

Personal Experimentation for Gastrointestinal Health Triggers

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Personal Triggers in Gastrointestinal Health

Irritable bowel syndrome is characterized by chronic abdominal pain with diarrhea and/or constipation despite normal blood tests, x-rays, and even colonoscopies. IBS affects up to 20% of the US population, is one of the top ten reasons patients seek primary care, and accounts for a third of all gastroenterology consultations. Up to 70% of IBS patients identify certain foods as symptom triggers, and the American Gastroenterological Association advises *“symptom monitoring using a [journal to] help identify possible triggers to symptom exacerbation.”* Unfortunately, identifying personal food triggers remains burdensome and is often ineffective. This workshop paper overviews some of our ongoing research in personal gastrointestinal health triggers as a context for broader advances in small data experimentation.

Challenges in Identifying Personal Triggers

Our approach to identifying personal triggers is informed by challenges uncovered in our analyses of practices of people in the Quantified Self movement [1]. This community consists of self-trackers that are highly motivated and educated, with 40% working at technology startups, 37% describing themselves as software engineers or developers, and many building their own tracking tools. Yet they still struggle to make sense of their data. We qualitatively coded and analyzed 52 Quantified Self blog videos, in which self-trackers share what they did, how they did it, and what they learned. We identified three challenges these motivated and educated early adopters encounter in self-tracking. First, it is often difficult to understand what data to collect, so people attempt to track too much, quickly burn out, and abandon tracking or find collected data irrelevant. Second, people often track the wrong data, such as tracking symptoms but not the context that would help identify triggers and make changes to reduce symptoms. Finally, people often lack scientific rigor in analysis, reaching and acting upon incorrect conclusions without the consultation of a medical professional and without sufficient understanding of causal relationships. Informed by this, our research in personal gastrointestinal health triggers is examining a process of personal hypothesis generation paired with new designs for robust personal hypothesis testing using a combination of single case experimental designs and randomization tests [5].

Challenges in the Burdens of Journaling

Food journaling is highly burdensome, and many people are unable to sustain journaling beyond a few days. To better characterize barriers and burdens in food journaling, we qualitatively analyzed a survey of 141 current and lapsed food journalers together with 5,526 posts in community forums for three commercial mobile food journals [4]. A dominant barrier is the high effort required to keep an accurate journal, including challenges in a person not knowing exactly what or how much they ate, unreliable community-created database entries, difficulty knowing how to journal foods prepared by others, and simply forgetting. We also uncovered negative nudges, wherein current designs encourage behaviors contrary to personal goals. For example, journalers report the ease of entering processed foods encourages consumption contrary to their personal goals for healthier foods. Journalers also reported actively choosing not to enter foods in order to avoid feelings of judgment associated with negative feedback for exceeding a daily calorie budget. Informed by these results, we have recently explored a

food journal design emphasizing lightweight reflection through photo-based capture [3]. Our research in personal experimentation for gastrointestinal health triggers is also examining how the burdens of current approaches to food journaling can be minimized according to the particular context of self-experimentation (e.g., limiting journaling to a potential trigger food within a current experiment).

Challenges in Sharing and Communicating with Self-Tracking Data

People often turn to experts, peers, and support networks for help in interpreting and acting upon self-tracking data (e.g., health providers, family, people with similar challenges). Approximately one third of self-trackers have shared data from self-tracking applications with their health providers, but providers rarely engage with this data, resulting in a frustrating experience for many of those self-trackers. 63% of IBS patients report dissatisfaction with the feedback they receive from healthcare providers based on their journals. To better understand provider experiences with patient-collected journals, we have conducted an interview study with 21 providers, most of whom see IBS patients [2]. Providers confirmed having experience with patient-collected journals, and providers reported they use the data for diagnosis and treatment management. They also reported using data to support their communication and relationships with patients, including building rapport and prioritizing conversation topics during visits. Providers recognize the value of consumer-centric applications, but few of these applications were designed with consideration for providers. As a result, their data sharing and presentation features do not meet provider needs. Although patients prefer electronic journals and they support greater adherence than paper, none of the providers we interviewed preferred current electronic journals over paper journals for working with IBS patients. Despite the fact paper journals are often disorganized, unreliable, missing critical data, and cumbersome for patients to use, providers ask patients to use handwritten paper journals because they better integrate into provider workflows. Regardless of tracking tools, there is also no validated method for determining individual triggers from journals, so providers are often left to sift through journals in search of apparent correlations. Informed by these findings, our research is examining how our self-experimentation perspective can help enable distillation of self-tracking data into actionable summaries supporting patient and provider needs as well as improved communication between patients and providers.

Workshop Participation

Our work in personal experimentation for gastrointestinal health triggers examines many dimensions of this problem area, including new approaches to data capture, new designs for data analysis, and new approaches to patient interaction with health providers. We look forward to participating in a broader discussion regarding how our work can help shape a broader understanding of technology needs in this important and emerging field of research.

Selected Publications

- [1] Choe, E. K., Lee, N. B., Lee, B., Pratt, W., Kientz, J. A. (2014). Understanding Quantified Selfers' Practices in Collecting and Exploring Personal Data. *CHI 2014*, pp. 1143-1152.
- [2] Chung C. F., Cook J., Bales E., Zia J., Munson S. A. (2015) More Than Telemonitoring: Health Provider Use and Non-Use of Lifelog Data in Irritable Bowel Syndrome and Weight Management. In Submission.
- [3] Cordeiro, F., Bales, E., Cherry, E., Fogarty, J. (2015) Rethinking the Mobile Food Journal: Exploring Opportunities for Lightweight Photo-Based Food Capture. *CHI 2015*, To Appear
- [4] Cordeiro, F., Epstein, D. A., Thomaz, E., Bales, E., Jagannathan, A. K., Abowd, G. D., Fogarty, J. (2015) Barriers and Negative Nudges: Exploring Challenges in Food Journaling. *CHI 2015*, To Appear.
- [5] Vilardaga, R., Bricker, J.B., McDonell, M.G. (2014). The Promise of Mobile Technologies and Single Case Designs for the Study of Individuals in their Natural Environment. *Journal of Contextual Behavioral Science*.