monthly payments of about \$200)

You will first review how her disease course has been lately, and then use shared decision making to start a discussion regarding screening for colon cancer.