

Patients seek greater ownership of health-care decisions

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Patients faced with a choice of surgical options want to engage their physicians and take a more active role in decision-making, according to a study (abstract 567) released at Digestive Disease Week (DDW) 2015. Further, those physicians must provide better support tools to help patients participate in the decision-making process. The study found that patients consult multiple sources (Internet, family, friends, doctors, etc.) and say that while doctors provide the most believable information, it was also the least helpful.

"In this evolving health-care landscape, there is an effort to involve patients in decision making about their health care," said Jessica Cohan, MD, the study's lead researcher and general surgery resident and fellow at the Institute for Health Policy Studies at the University of California, San Francisco (UCSF). "Given this pattern, it's not surprising that they are now doing more research on their [surgical options](#) and taking a more proactive role in deciding which therapy is right for their unique situation."

In this pilot study, researchers at UCSF surveyed 18 patients with [ulcerative colitis](#) (UC) who were referred for surgical evaluation because they needed their large intestine removed, with a subsequent procedure to compensate for this removal. Patients had to choose between an end ileostomy or an ileal pouch-anal anastomosis (IPAA). Before patients met with a surgeon, Dr. Cohan and her team gauged the patients' desire to actively participate in the [decision-making process](#) in choosing between the two procedures.

While both are effective options, the surgeries are completely different in methodology and in their impact on everyday life. With end ileostomy, the patient undergoes surgery during which clinicians remove the large intestine and connect the small intestine to a bag that is outside the patient's body, through which waste is emptied, requiring the patient to empty the bag as needed. With IPAA (or J-Pouch), the patient undergoes two surgeries in which clinicians connect the [small intestine](#) to the rectum, through which the patient can eliminate waste as they normally would.

The 18 patients surveyed indicated that they spent an average of 5.5 hours researching the two procedures before coming in for the surgical evaluation, citing the Internet and information given to them by their physician as the most frequent sources of information. Interestingly, patients reported that the physician-provided information was the most believable, but least helpful. Sixteen patients also said that they spoke to a spouse, friends, parents and/or siblings about this decision. Ultimately, 17 of the 18 patients expressed a desire for ownership by saying they wanted to make the decision "on my own" or "on my own after seriously considering my doctor's opinion."

"While our study demonstrates that patients seriously consider the advice and information provided by their doctor, it also shows that the information and how it's presented needs to be revised to meet patient needs," added Dr. Cohan. "Decision-support tools, such as pamphlets, need to be written for a general consumer audience and present all the information needed for patients to actively participate in the surgical decision-making process. The materials should be designed in a way that supports patient desire to speak with the various people in their lives about these important medical decisions."

Dr. Cohan also added that these findings are applicable to many other situations in which patients need to decide between multiple medical

options. For example, breast cancer patients can also find themselves in a similar circumstance in which they may need to decide between a mastectomy or lumpectomy, and could benefit from easy-to-understand [information](#) on what lies ahead.

As a follow up to this [pilot study](#), researchers are speaking with ulcerative colitis [patients](#) after surgery to understand their perspective on the pre-surgery decision-making process with the benefit of hindsight. Dr. Cohan's team is also testing paper-based decision-support tools that address some of the patient concerns discovered during the study, including increased clarification of medical procedures. Researchers intentionally chose to print these materials as to make them easily accessible and shareable.

More information: Dr. Jessica Cohan will present data from the study "Surgical decision making in patients with ulcerative colitis: the patient perspective," abstract 567, on Monday, May 18, at 9 a.m., in 204C of Walter E. Washington Convention Center.

Provided by Digestive Disease Week

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