Transparency at the Point of Care

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Defining shared decision making

"In shared decision making, both parties share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values."

"Recognition of shared decision making as the pinnacle of patient-centered care is overdue."

Barry & Edgman-Levitan; 2012, NEJM



A common sentiment among clinicians:

"We already do that all the time."

How do we involve patients in medical decision-making?

- Explaining complex medical decisions to patients can be very challenging.
- Physicians have little time to accomplish this task.
- Decision support interventions:
 - Explain what the problem is in language patients can understand
 - Provide detailed information about the options, their risks and benefits

One patient's story

- Patient saw physician for annual physical exam.
 - MD provided decision support intervention (DESI) on colon cancer screening.
 - Patient watched DESI, read booklet, reviewed screening options.
- Patient contacted physician via online patient portal.
 - Not high risk, appropriate candidate for stool test.
 - Patient requested stool test option.
 - Physician refused: "We only believe in 2 options: colonoscopy or flexible sigmoidoscopy".
- Patient confused, unsure what to do and indicated she was unwilling to assert her preferences and disagreement.

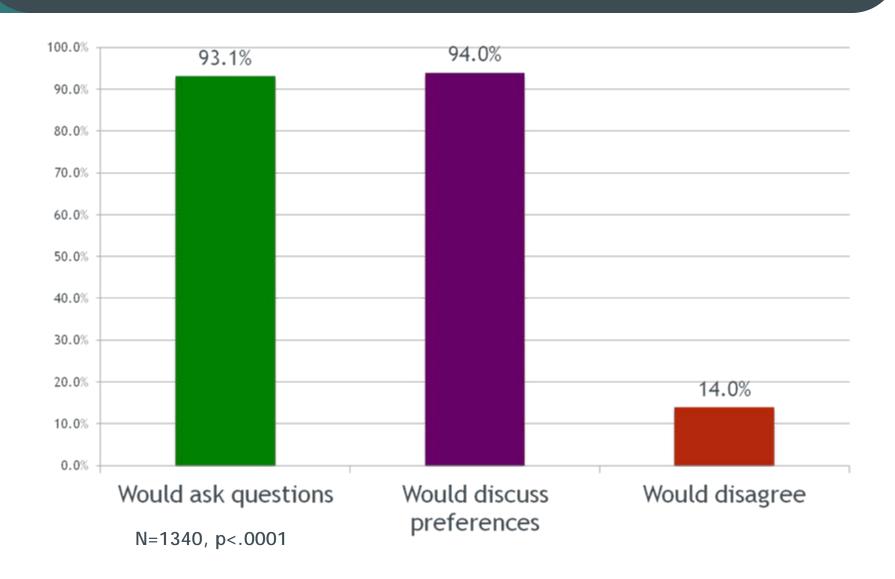
Lin, Trujillo & Frosch, 2012; Archives of Internal Medicine

Conforming to socially sanctioned roles

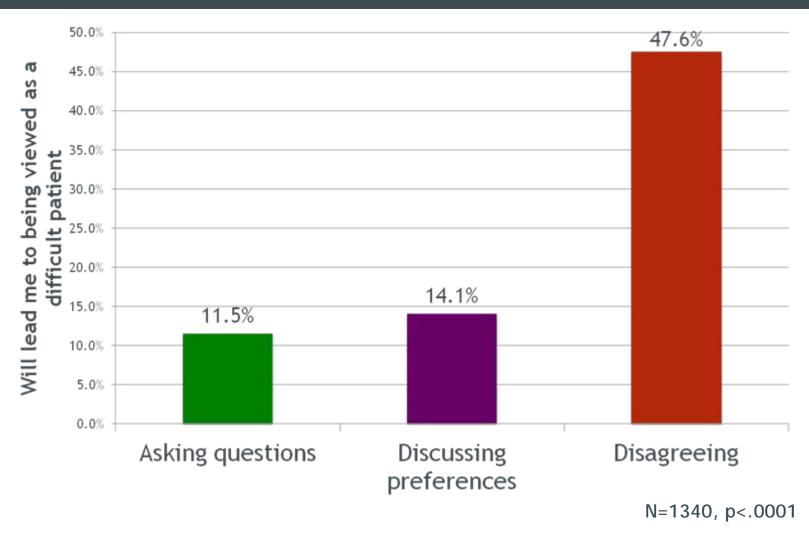
"If I were to do that I would think...is the guy going to be pissed at me for not doing what he wanted? ...is it going to come out in some other way that's going to lower the quality of my treatment? ...will he do what I want but....resent it and therefore not be quite as good...or in some way...detrimental to my quality of care." (Respondent #36, Male, Age 64)

Frosch, May, Rendle, Tietbohl & Elwyn, 2012; Health Affairs

Most people don't feel comfortable disagreeing with a physician's recommendation



Because they fear being labeled "difficult"



Adams, Elwyn, Legare and Frosch, 2012, Archives of Internal Medicine

"I do not regard my doctor as my savior. What I want them to be is my friendly native guide through this jungle of decisions and a full partner in executing that decision."

67 year-old white male focus group participant