COLLABORATION

A Personalized Learning System for Improving Patient-Physician Collaboration

by Heather C. Kaplan, Jeremy Adler, Shehzad A. Saeed, Ian Eslick, and Peter A. Margolis

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Patients and care providers need methods and tools to personalize care in a collaborative and evidence-based manner. Today, physicians and patients use imperfect strategies to achieve this goal: Clinicians often conduct informal trials of therapy, and patients often experiment with modifications in their behavior and lifestyle. However, such informal trials are methodologically imprecise, frequently occur with too little data about effectiveness, and happen without collaboration between patients and providers.

To address this need, a multi-disciplinary team of health-services researchers and system designers at Cincinnati Children's Hospital Medical Center, the University of Michigan, the Massachusetts Institute of Technology Media Lab, and Lybba (a non-profit with expertise in interaction and visual design), in partnership with patients and physicians in the ImproveCareNow Network, have developed a "Personalized Learning System" designed to make possible a more rigorous, collaborative, and individualized approach to care. This idea emerged from the Collaborative Chronic Care Network (C3N), a larger project to design a system that enables patients, families

clinicians, and researchers to work together to accelerate innovation, discovery, and the application of new knowledge for children and adolescents with Inflammatory Bowel Disease (IBD).

The Personalized Learning System allows patients with chronic diseases to work collaboratively with their clinicians to identify issues of importance to them, track outcomes, and learn both from the routine changes patients make in everyday life (e.g., diet changes, travel, sleep patterns) and formal planned experiments aimed at improving the outcomes most important to them. A web-based interface permits patients and providers to set shared goals and co-design experiments and lets patients customize data collection via cellular short messaging system (SMS), e-mail, web-survey, and commercially available biosensor devices (e.g., Fitbit). The web interface also provides graphical reports of data collected by patients in real time for immediate review by patients and providers and provides tools for patients and providers to chronicle their observations.

A beta version of the web-based Personalized Learning System is now being used by seven ImproveCareNow physicians with a subset of two to four of their motivated pediatric IBD patients, and the experience to date is very promising. Patients and providers universally report that using the Personalized Learning System enhances the patient-physician relationship, helps patients and physicians recognize possible associations between symptoms and lifestyle triggers or medication changes, makes visits and telephone encounters more productive by offering much richer information about experiences related to the illness, and provides critical information about the patient's symptoms and quality of life in a way that is currently unavailable in traditional episodic chronic-care management.

In engaging with the Personalized Learning System, motivated patients collaborate with their physicians to develop a learning plan that is designed to help them establish shared goals and clearly articulate their hypotheses about which treatments and lifestyle modifications will improve patient symptoms. As part of the learning plan, the patient and physician agree on a set of measures that the patient will collect to track symptoms of interest, including both traditional validated patient-reported outcome measures (e.g., PROMIS, PedsQL measures) and measures customized by patients (e.g., counts of the number of bowel movements, severity of abdominal pain).

Regular data collection (or data tracking), real-time review of graphical displays of the data using statistical process control methods, and documentation of observations made in reviewing the data all help the patient and provider understand the extent of day-to-day variation in symptoms and learn from changes in symptoms, behavior, or the introduction of a new medication. Regular tracking of data also helps the patient and clinician monitor the patient's overall health status and more quickly identify a change in status between visits.

Data tracking can also assist the patient and provider in formulating hypotheses about changes that might improve the patient's symptoms. These hypotheses can then be tested using formal experimental methods. For example, if a patient has considerable daily variation in symptoms, patients and providers may design experiments to reduce unwanted variation through standardization of a daily routine (e.g., going to bed at the same time each night).

They may also test interventions using simple pre/post designs to further refine hypotheses and learn more about the effects of a particular intervention. Some patients, particularly those with a high degree of belief in a specific intervention, may be satisfied with simple pre/post design even though it is difficult to be certain that the results they documented are directly attributable to the intervention. Others who want more certainty regarding the cause-effect relationship between an intervention and the outcomes observed may want to use more rigorous designs that test the effectiveness of an intervention — for example, N-of-1 designs (i.e., those for a single subject where the patient systematically switches between two treatments) or factorial designs (i.e., those with two or more independent variables). Taken as a whole, these activities can help provide both patients and clinicians with the information they need to personalize the patient's care.

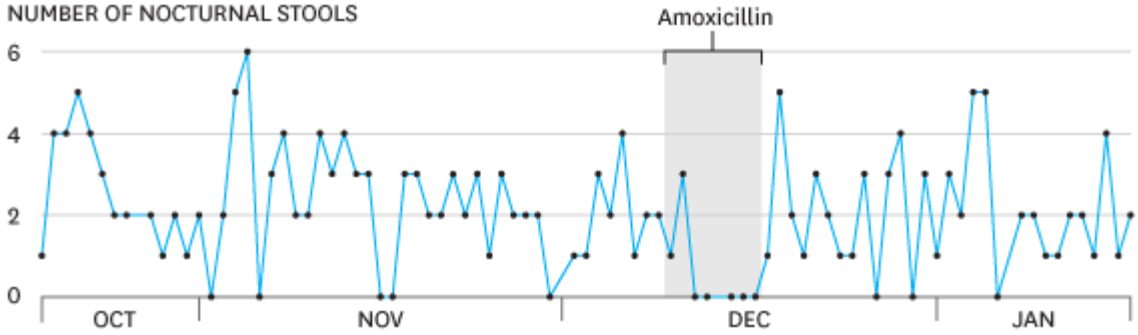
The following examples illustrate selected patient experiences with the Personalized Learning System:

Data Tracking

Patient 1 is a 20-year-old with longstanding indeterminate colitis who underwent a colectomy at age 10. She had frequent (up to six) bowel movements each night that interfered with her sleep and contributed to her fatigue and poor quality of life. In collaboration with her physician, she decided to track the number of bowel movements at night. During the baseline period, she awoke two to six times per night to move her bowels. During this period, she developed a respiratory infection and was treated with amoxicillin. Within two days after she had started antibiotics, she experienced a decrease in the number of bowel movements over six consecutive nights (see the exhibit "Number of Night-time Bowel Movements"). She was later treated with a second course of antibiotics for recurrent sinusitis and her stool pattern again improved (data not shown). This observation led to a hypothesis that antibiotics could reduce her nocturnal bowel movements, and an experiment was designed to test whether Rifaximin (a non-absorbable antibiotic) would work to improve her symptoms.

NUMBER OF NIGHT-TIME BOWEL MOVEMENTS

This graph displays the number of the patient's bowel movements per night. The data was collected via a daily SMS text exchange. Coincident with receiving amoxicillin for a sinus infection (12/9/11 through 12/16/11, shaded area) she had a significant reduction in the number over a six-day period.



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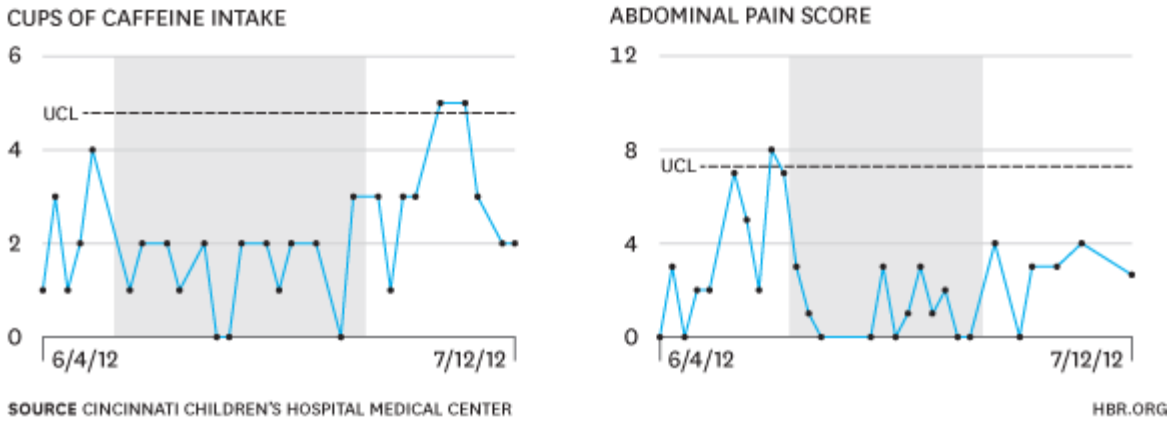
Interventions to Reduce Variation

Patient 2 is a 16-year-old with Crohn's Disease who has had longstanding abdominal pain and bloating. She reported drinking a large amount of caffeinated beverages, including coffee, soda, and Red Bull. While she did not appreciate any association between her symptoms and caffeine intake, her physician believed there was one. After a discussion, she agreed to reduce consumption from two to five cups per day to one or two. During a test period of just over two weeks, her abdominal pain decreased significantly. Her pain returned after she resumed her previous intake of caffeine (see the exhibit "Daily Caffeine Intake and Abdominal Pain Score"). The data helped her recognize the role caffeine played in her pain.

DAILY CAFFEINE INTAKE AND ABDOMINAL PAIN SCORE
The left panel displays the number of cups of caffeinated beverages consumed by the patient. The data was collected via daily SMS text exchanges. The right panel depicts the patient's daily rating of abdominal pain on a scale of 1 to 10 (10 reflecting worst pain). There was a reduction in pain associated with a planned decrease in the number of caffeinated beverages (shaded areas).



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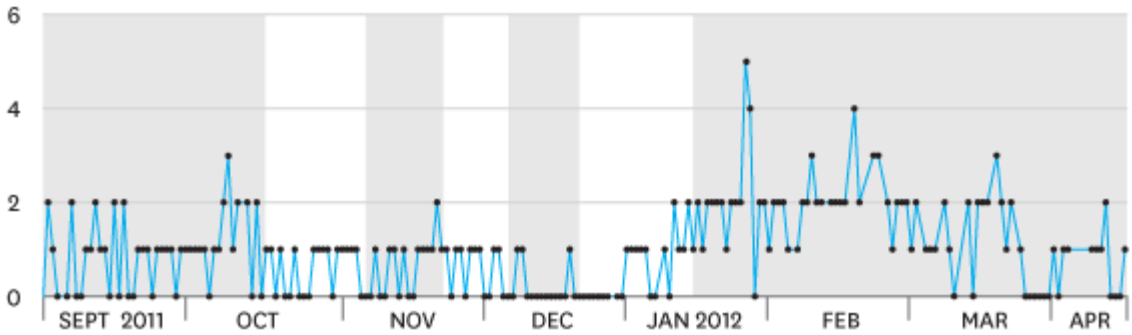
Formal N-of-1 Experimentation

Patient 3 is an 11-year-old with Crohn's Disease. She and her mother were interested in testing whether a change from one probiotic to another one would improve her stool urgency (sudden, irresistible need to have a bowel movement). At the beginning of the trial, the patient changed her probiotic treatment. To establish a baseline, she stayed on the new probiotic for six weeks and then conducted repeated treatment periods on and off the new probiotic (two weeks taking the new probiotic, two weeks completely off the probiotic). She completed three treatment cycles and found there was no difference in her symptoms when she was on the probiotics and when she was not (see the exhibit "Number of Urgent Bowel Movements"). Despite these findings, the patient and her mother were unconvinced. In consultation with her physician, they planned to continue the experiment (complete more treatment periods on and off probiotics) in

order to determine if the results persisted and gain more confidence in the observation that the probiotics had no effect. However, the experiment was stopped when her disease worsened — a common occurrence for IBD patients, who often experience periods when the disease is active and periods when there is little or no disease activity. At the time of the flare, the patient and her mother elected to continue treatment with the probiotic while other medications were added to help control the flare. They continued to track data for the next six months in order to monitor for resolution of her clinical flare.

NUMBER OF URGENT BOWEL MOVEMENTS
This graph displays data collected by the patient's mother via a web-based survey that asked about the number times the patient had to rush to the bathroom for a bowel movement in the past 24 hours. Shaded areas indicate time periods on the new probiotic. A general worsening in symptoms occurred in 01/2012 related to a disease exacerbation.



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At its core, the Personalized Learning System is intended to help patients take a more active role in personalizing their care by providing the information that is crucial for collaborative, informed decision-making. We are continuing to use the beta version of the web-based Personalized Learning System application with interested patients and physicians in the ImproveCareNow Network. Based on feedback from clinicians and patients, we are iteratively improving the user experience and at the same time expanding the technology to apply to other diseases beyond Inflammatory Bowel Disease within Cincinnati Children's Hospital Medical Center and through other chronic disease networks. We are also planning to undertake a more definitive evaluation of the impact of the Personalized Learning System on patient outcomes, experience, and value (resource utilization) as compared to usual care.

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Heather C. Kaplan (MD, MSCE) is a neonatologist and health services researcher at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center (CCHMC).

Jeremy Adler (MD, MSc) is a pediatric gastroenterologist, ImproveCareNow physician, and health services researcher at the University of Michigan.

Shehzad A. Saeed (MD, FAAP, AGAF) is a pediatric gastroenterologist, clinical director of the Schubert-Martin Pediatric IBD Center at Cincinnati Children’s Hospital, and an ImproveCareNow physician.

Ian Eslick (PhD) is managing partner of Vital Reactor, a health-information-technology firm, and an architect for the C3N Project at Cincinnati Children’s Hospital.

Peter A. Margolis (MD, PhD) is a pediatrician, a clinical epidemiologist, and director of research at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center.

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Docmcnash 2 years ago

I have done this type of thing with a few people with severe symptoms who were ver motivated with great success.

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