Inward and Outward: The Role of Patient Self-Monitoring and Patient Communities in IBD

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Background
- IBD is a lifelong disease for patients and their families, in part because of the chaotic and unpredictable nature of the disease process, the need for disciplined medication adherence, and the need for ongoing medical care. It is often a disease that requires self-monitoring, as well as help from others.
- We hypothesize that participating in patient communities and self-monitoring may help identify disease trends in patients’ own ways and may thereby be of some therapeutic value.

Methods
- An online survey was distributed to approximately 700 IBD patients via an overlapping network of patient communities conducted through Facebook and group email, beginning with attendees of local CCFA support groups in San Francisco.
- To increase participation, several key reminders also distributed the survey, along with a personal request to participate to their own network of contacts with IBD.
- The survey asked about formal tracking (monitoring symptoms, diet, or other aspects of IBD using paper graphs or online channels); mindful tracking (careful awareness without any writing or keystrokes); attending support groups; and journaling of feelings.

Survey Results
- 76 people responded to the survey, giving a response rate of ca. 10%.
- The response rate was not unusual for internet-based surveys (1) and may in part reflect that many people who responded were already part of other patient groups.
- 60% of participants were female, and ages ranged from 30-70.
- The survey sent out 87% of participants had tried formal tracking, and 38% have ever attended a CCFA support group.
- 68% of participants were female, and ages ranged from 30-70.
- To learn how to work more effectively with my IBD (49%, 74%)
- To get answers to specific questions (28%, 42%)
- To help me to identify symptoms (53%, 77%)
- To help my doctor to treat me better (26%, 43%)

Table 1. Why IBD patients跟踪 support group meetings (n=76)

Table 2. What IBD patients formally track, using paper and pen or an electronic app (n=76)

Table 3. IBD patient experiences with formal tracking, mindful tracking, and journaling of feelings (n=76)

Conclusions
- The results of this survey and key informant interviews demonstrate that many patients find value in formal tracking, mindfulness, and participating in patient communities.

Key Informant Interview Results (selected)
Interviews with IBD patients who attend a support group indicate that tracking is perceived as most valuable when delivered both aloud and written. To others, tracking is more of a tool for patients to explore on their own, the patients described before mentioned themes that echoed across interviews and survey responses.

Online Patient Communities and Apps
Many online forums and apps exist for patients with IBD and other diseases. Pictured below, four local CCFVA support groups, which I interacted with during interviews, are highlighted.

References