Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals

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Abstract

Patient-generated data can allow patients and providers to collaboratively develop accurate diagnoses and actionable treatment plans. Unfortunately, patients and providers often lack effective support to make use of such data. We examine patient-provider collaboration to interpret patient-generated data. We focus on irritable bowel syndrome (IBS), a chronic illness in which particular foods can exacerbate symptoms. IBS management often requires patient-provider collaboration using a patient's food and symptom journal to identify the patient's triggers. We contribute interactive visualizations to support exploration of such journals, as well as an examination of patient-provider collaboration in interpreting the journals. Drawing upon individual and collaborative interviews with patients and providers, we find that collaborative review helps improve data comprehension and build mutual trust. We also find a desire to use tools like our interactive visualizations within and beyond clinic appointments. We discuss these findings and present guidance for the design of future tools.

Author Keywords

Patient-Provider Collaboration; Patient-Generated Data; Self-Tracking; Symptom Triggers; Interactive Visualization

ACM Classification Keywords

H.5.2 Information Interfaces and Presentation; User Interfaces

INTRODUCTION

Healthcare providers often rely on patient data to inform diagnoses and treatment decisions. Such patient data has traditionally been obtained through verbal summaries from patients and infrequent clinical data collection (e.g., vital signs, blood tests, overnight sleep studies). However, both patients and providers are increasingly interested in augmenting this data with patient-generated health data (e.g., food journals, physical activity logs, wearable sensor data) [13]. A recent study found 69% of U.S. adults report tracking a health factor, with 14% using technology to do so [19]. Because tracking, and its use in clinical care, are

expected to continue increasing, many patients and providers believe that patient-generated data has the potential to capture a more complete, accurate, and longer-term understanding of a patient's health [11, 12].

Unfortunately, attempts to collaborate using patient-generated data in a clinical environment often leave both patients and providers dissatisfied. Many patients who share data with their providers report feeling their providers were insufficiently engaged with the data [18]. Providers in turn encounter a myriad of barriers when attempting to use patient-generated data to inform diagnoses. For example, commercially available self-tracking tools (e.g., *Fitbit*, *MyFitnessPal*) present data in non-standardized formats and generally lack features for sharing or collaboration [11]. Furthermore, many providers question the accuracy of such data, lack the time necessary to analyze it, or feel unequipped to interpret it [11, 55].

This work examines patient-provider collaboration using patient-generated food and symptom journals to identify nutrients that trigger an individual patient's symptoms. This practice is an example of *diagnostic* self-tracking, which prior research in the Quantified Self community has found broadly important but also difficult and error-prone [10]. We focus on irritable bowel syndrome (IBS), a chronic illness that often requires sustained patient-provider collaboration to manage.

We contribute two exploratory, interactive visualizations that represent different design trade-offs in supporting collaborative interpretation of patient-generated food and symptom journals. By applying visualization techniques to the domain of patient-generated health data, we created novel opportunities to help patients and providers discover and examine trends in the data and identify dietary changes that might help the patient manage their symptoms.

We further contribute an examination of patient-provider collaboration in the interpretation of patient-generated data using exploratory interactive visualizations. We observed and interviewed 10 patients with IBS and 10 providers, both individually and in pairs, as they examined the patient's data in our visualizations. The visualizations allowed the patient and provider to identify concrete examples in the patient's data, which helped build understanding and encouraged a dialogue supported by the expertise of each collaborator, leading to mutual trust in the collaboration. Our findings emphasize the need for tools for patient-provider collaboration with patient-generated data to be *flexible* in their presentation of a patient's data, provide *simple* and *exploratory* environments to foster collaboration between collaborators with different expertise, and support the development of *actionable* insights.

RELATED WORK

We review relevant work in the collection and interpretation of patient-generated health data and in data visualization.

Interpreting Patient-Generated Health Data

Self-tracking has become increasingly popular as technology has advanced to allow people to track more information and to reduce barriers and burdens in that tracking [28]. However, many self-trackers struggle to find value in their data after collecting it. This challenge often stems from a lack of time or skills needed to analyze the data, as well as a lack of suitable analysis or visualization tools to aid interpretation [10, 28]. In Choe et al.'s examination of self-tracker practices in collecting and exploring personal data, 35% of self-trackers reported having a health condition [10]. Many were self-tracking to identify symptom triggers. Although the participants were technology-fluent, they often encountered insurmountable barriers (e.g., a lack of contextual information, insufficient scientific rigor to form reasonable hypotheses).

One approach to overcoming barriers in interpreting self-tracking data is to seek expert help. Many self-trackers attempt to share their patient-generated data with providers in various health domains [18, 13, 57]. Providers also commonly ask patients to track and review lifestyle indicators to help manage chronic diseases or conditions (e.g., diabetes [1], heart failure [49], IBS [3]). Reviewing this data can help providers understand the everyday behavior of patients and provide better diagnoses or personalized treatments [11]. Interpreting such data often requires collaboration between the patient and provider, with the provider contributing medical expertise while the patient contributes detailed knowledge of their day-to-day life [4]. Prior systems have enabled such collaboration by helping patients engage in the decision-making process [2, 49] and by supporting long-term care management [27, 42, 51]. These systems help providers contextualize the data necessary for informed diagnoses [49] and facilitate patient-provider communication [1, 32, 39], which can often improve patient health outcomes [37, 48].

Just as trust is important in many collaborative contexts (e.g., [5, 36]), mutual trust is a requirement for successful patient-provider collaboration. Patient trust and engagement in the collaboration requires explicit communication about how a provider is using their data [12, 30, 40]. Providers need confidence in patient-generated data to feel comfortable using it for diagnoses and decision-making processes [55, 57]. Designing for successful patient-provider collaboration with patient-generated data therefore requires understanding how to support trust building: between the patient and provider, in the patient-generated data, and in the performed analyses.

Our study builds upon this prior work to understand how patients and providers collaboratively identify and manage a patient's individual symptom triggers, focusing on patients with IBS as our particular study context. We aim to help patients and providers avoid common pitfalls in the interpretation of patient-generated data by performing statistical analyses to determine what nutrients are significantly correlated to their symptoms and appropriately presenting results for patient-provider collaboration in their interpretation.

Visualizations for Data Analytics

Prior research has examined transforming self-tracking data into actionable information by showcasing aspects of the data in summary visualizations [15]. Visualizations can also help

ensure data is considered objectively. For example, Reeder et al. studied older adult perceptions of health-related self-tracking data and found that visual presentation was useful for objectively identifying trends [44]. We similarly aim to use visualizations of patient-generated data to support the development of actionable treatment plans.

More generally, prior work has examined the design of collaborative systems [26, 45, 56]. This work largely guides the design of environments and visualizations that support distributed collaboration. For example, environments should locate visualizations so that everybody can see them [45, 54]. Heer and Agrawala identify seven important considerations for the design of asynchronous collaboration systems for visual analytics, including: common ground and awareness; identity, trust, and reputation; and consensus and decision making [22].

Our research examines how interactive visualizations can support patients and providers working to identify nutrients and foods that trigger an individual patient's symptoms. We develop and investigate interactive visualizations in the context of both individual use and synchronous, co-located collaborative use. The visualizations support both the provider (i.e., a medical expert) and the patient (i.e., the expert in their own lived experience). We designed the visualizations to incorporate the principles identified in prior research that were applicable in the context and questions of our work.

STUDY CONTEXT: IRRITABLE BOWEL SYNDROME

Irritable bowel syndrome (IBS) is a chronic illness that requires a high degree of patient-provider collaboration to diagnose and manage. We believe our results apply more broadly to patient-provider collaboration to interpret patient-generated data, but we provide background on IBS to situate our current work. IBS causes gastrointestinal symptoms (e.g., abdominal pain, bloating, constipation, diarrhea) despite normal clinical test results. IBS affects up to 20% of the population [14], and no cure currently exists. Up to 70% of people with IBS report certain foods can cause or worsen symptoms [21], but different foods and nutrients are problematic for different people, so population-level recommendations are often inappropriate [34, 46, 61]. Individuals with IBS currently must either eliminate all nutrients thought to correlate with IBS symptoms (e.g., FODMAPS, gluten, caffeine [21, 34]) or try to identify particular nutrients that cause their individual symptoms. Dramatic elimination diets can be highly burdensome, and can even lead to malnutrition [21, 29], so many people with IBS want to identify their personal triggers.

Unfortunately, identifying which nutrients are correlated with an individual's IBS symptoms is a difficult and unreliable process. The American Gastroenterological Association advises practitioners to have patients keep food and symptom journals to attempt to identify triggers [3]. However, no validated method exists to determine significant nutrients from such journals. Patients and providers must instead hunt through pages of journals to try to find plausible correlations.

Despite their effort to identify such correlations, providers often lack the time and training necessary to do so [11]. The majority of patients with IBS are dissatisfied with the feedback

their healthcare providers give based on their journals [24]. An analysis of the recommendations given by 8 experienced providers after reviewing 17 paper food and symptom journals found poor reliability in their recommendations: recommendations for the same patient were inconsistent across providers, and individual providers showed biases toward identifying particular triggers regardless of the patient's data [59]. Patients and their providers are often dismayed by the lack of tools to help identify trends in food and symptom journals [7, 12]. By visualizing significant trends in the context of a patient's original data, we hope to improve the process and outcome in collaborative identification of symptom triggers.

ANALYSIS OF FOOD AND SYMPTOM JOURNALS

Motivated by the difficulty of identifying symptom triggers in food and symptom journals, we recruited 10 participants from a prior study of the feasibility of food and symptom journaling for IBS patients [58]. Where prior work focused on the collection and analysis of food and symptom journals [58, 60], our focus is on patient-provider collaborative review in interpreting the journals and associated analysis via interactive visualizations. We briefly review the journal collection and analysis process, with additional details available in [58].

Journal collection was designed to provide detailed symptom and diet capture while limiting burdens. Consistent with established dietary protocol [43, 52], patients journaled for 3 sets of 3-day "on" periods, separated by 3-day "off" periods. Patients were asked to record all food and drink with the corresponding time. At each meal entry, and again at bedtime, patients reported their peak symptoms since the prior entry using a 4-point scale. Trained research dietitians analyzed the journals using the Nutrition Data System for Research (NDSR) [9], decomposing each food in a journal into its constituent nutrients, which were mapped to 19 nutrients believed to be correlated with IBS symptoms (e.g., sugars, caffeine, lactose).

For each patient's journal, for each symptom they experienced, we performed regression analyses to identify correlations between food and gastrointestinal symptoms. Informed by prior IBS patient reports on the timing of symptoms following foods they believe triggered those systems [17, 41], independent variables were defined as the sum of a nutrient in all foods reported within the 4-hour window preceding a symptom report. Dependent variables were defined as the corresponding symptom reports. Symptom entries without meal entries in this 4-hour window were excluded.

Patient-specific feature selection was performed prior to regression analysis. Nutrients can have a high collinearity, due to both natural co-occurrences (e.g., foods with higher total fat tend to have higher total calories) and personal dietary habits (e.g., some people always drink their caffeinated beverages with milk). However, regressions assume a high degree of independence between predictors. For any pair of nutrients that had a high pairwise correlation in an individual's data (> 0.75), we removed the nutrient with the highest average correlation to all other nutrients (i.e., the most redundant). Regressions were performed with the remaining nutrients.

VISUALIZATION DESIGN

This section discusses our design of two exploratory interactive visualizations, created to help patients and providers interpret what nutrients correlate with an individual's IBS symptoms and what foods in the individual's diet contain those nutrients. Both visualizations are presented in a web environment created using the D3 package [6]. We informally presented early iterations to two patients with IBS to inform iterative design prior to the patient and provider interviews we present next.

Design Goals and Tradeoffs

We identify four goals motivating our visualization designs, and we consider these goals relative to the different expertise of patients and providers (e.g., patients have more familiarity with the data, providers have more clinical expertise).

Flexible—Journaled data is highly particular to each individual patient. To personalize support for trend identification, a visualization must be able to present patient-generated data for vastly different diets, nutrient ranges, and symptoms.

Simple—To facilitate collaboration within a clinic appointment, visualizations should allow both patients and providers to easily view and understand the patient-generated data. Our visualizations show each of the patient's symptoms separately, allowing them to focus on the symptoms most important to them. A primary goal is to identify nutrients that *improve* or *worsen* symptoms, so visualizations need to support simple identification of such trends in an individual patient's data.

Exploratory—Simplicity should be paired with support for thorough exploration of the data. For example, a patient or provider may have a pre-existing belief that a particular nutrient impacts a patient's symptoms. In addition, all correlation analyses have limitations (e.g., the possibility of overfitting, potential confounds). All nutrients and symptoms should therefore be available in the visualization, even those not found to be significantly correlated. We defined nutrients as *significant* to a symptom when they had a p value of $p < 0.1$, considering other nutrients *non-significant*. This p value threshold encourages consideration of more potential triggers, rather than only extremely confident results. Our visualizations also encourage exploration of *correlated nutrients* (i.e., those removed from analysis during feature selection due to their high correlation with another nutrient). When nutrients are highly correlated, more data is needed to determine which nutrient is most relevant to a symptom, so encouraging exploration allows patients and providers to collaboratively apply their understanding and expertise.

Actionable—Visualizations should foreground information that helps patients and providers develop diagnoses and treatment plans based on the patient's data. Because strong correlations are most likely to be actionable, we default to visualizing *significant* nutrients for each symptom. Developing actionable plans also requires patients and providers to determine which foods contain which nutrients. Our visualizations therefore emphasize relationships between nutrients and the foods an individual patient actually consumed (i.e., rather than generic examples of foods high in a nutrient).

Motivated by these design goals, our two visualizations explore tradeoffs in complexity. The *bubble and bar chart visualization* emphasizes the exploration of high-level trends, sacrificing detail in favor of simplicity. This visualization is more likely to be familiar, as its component visualizations are often covered in K-12 curricula [20]. In contrast, the *parallel coordinates visualization* exposes greater detail, and can display correlations among many variables (e.g., between symptoms and nutrients, among multiple nutrients) [23], but are less likely to be familiar. Both designs visualize the same data, as analyzed via the methods in the previous section.

Data Visualizations

The *bubble and bar chart visualization* (Figure 1) emphasizes exploration of high-level trends and the relationship between a selected symptom and a selected nutrient from a patient's data. Each meal from the patient's journal is displayed as a point in a faceted bubble chart (Figure 1A, also called a gatherplot [38]). Meals are bucketed by symptom severity and the amount of the nutrient in the meal (*Low*, *Medium*, *High*, corresponding to thirds in the distribution of the nutrient in that individual patient's data). A stacked bar chart aggregates the information in the bubble chart to facilitate identification of trends (Figure 1B). The visualization incorporates multiple bubble and bar chart units to facilitate comparison across nutrients (e.g., correlated nutrients can be added from Figure 1F's table, non-significant nutrients from Figure 1D's dropdown).

The *parallel coordinates visualization* (Figure 2) emphasizes relationships between nutrients and includes more detailed information (e.g., explicitly showing nutrient ranges in the patient's journal). Each meal corresponds to a line through the axes, thus showing the symptom severity and the amount of each nutrient consumed in that meal (Figure 2A). Dragging vertically along an axis creates a filter that grays all excluded lines (Figure 2B). Correlated nutrients can be expanded from the label below the name (Figure 2C), and non-significant nutrients can be added from the menubar dropdown.

For both visualizations, hovering over a meal shows the food in that meal that contained the highest amount of the nutrient (Figure 1C, Figure 2D). Selecting a meal displays a food table, which includes food names and nutrient amounts for each visible nutrient (Figure 1H, Figure 2E). Foods with a nutrient amount in the top 75% of foods the patient consumed are highlighted in the color of the meal's symptom severity.

Both representations aim to support patient and provider interpretation by make correlations visually salient. In the *bubble and bar chart visualization*, correlation is indicated by the relative area of the stacked bars for each nutrient amount. For example, Figure 3A shows that as the amount of starch in this patient's diet increases, so does the severity of their symptoms (i.e., the portion of red in the bar grows from left to right). In contrast, Figure 3B shows that the amount of fructose does not seem to impact symptoms (i.e., no clear increasing or decreasing trend can be seen in the bars). For the *parallel coordinates visualization*, Figure 3C shows a strong positive correlation between soluble dietary fiber, total dietary fiber, and insoluble dietary fiber in an individual patient's data (i.e., straight horizontal lines between these nutrients). A strong negative correlation would be indicated

by a tight grouping of line crossings (i.e., an "X" shape). Figure 3D shows no clear correlation between lactose and fructose (i.e., no clear trend in slopes between the nutrients).

Interactive Experience

Upon opening either visualization, an interactive tutorial explains how to view, interpret, and interact with that visualization. Our goal for these tutorials was to familiarize patients and providers with the interface and its depiction of data, helping them be more comfortable interpreting the visualizations. After the tutorial, a summary page presents actionable entry points into the visualization. The summary page shows a table of the patient's symptoms, the significant nutrients to those symptoms, foods in the particular patient's diet that are high in those nutrients, and any nutrients that were correlated to the significant nutrients. Nutrients with positive effect sizes (i.e., symptoms tended to be more severe when more of the nutrient was consumed) are described as *worsening*, and those with negative effect sizes (i.e., symptoms tended to be less severe when more of the nutrient was consumed) are described as *improving*. Selecting a symptom, nutrient, or correlated nutrient navigates to that view in the visualization. Each symptom is also accessible from a separate tab in the top menubar, and defaults to showing nutrients determined to be significant for that symptom. If no nutrient was found to be significantly correlated, an initially empty tab is shown with a short explanation of why nothing is visible. A symptom summary tab also shows an overview of a patient's reported symptoms without relating them to nutrients.

During our early informal iterations, we found that *patients* often found *p* values unfamiliar and somewhat intimidating. However, *providers* considered *p* values essential to a more complete understanding of the information. We therefore introduced two modes in the visualizations. In patient mode, *p* values are hidden from the summary table and correlated nutrients are described as "related". In provider mode, *p* values are included in the summary table, the term "correlated" is used as appropriate, and the summary table emphasizes that example foods are taken from the individual patient's diet (rather than generic examples of foods high in that nutrient). When interacting with the visualizations, *p* values are shown regardless of mode (Figure 1G, Figure 2C). The mode was set prior to each session, and cannot be changed in the interface.

PATIENT AND PROVIDER INTERVIEW METHODS

We envision the analyses and visualization environments we developed as collaborative tools for people with IBS and their providers. To examine the implications for patient-provider collaboration, we conducted semi-structured interviews with patients and providers, both independently and together.

We recruited 10 providers with experience working with patients with IBS (4 male) and 10 patients with IBS (2 male, age *mean* = 33, *min* = 22, *max* = 46) (Table 1). We note this patient gender distribution reflects that of IBS diagnoses [8]. Patients were compensated with a $25 Amazon gift card, analysis and interpretation of their data, and a free consultation with a provider experienced in working with patients with IBS. Providers were compensated with a $50 Amazon gift card.

Because visualizations of personal data are most meaningful to the person who provided the data, we recruited patients from participants in a prior study that involved keeping food and symptom journals [58]. The prior study was completed about a year before our analyses and visualizations were developed, so the journals were not recent. We nevertheless believed that personalizing the study with a participant's own data would be a good representation of the system's intended use, as patients might have detailed questions or hypotheses surrounding their own food and symptom data. At the time of the prior study, all patient participants met the Rome III criteria for IBS and had experienced IBS symptoms within the previous month [31]. Provider participants all had experience working with patients with IBS, but had not met the patient participants prior to the study. Recruiting an already-known provider for each patient participant was infeasible, and we decided to be consistent in having all patient-provider pairings be new collaborations.

Interviews included two phases: individual and collaborative. In the first, one researcher interviewed the patient while another interviewed the provider. This phase lasted 40 minutes, with approximately 20 minutes dedicated to each visualization and follow-up questions. The order visualizations were shown was held constant within a patient-provider pairing and counter-balanced across pairings. Participants completed the tutorial and then explored the visualization of the patient's data. They were encouraged to talk aloud during their data exploration and to ask any questions they had. Researchers then asked about participant opinions of the visualizations, whether and when they would use them, and what conclusions they would draw from them. In the collaborative phase, the patient and provider were brought together to explore and interpret the visualizations, simulating a clinic appointment. Participants were given their choice of which visualization(s) to use, and were able to switch between them at any time. They were then jointly asked to compare their experiences using the visualizations alone versus collaboratively. The full protocol can be found in the supplementary materials.

We structured the interviews to be exploratory, with limited guidance, for multiple reasons. We wanted to observe how providers would use the tools to investigate their hypotheses and questions based on their years of experience treating patients with IBS. Similarly, we wanted patients to explore questions about their symptoms, foods, and nutrients according to their personal interests, rather than because we had artificially instructed them to complete a particular task. Our goal was to understand how patients and providers would collaboratively use the visualizations to manage the patient's IBS in a clinical setting, based on the patient's own experience and the provider's expertise. Directing participants to answer pre-formulated questions might have better compared how each visualization addressed those particular questions, but it would have been less representative of our real-world use-case. However, our method has limitations, as it cannot evaluate how the visualization techniques influenced the quality of the data interpretation. We instead focus on the overall experience of using data visualizations for collaborative interpretation.

When quoting participants from these interviews, we refer to patients as *P#* and providers as *R#*. *P9* was uncomfortable with the prospect of a collaborative interview, expressing unease about *"bothering somebody to come in"*. We therefore only interviewed *P9* and *R9* separately. *P4* had no significant nutrients in their data. To help *R4* understand what the

visualizations would look like with significant findings, we showed *R4* visualizations for both *P4* and *P3*. For privacy reasons, patients were only shown their own data.

We audio-recorded and transcribed all interviews. We then conducted an affinity diagram analysis to identify emergent themes. Two researchers transformed interview transcripts into approximately 800 affinity notes and iteratively organized these notes into 75 categories. A third researcher verified and discussed the emergent themes with the analysis team. We then identified several key themes regarding patient-provider collaboration and use or non-use of the tool to support collaboration. We discuss our findings in the next section.

RESULTS

Participants felt the presented analyses and visualizations would be an asset for patients and providers struggling to interpret food and symptom data. The interviews also surfaced requirements for successful patient-provider collaboration. These span from design necessities for systems to support patient-provider collaboration to issues of trust and feeling trusted in the collaboration. We discuss these themes below.

Trust in Patient-Provider Collaboration

A recurring theme was the concept of trust in patient-provider collaboration to interpret patient data. Providers need to trust their patients to correctly interpret the data visualizations. Both patients and providers were concerned about whether the other trusted them. Although visualizations helped build trust in some cases, they also introduced new considerations concerning trust during patient-provider collaboration.

Provider Trust in Patient Data Interpretation Abilities—An important question for many providers was whether they could trust patients to correctly interpret their data. Five providers (*R2*, *R6*, *R7*, *R8*, *R9*) worried the visualizations were too complicated for patients to interpret and would confuse them. This concern impacted how they expected to use the visualizations and whether they wanted the patient to be able to access the visualizations before the clinic appointment.

During individual interviews, *R7* and *R8* explicitly mentioned they would likely focus on the summary page during a clinic visit, only showing patients the data visualizations if they had been able to identify a clear trend or an example they wanted to emphasize to the patient. Four providers (*R2*, *R6*, *R7*, *R8*) indicated being wary of giving a patient the ability to review the visualizations before the appointment, although three of the four (*R6*, *R7*, *R8*) indicated they still thought the patient should have access if they wanted. *R7* believed that the patient should have access, despite her worries, only because the patient should *"have the right"* to see their own data. Only *R2* said that he did not want a patient to be able to review the visualizations beforehand. When asked during the individual interview, he said the patient would find the visualizations too complicated and would end up fixating on irrelevant things.

Patient Demonstration of Data Interpretation Abilities—The collaborative interviews assuaged many of the concerns providers initially had about patient abilities

regarding data interpretation. *R2* originally did not want patients to have independent access to the visualizations, but he changed his mind after the collaborative interview. He appreciated that the patient could set her own agenda, bringing things she considered important to the provider's attention. The patient's familiarity with the data also allowed her to feel comfortable explaining different aspects of the data. The provider therefore felt more capable of making recommendations, because the patient could contextualize the data. By combining the provider's expert knowledge with the patient's personal knowledge, they were able to have a deeper conversation about possible problems and solutions, instead of the provider just *"coming in and being like, here's what I found"* (*R2*).

The other three initially skeptical providers (*R6*, *R7*, *R8*) also seemed more confident in the abilities of the patients after the collaborative interview. The patients they were paired with all said they would want to be able to review the visualizations before a clinic appointment, and the providers agreed the exposure would be helpful. *R8* commented that having both collaborators be familiar with the data would help *"focus [their] energies during the visit"*. She explained:

> I don't like to deliver news to patients that is surprising if I don't have to. If [the patient] saw this and [was] like, "Fiber and caffeine? That's not what I expected", [the patient] would be processing that … as opposed to focusing on … how I'm interpreting [their] data.

Need to be Trusted by the Collaborator—Patients and providers both commented on the need for their collaborators to trust what they say. Patients needed providers to understand their experiences, and providers needed patients to understand why they made certain recommendations. Six providers (*R2*, *R4*, *R6*, *R7*, *R9*, *R10*) and five patients (*P1*, *P5*, *P6*, *P7*, *P8*) described that being able to go through an objective view of the patient's food and symptom data, rather than talking abstractly about the patient's experiences, helped them feel they could more successfully communicate their views. *P1* and *P8* explicitly mentioned that the tools provided a good way to explain the severity and frequency of symptoms they were experiencing. *P1* remarked that such information is *"kind of hard to put into words, but [the visualization] kind of quantifies it"*. Four providers (*R2*, *R4*, *R6*, *R9*) mentioned the importance of being able to show their patients concrete, personal data to explain their recommendations. *R4* explained:

> It really helps them understand how what they eat affects their symptoms, which is the most important thing. If they don't understand that then they can't change it, right? I think it's a really objective way to show them "you've been telling me that every time you have pizza your belly hurts, look, this is it, believe it, stop".

However, the visualizations also caused some unease for *R8* and *R10*, who mentioned feeling *"embarrassed"* or *"anxious"* about giving the impression that they lacked necessary knowledge to explain the visualizations. Although they found collaborative review of the data helpful, they also doubted their abilities to correctly interpret the data or describe what foods contain certain nutrients. They therefore needed the tool to have enough information for them to quickly answer questions that patients might have. Although the visualizations helped assuage some concerns regarding trust, systems designed to support patient-provider

collaboration must also be careful not to introduce new trust-related concerns in the collaboration.

Confidence in Data, Analyses, and Visualizations

Some patients and providers expressed uncertainty when viewing the visualizations: regarding the data quality, the correlation analyses, or the graphical depictions of the data.

Possible Data Confounds—Visualizations helped patients and providers raise questions regarding the quality of data collection and analysis with respect to their original expectations. Four providers (*R3*, *R4*, *R5*, *R8*) and four patients (*P2*, *P3*, *P5*, *P8*) mentioned needing to know more about the context of the data in order to trust it, citing possible confounds including emotional and physical health, hydration, and exercise. Similarly, two providers (*R2*, *R7*) and three patients (*P6*, *P8*, *P10*) expressed uncertainty because they lacked confidence in the patient's judgment of symptom severity during data collection. *P8* mentioned:

> [A]m I PMSing? If I am, maybe everything is terrible. I'm like, "Pain is terrible. Bloating terrible. Diarrhea? Didn't really happen, but it's terrible anyways".

In addition, five patients (*P1*, *P3*, *P4*, *P6*, *P8*) mentioned feeling their personal experience was not accurately reflected. As discussed in our correlation analyses, we defined potential triggers in terms of the preceding 4-hour window and discarded any symptom entries lacking corresponding meal entries. Some patients felt that this strategy did not accurately reflect their experience with their symptoms and potential triggers, and others recalled symptoms that were not visualized. The time elapsed between data collection and our study also may have impacted patient recall and perspective on their data.

Personal vs Population-Level Information—Many participants wanted to verify regression results were biologically plausible. Three patients (*P5*, *P9*, *P10*) and two providers (*R7*, *R10*) mentioned wanting to see corresponding population-level data, because it would help them determine whether the individual data and results were normal. *P10* said she needed to do more research about the significant nutrients from her analysis to learn whether they often cause IBS symptoms before deciding whether she trusted the results.

Participants were occasionally confused because the nutrient analysis was based in the range observed in that patient's data, not some population-level average range. For example, *P7* was perplexed her results indicated her symptoms improved when she consumed meals with higher fat. She knew from experience she consistently feels worse when she consumes high-fat meals. In fact, *P7* had that knowledge at the time of data collection and was already avoiding high-fat meals. Her analysis therefore did not suggest high-fat meals relative to the broader population, but rather that she tended to experience reduced symptoms with meals that were higher in *her personal range* of fat content, which was already low compared to the population average. Including typical diet information or population-level context may improve patient and provider understanding and confidence in personalized analyses.

Visualization Complexity—Our visualizations illustrate different tradeoffs in simplicity versus expressiveness. The bubble and bar chart visualization shows high-level trends, while

the parallel coordinates provide more detail. We thought some clear preference might emerge, but found diverse reactions to the alternatives. Some participants felt both were simple and straightforward, some expressed a preference, and others felt both were overwhelmingly complex. Participant confusion sometimes had consequences for their interpretation of a visualization. Two patients (*P2*, *P5*) and one provider (*R2*) indicated their ability to interpret the visualization directly informed the trust they had in the presented symptom analyses. *R2* explained:

> I feel more comfortable with the interpretation than I did before where I really don't think, even toward the end and answering all your questions, that I actually understand [the parallel coordinates visualization]. Whereas I feel like I can understand [the bubble and bar chart visualization] and make my own conclusions here.

We also observed the opposite: *more* trust in a visualization participants found confusing. For example, *R6* started with the parallel coordinates visualization. Although he claimed to find it straightforward, he drew most of his conclusions from the summary page. When asked, he stated he had confidence in the results. However, upon switching to the bubble and bar chart visualization, he expressed less confidence, pointing out that the analysis *"relies on how accurate that data is that the person is inputting"*. *P8* similarly stated she had confidence in the bubble and bar chart visualization, but upon switching to the parallel coordinates remarked *"this is a really clear visualization to me of the range of how much fiber did I eat. I ate a really wide range of fiber from my 'no symptoms'"*, thus revealing that she had not comprehended that range with the prior visualization. We wanted the visualizations to provoke such critical thinking, as statistical analyses are limited (e.g., due to possible overfitting, due to correlated nutrients, due to other potential confounds). Results therefore require interpretation to determine if and how they likely apply for a particular patient. Confusion regarding the visualizations often limited such critical thinking, leading participants to rely on the summary page and deemphasize the backing data.

Use Within and Beyond a Clinic Appointment

Although we intended the visualizations for collaboration in and surrounding a single clinic visit, participants identified opportunities and expressed desire for longer-term use.

Use During the Clinic Appointment—Patients and providers both wanted to use the visualizations collaboratively in clinic appointments. Eight providers (*R1*, *R2*, *R3*, *R4*, *R5*, *R7*, *R8*, *R10*) mentioned that talking to the patient helped their interpretation of the visualizations. They felt learning more about the patient helped them give effective recommendations: they were interested in patient goals, perception of their symptoms, opinion on their results, thoughts about their current diet, and willingness to change their diet. Five patients (*P5*, *P6*, *P7*, *P8*, *P10*) mentioned valuing having an expert's interpretation of their results, to ensure their own interpretations were correct (in some cases wanting interpretation guidance from an expert) and to verify the results made sense to a provider with experience with IBS.

Use Before the Clinic Appointment—Participants overwhelmingly wanted to be able to access and review the visualizations before a clinic appointment. Eight providers (*R1*, *R2*, *R3*, *R4*, *R5*, *R6*, *R7*, *R8*) and six patients (*P1*, *P2*, *P4*, *P6*, *P7*, *P8*) wanted the visualizations to help prepare for the appointment. *P8* also expressed the need to be able to come to terms with any surprising or bad news:

> If something came up [in the visualization] that I was unhappy about … for me to be able to be unhappy about it on my own, and then come to the visit with, "Okay, what are we going to do?" [would be helpful]. Either I think this is bogus and we should try it again, or I've come to terms with the fact that we need to do this.

However, four providers (*R3*, *R6*, *R8*, *R10*) doubted whether they would have the time to review the visualizations between clinic appointments. Designs must therefore emphasize the ability to quickly understand and interpret the results.

Longer-Term Use Over Multiple Clinic Appointments—Eight providers (*R1*, *R4*, *R5*, *R6*, *R7*, *R8*, *R9*, *R10*) and six patients (*P1*, *P4*, *P5*, *P6*, *P8*, *P10*) expressed a desire for the visualizations to enable longer-term, iterative use. IBS is a chronic condition, and participants wanted to be able to view changes in a patient's diet and symptoms over time. *R8* also mentioned wanting to be able to take notes about patients and review those notes before subsequent appointments. Although the analyses and visualizations were designed for a single food and symptom journal dataset, participants wanted to extend the system to aid the ongoing management of their IBS.

Use as a Tool for Hypothesis Formation—Six providers (*R4*, *R5*, *R6*, *R7*, *R8*, *R10*) and one patient (*P8*) expressed a desire to use the visualizations to form hypotheses about what nutrients may be impacting a patient's symptoms. They then wanted to follow up this hypothesis formation with an experimental step testing whether limiting the nutrient improved the patient's symptoms. Integrating exploratory analyses for hypothesis formation with hypothesis testing through self-experimentation [25] is one potential approach to addressing this desire and providing more actionable results.

DISCUSSION

Patient-generated data is transformed into different types of boundary negotiating artifacts during patient-provider collaboration [12]. Building on the lens of this theory, we considered our visualizations as inclusion artifacts that summarize data to facilitate patient-provider discussion. Computer-supported analyses and visualization reduce the time and effort needed for a provider to perform on-the-spot mental analysis, thus allowing more interaction with the patient. Visualizations also help patients communicate their experiences clearly and concisely, making them feel more comfortable and involved in the clinic appointment. Our designs focus on exploratory, interactive visualization and interpretation, providing the opportunity for patients and providers to negotiate which potential triggers to consider in a treatment decision. This section draws upon our interviews to discuss considerations for tools to support patient-provider collaboration in the interpretation of patient-generated data.

Encouraging Provider Trust in Patient Abilities

Many providers were initially skeptical of whether patients would be able to correctly interpret the data visualizations. Although this concern was often assuaged during the collaborative interviews, more dramatic differences between patient and provider modes might be helpful to mitigate their initial concerns. Another approach to increasing provider confidence in patient abilities may be to support different levels of exploration with different levels of complexity. For example, we designed: (1) the summary page as an overview of the main takeaways, (2) the bubble and bar chart visualization as a simpler view of high-level trends, and (3) the parallel coordinates visualization as a more detailed view of the patient's nutrients and symptoms. By supporting different levels of complexity, patients who are comfortable exploring complex visualizations can do so, while patients who are confused or intimidated can explore the simpler representations to assess their data before a clinic appointment. When the patient then reviews the data with their provider, the provider could determine the patient's level of understanding by inquiring about the complexity level they reviewed at home and what interpretations they formed during this review. The provider could then explain the data at an appropriate level.

When providers are first introduced to patient-generated data, they often doubt the patient's ability to correctly collect or interpret the data [55]. Recent research has also found that patients often have difficulty understanding common visualizations of health data [35]. However, our study found that many patients were able to navigate a complex visualization when aided by a short interactive tutorial. Fully developed tutorials could support patient interpretation and help address provider concerns. A related opportunity is suggested for provider-directed tracking (i.e., when a patient initiates tracking at the request of a provider, a common practice in IBS management). Educational materials and protocols could help ensure patients develop the knowledge necessary to both collect and interpret data, while simultaneously helping to mitigate provider concerns.

Providing Clear and Comprehensive Visualizations

Both patients and providers were concerned that their collaborator would not trust or understand what they were trying to communicate. Patients were concerned providers would not understand their symptoms, and providers were worried patients would not believe recommendations the providers could not illustrate or support. The visualizations helped assuage many of these concerns by providing clear and objective views of the patient's experiences, rather than relying on abstract conversations about them. As we previously discussed with *R4*'s explanation of the importance of concrete examples, the visualizations helped foster a feeling of collaboration by giving them something to examine together. Tools designed to help promote patient-provider collaboration should emphasize such collaborative exploration.

However, the visualizations also introduced potential new concerns. Providers did not want to be seen as incompetent, and worried they might not be able to quickly and easily navigate and interpret visualizations in the presence of a patient. To ensure a provider is comfortable, systems should be simple to understand and interpret, with educational information immediately accessible (e.g., in case a patient asks a question that a provider cannot answer).

In addition, systems should support patients and providers reviewing data individually before an appointment, so that both are confident about the data and agenda during collaborative interpretation.

Systems should also surface information about data processing. Prior work in algorithm transparency has suggested making system logic explicit may increase engagement [16, 47, 50]. We included details of data analysis as a help page in the interface, and the tutorial alerted participants to its existence. However, few participants attempted to read this information. Participants may not have seen a need to consult this resource during the short interview study, but patients were sometimes confused about why the displayed data differed from their recollection. The fact that participants did not access the information may therefore illustrate a need to better integrate it into the visualization itself, rather than presenting it as a separate page. In addition to supporting understanding, better surfacing analysis details and assumptions can support patient and provider evaluation of whether those details and assumptions are appropriate for an individual patient's case.

Supporting Use Inside and Outside the Clinic

Patients and providers wanted to access the visualizations both before and during clinic appointments, and also expressed a desire for long-term use. Providers were concerned the visualizations may take too long to interpret, which would hinder their ability to review data before a clinic appointment. A key requirement for supporting provider use before an appointment is therefore ensuring that interpretation is easy enough for providers to quickly review and get a sense of the data between clinic appointments. Another approach is to help the provider prepare for the goals and questions the patient is bringing to an appointment. Prior research has found that patient-generated data prepares patients for questions and conversations in face-to-face and remote provider appointments [1, 2, 32]. If a system could support patient annotation before or between appointments, it might help providers understand a patient's goals and what questions they have for the appointment, thereby allowing the provider to efficiently prepare [11]. Future work should further explore opportunities and challenges with longitudinal data.

We designed our visualizations to support independent use by a patient or provider as well as synchronous, co-located use by a patient-provider pair. We did not design or evaluate our visualizations for use in asynchronous or remote synchronous collaboration. Additional features may help support effective asynchronous collaboration, such as support for common ground and awareness suggested by Heer and Agrawala [22] or digital traces suggested by Trainer et al. [53]. Future research should develop and evaluate such additional enhancements.

Providing Understandable and Actionable Information

The visualizations sometimes lacked necessary context for interpretation. For example, five patients (*P5*, *P7*, *P8*, *P9*, *P10*) and one provider (*R10*) mentioned not knowing exactly what certain nutrients were. This confusion was exacerbated when participants forgot the data was based entirely on the patient's diet. *R10* was confused because the visualization indicated that coffee had a large amount of soluble fiber, which *R10* knew was false. However, *P10*

consumed little dietary fiber. The visualization indicated that coffee was *High* in soluble fiber only relative to that patient's diet, not relative to any absolute notion of a large amount at the population-level.

Similarly, we have reported that *P7* was confused about the role fat played in her symptoms. If she understood that she tended to feel better when she ate meals that were *relatively* high in fat, that information might help her liberalize her diet (e.g., trying meals with slightly higher fat to see whether she continues to avoid symptoms). Even if *P7* did not want to experiment, better conveying the context for these analyses would prevent confusion over an indication that she tended to feel better with higher-fat meals. Providing the context necessary for interpretation is important for all data visualizations, and is particularly important for designing systems that are intended to provide actionable information.

Actionable insights are a common goal of patient-provider collaboration, so supporting the translation of results into action is essential. However, with data as complex as that considered here, designers should resist the temptation to jump from summaries and recommendations to automated plan generation. Three providers (*R6*, *R7*, *R10*) and two patients (*P5*, *P8*) wanted the system to tell them exactly what foods the patient should avoid. *R10* expressed a desire for the system *"to be smarter than a human and come up with its own recommendations … which it could be, because it's a computer"*. Unfortunately, determining exactly what foods are causing an individual's IBS symptoms is beyond the scope of what can be done with food and symptom journals of the type considered in this work (e.g., due to concerns for correlations and confounds). We did not want the presentation of an analysis to imply greater confidence than is warranted, but instead focused on using analyses to scaffold exploratory visualizations. Patients and providers can then collaborate in applying their knowledge and expertise to interpret the data.

One approach to actionability in the face of uncertain results is to support hypothesis testing with self-experimentation [25]. IBS management is a long-term process that often involves iterative hypothesis formation and testing, as well as changes in the habits and goals of the patients [33]. Our visualizations provide support for identifying potential relationships between nutrients the patient eats and their subsequent symptoms. Utilizing self-experimentation for hypothesis testing would then provide actionable next steps for patients to determine whether dietary changes based on these relationships will help with the long-term management of their symptoms.

CONCLUSION

Building upon prior research in supporting patient-provider collaboration, we developed two visualizations to support patients with IBS and their providers in collaboratively identifying individual symptom triggers. We designed the visualizations to be both actionable and exploratory, allowing patients and providers to collaboratively apply their knowledge and expertise in interpreting the visualizations to reflect, negotiate, and make treatment decisions. We found that collaborative review helps both patients and providers better understand patient-generated food and symptom data, supporting mutual trust in their

relationship. We also revealed a need to use such tools beyond a single clinic appointment to support the long-term management of the patient's illness.

Designers of such systems should help healthcare providers understand patient abilities for data interpretation and should support patients and providers through tutorials and other educational support. Tools should also be *flexible* to a range of patient data and experiences. To help patients and providers build confidence in *exploring* the data together, designers should strive to provide *simple* and understandable views of the data, as well as the process of data collection and analysis. Providing more context surrounding patient-generated data can help patients and providers form better interpretations and decisions. Finally, as symptom management is a long-term process, patients and providers need *actionable* support to help them test and adjust their decisions throughout long-term care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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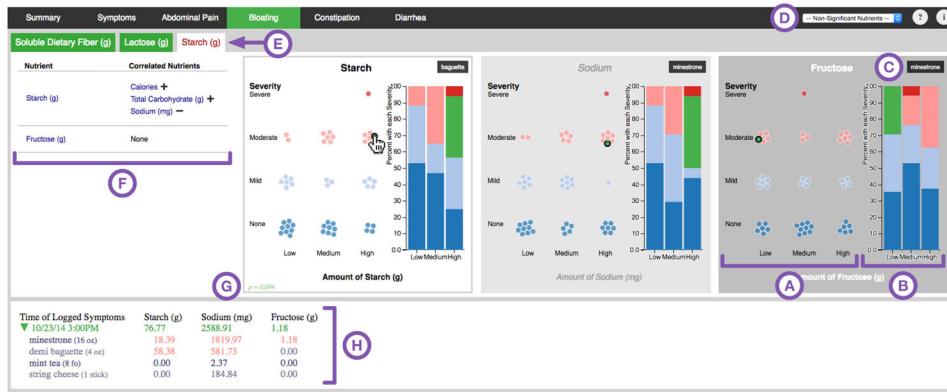
Figure 1.
Each nutrient plot consists of (A) a bubble chart and (B) a bar chart. (C) Hovering over a point shows the food in that meal highest in the nutrient for each plot. (D) Non-significant nutrients (e.g., fructose) can be added from a dropdown. (E) Each significant nutrient for the selected symptom is shown in a separate tab. (F) Nutrients correlated to significant nutrients (e.g., sodium) are shown in a table, from which they can be added to the visualization. (G) The *p* value of the nutrient appears when interacting with the plot. (H) Selecting points displays the food and nutrient information.

Figure 2.
(A) A line corresponds to a single meal in the patient's journal. (B) The user can specify a filter on a variable to only view meals within that range. (C) The axis title shows additional information above (the *p* value on hover) and below (the number of correlated nutrients). Clicking the number of correlated nutrients expands the visualization to include those nutrients. (D) Hovering over a line fades the other lines out and shows annotations of the food in that meal highest in each nutrient, at the appropriate position on the axis for that food and nutrient. (E) The foods and nutrient values for the hovered line are expanded in the food table below the visualization. The other meals correspond to ones within the current filter.
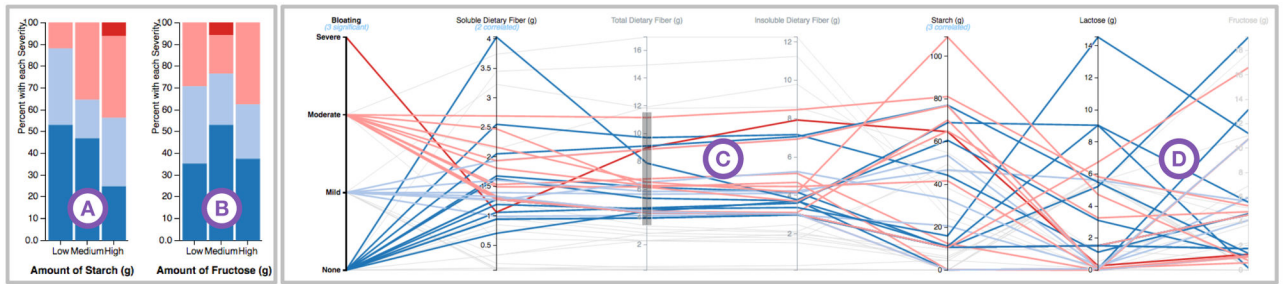
Figure 3.
(A) A nutrient with worsening symptoms in the bar chart: the size of the red bars increases as the nutrient amount increases. (B) A non-significant nutrient does not show a strong trend: the bars are fairly equal for each symptom severity. (C) Correlated variables show mostly parallel lines between the axes in the parallel coordinates visualization. (D) Nutrients without a clear relationship are more jumbled.

Table 1

Demographic information for patients and providers. Each patient-provider pair was a new collaboration.

Participant	Provider			Patient			Analysis Results	
	Gender	Type	Years of Experience	Gender	Age	Years of Symptoms	Symptoms[a]	Nutrients[b]
1	F	Medical Doctor	17	M	35	18	1	1
2	M	Medical Doctor	5	F	43	3	1	2
3	F	Nurse Practitioner	1	F	34	3	3	5
4	M	Medical Doctor	20	M	25	2	0	0
5	M	Medical Doctor	5	F	22	15	2	3
6	M	Medical Doctor	6	F	34	10	1	2
7	F	Dietitian	16	F	30	9	2	4
8	F	Medical Doctor	5	F	33	5	1	2
9	F	Medical Doctor	2	F	46	33	3	7
10	F	Medical Doctor	6	F	32	17	4	8

[a]The number of symptoms with at least one nutrient identified as significantly correlated in our analyses.

[b]The total number of significantly correlated nutrients identified in our analyses (across all symptoms).