Patients with ulcerative colitis are more concerned about complications of their disease than side effects of medications

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ABSTRACT

Background: Patients with ulcerative colitis (UC) are often fearful about medication side effects and how the disease will affect their future. Our aim was to better understand what aspects of UC, and UC management, are most concerning to patients, and how they would like to be informed about treatment options.

Methods: A Web-based survey was sent to UC patients throughout the United States and Australia. In addition to standard closed-response questions, audio clips were embedded in the survey and respondents showed their strength of agreement or disagreement using moment-to-moment affect-trace methodology. Standard quantitative analysis was used for the survey results, and cluster analysis was performed on the affect-trace responses.

Results: A total of 460 patients with UC (370 patients from the United States and 90 patients from Australia) responded to the survey. Of them, 53% of the respondents were women, with a mean age of 49 (range 19–81) years. Most patients (87%) wanted to share treatment decision making with their doctors. The majority, 98%, wanted more than just a basic understanding of their disease. Patients were most concerned about the risk of colorectal cancer (37%), and the possible need for an ileostomy (29%). Only 14% of patients indicated that side effects from medications were their biggest concern. On affect-trace analysis, the most divergence in opinion centered on the appropriate timing for colectomy.

Conclusions: To facilitate informed treatment decisions for UC patients, in addition to reviewing the benefits and risks of medications, it is also important to discuss the best strategies for decreasing the risk of colectomy and colorectal cancer.
Ulcerative Colitis Multimedia Decision Aid

Based on this research, a multimedia decision aid was developed to take the patient concerns into account. Given the competing fears of colon cancer and surgery (which erases the possibility of colon cancer), self-determination theory was used to provide viewers with competence and autonomy so they didn’t feel coerced into learning about the surgical options.

COMPETENCE & AUTONOMY

After viewing the program, UC focus group participants were more open to surgical options:

**Man:** I like the two different surgeries. Because I'd always been kinda scared to research that myself. So this was helpful to see those broken down and simplified.

**Woman 1:** I felt a little relieved watching the surgery options. I've always been so scared of that. And i think "relief" is a good way to... because it's like: Oh, OK. You can have a normal life afterwards and you don't have to live with a pouch forever. And there's other options. And all surgeries have risks. I didn't think the risks associated with these surgeries were any greater than any other surgery.

**Woman 2:** I agree about the feeling of relief. 'Cause like she said, I knew it was a surgery, but I was always kind of like: "Oh, I'm not doing that!" So I just never got into the details of what it was.

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