
“You Have to Know Your Body!”: The Role of the Body in Influencing the Information Behaviors of People with Type 2 Diabetes

BETH ST. JEAN, GAGAN JINDAL, AND KATHERINE CHAN

ABSTRACT

Although many information behavior studies have investigated the wide array of sources people turn to when they have a health-related information need, very few have looked at the roles played by the body in these processes. Drawing on a mixed-method exploration of the information behaviors of people with type 2 diabetes, this study identifies the important roles played by an individual’s own body (i.e., informant, motivator, demotivator, and barrier) and by the bodies of other people with diabetes (i.e., comrades/mentors, role models, galvanizers, inhibitors, inspirations, and potential mentees). One of the most significant findings is that a person’s own body and the bodies of others with diabetes can fuel incognizance (an enduring unawareness that one has a particular information need), information avoidance, and information nonuse; however, they also can interrupt incognizance, illuminating information needs and motivating information seeking and use. We propose a novel model of body-related information behavior and discuss the possibility that body-related information behaviors may not only affect an individual’s health trajectory but also reinforce health disparities within disadvantaged communities. In conclusion, we recommend strategies for ensuring everyone has optimal opportunities to benefit from body-related information behaviors and to live a long and healthy life.

INTRODUCTION

The burgeoning area of consumer health information behavior (CHIB) encompasses people’s health-related information needs as well as the ac-

tivities they engage in (or not) to look for and use this information. CHIB is important as it has been found to influence people's ability to cope with an illness (e.g., Ankem 2006), normalize their situation (Genuis and Bronstein 2017), and make informed decisions (e.g., Clark 2005), and to even impact their ultimate health outcomes (Longo et al. 2010). Although many CHIB studies have investigated the diverse set of information sources people draw on when faced with a potential or actual illness, very few such studies mention the important roles played by the body in people's health-related information behaviors. Body-related information behaviors encompass both learning from one's own body and learning by observing other people's bodies and hearing about their experiences. Such learning can enable people to overcome incognizance (St. Jean 2012, 2017); that is, it can help them to develop an awareness of a budding need for information and provide critical clues that enable them to specify and articulate that need. Furthermore, it can motivate, inform, and sustain (and, at times, demotivate, impede, or interrupt) their information seeking and use.

Although body-related information behavior appears to be largely absent from the library and information studies literature, several forms of this type of information behavior have been identified in related literatures (such as nursing and psychology), including body listening, self-monitoring, and observational learning. Each of these is explored in more detail in the literature review section below. As body listening and observational learning frequently impact people's health behaviors, they are likely important contributors to people's long-term health trajectories and ultimate health outcomes. Furthermore, as much observational learning is limited to those whom one observes (and relates to) within one's everyday life, it is possible that body-related information behaviors may reinforce health disparities in communities that are already facing severe health inequities. Body-related information behaviors, therefore, can obstruct the path toward health justice, an ideal state in which everyone is recognized and supported as an individual who is morally entitled to "a sufficient and equitable capability to be healthy" (Venkatapuram 2011, 20).

This paper draws on data collected during a mixed-method investigation into the information behaviors of thirty-four adults with type 2 diabetes to investigate the following research questions: (1) What are the roles of a person's own body in their diabetes-related information behavior?; and (2) What are the roles of other people's bodies and experiences in an individual's diabetes-related information behavior? Through their responses to questionnaires, semistructured interviews, card-sorting exercises, and a timeline construction activity, participants described how listening to their own bodies, as well as observing other people's bodies and hearing about their experiences with type 2 diabetes, brought them awareness of

previously unknown information needs and motivated, demotivated, or impeded their diabetes-related information seeking and use.

The metatheoretical position underlying this investigation is social constructivism (Talja, Tuominen, and Savolainen 2005), which recognizes the social influences on a person's mind as they construct their own reality. However, information behavior is shaped not only by external social influences but also by one's own body (Cox, Griffin, and Hartel 2017; Lloyd 2010; Lueg 2015). As Lueg (2015, 2706) describes, "Information needs may emerge (and be resolved) in the situated, embodied interaction with one's environment." In fact, to derive a full picture of an individual's information behavior requires examining many types of factors, including cognitive, physical, affective, and social ones, all of which are intertwined and tend to drive and be driven by one another (St. Jean 2012). Social constructivism was deemed the best fit for this study as type 2 diabetes is a very social disease—for better (e.g., receiving advice and support from fellow sufferers) and for worse (e.g., experiencing stigma and feeling blamed for developing diabetes) (Bossy et al. 2017; St. Jean 2012, 2017). As there is a strong genetic component, there are frequently multiple people within a family dealing with this disease. Also, diabetes is increasingly prevalent—currently, 12 percent of U.S. adults (aged 20 and up) have diabetes, and 37 percent have pre-diabetes (CDC/NCCDPHP 2014), and it is projected that by 2050, 1 in 3 adults will have diabetes (CDC 2010)—meaning that many people also know and interact daily with nonfamily members who have this disease. Furthermore, the society in which we live tends to model and facilitate poor health behaviors that contribute to the development of this disease. Positive health behaviors, in comparison, are less frequently modeled, and people often encounter barriers in adopting and persisting at them.

In the remainder of this paper, we first review literature from various disciplines that focuses on different types of body-related information behaviors, including body listening, self-monitoring, and observational learning. Next, we outline the methods we used for this study, and then draw on our data to address the aforementioned research questions, focusing on identifying the various roles played by the body in participants' information behaviors. We then summarize our findings and propose a novel model of body-related information behavior. In conclusion, we discuss the potential roles that body-related information behaviors may play not only in an individual's health trajectory but also in the potential reinforcement of health disparities within disadvantaged communities and the lack of health justice in this country. We also offer recommendations for working toward ensuring optimal opportunities for all to benefit from our natural human proclivity to engage in both own- and other-body-related information behaviors and to live long and healthy lives.

LITERATURE REVIEW

Learning from One's Own Body: Body Listening and Self-Monitoring

Body listening, which Chen (2015, 4) defines as a process in which “patients come to utilize bodily sensations as information, including the learning of triggers and learning to re-interpret their bodily sensations,” can be an important self-management technique for individuals with chronic conditions. In both body listening and self-monitoring (Chen 2015; Paterson and Sloan 1994; Paterson and Thorne 2000; Paterson, Thorne, and Dewis 1998; Price 1993; Song and Lipman 2008; Wilde and Garvin 2007), people pay close attention to their own bodies so they can promptly perceive (and, ideally, act on) any signals. Chen (2015), for example, described how her participants learned over time to distinguish fibromyalgia pain from other types of pain, enabling them to determine the best pain management strategies and how to communicate their pain to their providers. Within the context of learning diabetes self-management, this body-centered information behavior was found to occur in later stages—people gradually advanced from relying on external sources of information to relying on information they obtained from their own bodies (Price 1993).

Body listening allows patients to take control and actively manage their condition(s) in partnership with their providers, rather than becoming merely passive recipients of clinical care. In one study (Paterson and Sloan 1994), individuals with type 1 diabetes explained how they made a conscious decision to take control of their condition and then developed strategies to maintain control over their own bodies. Specifically, participants began to know their body by becoming aware of specific cues. “Knowing the body,” in parallel with other self-care management strategies, allowed patients to make their own care decisions based on a combination of their knowledge of diabetes management basics, their knowledge about their own body, and their past experiences. In another study (Herre et al. 2016), participants in a diabetes self-management course felt more secure managing their own treatment after receiving practical skill-building training on performing concrete self-monitoring tasks and then connecting the information from their bodies to more theoretical information on diabetes. The insight from this training course gave participants greater confidence to independently assess and manage their condition based on the signals they received from their own bodies.

Body listening can be subjective or objective—patients may learn to listen to their bodies through a subjective awareness of their body by self-monitoring their symptoms and sensations; however, they may also learn to body listen through more objective means, such as through taking measurements (e.g., weight) and keeping a log of their behaviors (Wilde and Garvin 2007). Patients are often limited to strictly measurable, objective

measures in clinical settings, excluding their more subjective experiences. However, Song and Lipman (2008) point out that body listening may be more useful for patients when they are able to incorporate the subjective influences of their cultural context and individual disease experiences. Similarly, participants in another study (Versteeg, te Molder, and Sneider 2017) negotiated the value of scientific knowledge versus knowledge from their own bodies through online forum discussions on topics such as ADHD and aspartame. Participants explained the importance of recognizing the validity of the information and messages they received from their own bodies, even when they are not completely supported by objective, scientific data.

Individuals with a chronic condition may experience a fundamental shift from feeling controlled by their disease to feeling in control over the disease and its impacts on their body. Paterson and Thorne (2000) outlined four critical phases individuals may experience after being diagnosed with diabetes: passive compliance, naïve experimentation, rebellion, and active control. Although not all participants experienced all phases, many did eventually take control of their condition by developing their own expertise on their disease and became confident they could manage their diabetes through body listening and vigilant self-monitoring. Participants described maintaining meticulous records on their self-care activities, blood glucose levels, and other relevant metrics. They monitored their body's reactions to determine the most appropriate regimen for them to manage their diabetes. Paterson and Thorne (2000) emphasize that treating patients as active partners in, not just passive recipients of, their care through "collaborative mutual learning" (417) could be highly beneficial for patients who have a chronic condition.

Critical to long-term success in diabetes self-management is achieving a balance between focusing on diabetes management requirements and leading a "normal" life (Paterson, Thorne, and Dewis 1998). In their ethnographic meta-analysis of qualitative studies exploring people's lived experiences with diabetes, these authors found that many participants repeatedly adjusted their prescribed regimen until they discovered the most appropriate self-care techniques for them. These authors point out that while health care providers may assume patients are being "noncompliant" during these periods of discovery, patients are often actually performing an intricate balancing act in which they are drawing on their knowledge about diabetes and the information they've received from their bodies to identify and adopt the best strategies for them to take control of the disease. Another study (Gyllensten et al. 2010), which focused on the experiences of patients in psychiatric rehabilitation, posited that a form of body listening called "the embodied identity" (439) and further subcategorized as "living in the body" (439) could actually help individuals

learn to recognize tension signals and prevent the tension from progressing to pain through a perceptive awareness of their bodies' signals in the present moment.

Learning from Other Peoples' Bodies and Behaviors

Body-related information behaviors often also extend beyond people's own bodies. Social Cognitive Theory (SCT), an expansion upon Miller and Dollard's (1941) Social Learning Theory, examines the interplay between personal, behavioral, and environmental influences on human behavior, emphasizing the continual mutual interaction of these influences on one another (Bandura 1971, 1977, 2002; McAlister, Perry, and Parcel 2008). Observational learning, self-efficacy, and self-regulation are major concepts from SCT relevant to this paper.

Observational learning. Through observational learning, people learn by observing the experiences of others, particularly those of family members and friends. Bandura (2002) described how people verify their own thinking by observing others in their environment and the results that their behaviors produce. Observing other people's behaviors, as well as the positive or negative consequences of these behaviors on their bodies and their resultant quality of life, has been found to motivate (or, in some cases, demotivate or impede) health behavior change (Newton, Asimakopoulou, and Scambler 2015; St. Jean 2012, 2017). Newton, Asimakopoulou, and Scambler (2015) described how participants who had observed others with type 2 diabetes were especially motivated to manage their type 2 diabetes due to concern about the potential negative health consequences of this disease. Rabin and Pinto (2006) and Walter and Emery (2005, 2006) similarly found that having a family member with a chronic illness influences people's risk perceptions and their decisions to enact health behavior changes.

Friends and family members with the same chronic illness can serve as an important resource for informational and emotional support (Bernhard et al. 2017). Gallant, Spitze, and Prochaska (2007) found that people felt they benefitted from the understanding that came from others with similar health conditions, as it made it easier for them to adhere to their chronic disease-related regimens. Drawing on their interviews with diabetes patients, Johansson et al. (2016, 7) concluded that "learning is supported through the exchange of experience, and the reflection over it, and how others' experiences can be understood in relation to one's own experiences." However, sharing one's own experiences and observing or listening to others' experiences can sometimes prove problematic. St. Jean (2012, 2017), for example, found that while these processes frequently motivate information seeking and use in people with type 2 diabetes, they may sometimes demotivate individuals who may observe or hear about

experiences they find frightening and upsetting. Clark (2005) reached a similar finding regarding members of breast cancer support groups.

Self-efficacy. In addition to observational learning, an individual's beliefs about their ability to succeed influence their behavior. In particular, a person's level of self-efficacy (one's beliefs about one's ability to perform behaviors that will lead to desired outcomes) influences their chronic disease management efforts (Bandura 1977; McAlister, Perry, and Parcel 2008). Observing the impacts of a chronic illness on other people can impact an individual's self-efficacy with regard to their own ability to manage the illness. Walter and Emery (2006) found that seeing family members affected by a chronic illness can impact an individual's belief in their own potential for success regarding their disease management efforts.

Self-regulation. The concept of self-regulation is very closely related to the concept of self-management in relation to chronic disease and is defined as motivating and guiding one's actions through setting goals, receiving feedback, rewarding and teaching oneself, and mobilizing skills and resources (including social support) to fulfill one's goals (Bandura 1971; McAlister, Perry, and Parcel 2008). Information needs and the timing of information delivery can also act as an important prompt for self-regulation. St. Jean (2017) described people with type 2 diabetes who experienced a mismatch between when diabetes-related information was needed, when it was delivered, when it was understood to be significant, and when it was actually acted upon. These mismatches in timing engendered and sustained incognizance, limiting the potential usefulness of information and hindering some individuals' abilities to self-regulate before they developed diabetes-related complications. Technology can help to facilitate self-regulation in individuals with diabetes. For example, Johansson et al. (2016) described how self-monitoring of blood glucose levels gives individuals a sense of safety and control and provides them with an opportunity to adjust their treatment based on their own personal situation.

In summary, people gather health-related information from their own bodies through processes such as body listening and self-monitoring. They also gather information from other people's bodies and experiences through processes such as observational learning. This paper describes a study that investigated the information behaviors of thirty-four people who have type 2 diabetes, with a particular focus on the specific roles played by these individuals' own bodies, as well as by the bodies and experiences of other people with type 2 diabetes, in their information behaviors.

METHODS

A mixed-method study was conducted to learn about the experiences of people with type 2 diabetes, particularly their health-related information

needs and seeking practices, their perceptions regarding the usefulness of different sources of health information, and the types of factors that motivate, demotivate, or impede their health-related information seeking and use. Two interview sessions were conducted with each participant, spaced four to six months apart.

Recruitment

Participants were recruited in three ways: (1) An online ad was posted on a university clinical and health research website; (2) Flyers advertising the study were posted at a university hospital and associated health clinics; and (3) Flyers were distributed at local diabetes-related support group meetings. Participants had to be at least 18 and had to have received their initial type 2 diabetes diagnosis and/or experienced some type of exacerbation (such as being put on insulin or developing a diabetes-related complication) within the past year. Participants were paid a cash incentive of \$40 for the initial session and \$50 for the follow-up session.

Data Collection

Several methods were used to collect data from participants at each of the two sessions. At the initial session, participants were first informed about the study and asked to sign a consent form. Next, a background questionnaire (largely multiple-choice format) was administered to collect demographic information, as well as information about the participant's computer/internet access and use, type 2 diabetes diagnosis date, and any diabetes-related classes and/or support groups they had attended. Next, a semistructured interview was conducted to learn about the participant's experience with type 2 diabetes, particularly his/her diabetes-related information needs, seeking, and use. An adapted version of Dervin's (1992, 2003) Micro-Moment Time-Line Interview technique was used to conduct these interviews—information was sought regarding the participant's information behaviors during the prediagnosis period, the diagnosis process itself, and the postdiagnosis period. Sample interview questions include the following: (1) If your friend or family member were to tell you that he/she was recently diagnosed with diabetes, what would you tell him/her?; (2) Looking back, is there anything you know now that you wish you had known when you were diagnosed?; and (3) Can you recall any particular time after you were diagnosed when you tried to find out more about diabetes? If so, could you please walk me through what you did? Lastly, participants were engaged in a series of card-sorting exercises, eliciting their judgements regarding the relative usefulness of diabetes-related information from a variety of sources, including people (e.g., doctors, librarians, family members who have diabetes), media types (e.g., internet, television, radio), and internet site types (e.g., medical websites, search engines, blogs). Within each deck, "Other" cards were supplied so

participants could write in and rate responses other than those explicitly provided.

The second interview session began with a semistructured interview, which focused on any changes in participants' experiences with diabetes since the last interview session, as well as their diabetes-related information needs, seeking, and use. Next, participants were asked to think aloud as they indicated on a timeline any important points they had experienced along their journey with diabetes. They were asked to include about ten different events, placing positive ones above the timeline and negative ones below the timeline. Participants were provided with a list of the types of events they might like to include, such as received test results and experienced a turning point, but they were encouraged to include anything they felt was important. In closing, the same card-sorting exercises were readministered to gather participants' updated perceptions.

Data Analysis

Interview sessions were audio-recorded in their entirety. Transcriptions were prepared and imported into NVivo for qualitative data analysis. The data from the questionnaires and card-sorting exercises were entered into Excel and imported into SPSS for quantitative analysis. Two structural codebooks were derived deductively from the structure of the two interview sessions and the associated protocols. A thematic codebook was derived deductively (based on a review of the relevant literature and on the interview protocols), as well as inductively (based on all data provided by participants). The thematic codebook was iteratively revised as data collection and analysis progressed. This paper focuses, in particular, on the following thematic codes that naturally emerged from the data: (1) "Learning from one's own body and experiences" and (2) "Learning from others' experiences." Through inductive analysis of the data gathered across both sessions through the background questionnaires, interviews, card-sorting exercises, and the timeline activity, we identified four roles that participants described their own bodies playing and six roles that participants described the bodies and experiences of other people playing. The results section below has been organized around these roles.

Participants

A total of thirty-four people participated in an initial interview session, and all but two completed a follow-up interview session (one had passed away, and one became too ill to participate). Twenty women (59%) and fourteen men (41%) aged 32 to 81 participated (Table 1). The average age of participants was 53.4 ($SD = 10.6$), with most ($n = 29$; 85%) falling between 40 and 69. With regard to educational attainment (Table 2), half had completed some college or less, while the other half had at least a college degree (including associate's). Most participants were employed

(n = 12; 35%), disabled (n = 10; 29%), or retired (n = 8, 24%); however, four (12%) were unemployed (Table 3). More than three-quarters (n = 26; 76%) had a computer and internet access at home, and only five (15%) participants indicated that they do not use the internet at all. Among the participants who did use the internet, however, not all used it in relation to diabetes. Although 80% (n = 16) of the twenty participants in their 50s and 60s reported using the internet, only half (n = 8) of them had ever used the internet in relation to diabetes.

Table 1. Distribution of Participants by Gender and Age

Age	Men		Women		Total	
	n	%	n	%	n	%
30–39	2	6%	1	3%	3	9%
40–49	2	6%	7	21%	9	27%
50–59	7	21%	5	15%	12	35%
60–69	2	6%	6	18%	8	24%
70–79	0	0%	1	3%	1	3%
80–89	1	3%	0	0%	1	3%
Total	14	41%	20	59%	34	100%

Table 2. Distribution of Participants by Educational Attainment

Educational Attainment Level	n	%
Some high school	3	9%
High school graduate or GED	3	9%
Some college	11	32%
College degree (including Associate's)	5	15%
Some graduate or professional school	2	6%
Graduate or professional degree	10	29%
Total	34	100%

Table 3. Distribution of Participants by Employment Status

Employment Status	n	%
Employed	12	35%
Disabled	10	29%
Retired	8	24%
Unemployed	4	12%
Total	34	100%

RESULTS

RQ1: What are the Roles of a Person's Own Body in Their Diabetes-Related Information Behavior?

Participants described several roles their own bodies played in their diabetes-related information behaviors: (1) Informant; (2) Motivator; (3) Demotivator; and (4) Barrier.

Informant. Many participants described learning from their bodies, stressing the importance of “knowing” and “reading” one’s body. I31 described feeling angry when people told her that she had to know her body. Over time, however, she came to understand: “But now I know what they mean. You have to know what your body can absorb and what it cannot absorb. Now I know my body. I know what I can take and what I can’t take.” I09 similarly stated, “I’m trying to figure out . . . the role of exercise and diabetes management, like how much should I do, how much would be too much. . . . I’ve definitely looked for a lot of information on that. And then I sort of read my body and think about all the stuff that I’m taking in and think about what feels safe and healthy.” Some participants, however, felt that their health care providers didn’t believe their statements about their own bodies and/or didn’t value their knowledge about their own bodies. I01 stated, “The doctor said, ‘You must not be drinking enough water, you’re not eating right, blah, blah, blah.’ . . . I just look at him, he doesn’t believe that I drink . . . a gallon of water every day.” I20 shared, “Those other doctors . . . or even nutritionists and diabetic educators, they look at me, you know, ‘What does she know? She don’t have no letters behind her name.’ So . . . they assume I have no information, but I have more information about me than anybody else does.” She later described that she was more motivated to manage diabetes because her new doctor “gave value to what I had to say about my body.”

Symptoms were a communication tool used by the body. Participants learned through trial and error—engage in a behavior and then watch for symptoms. I31 described, “If you feel a certain way, that lets you know that your diabetes . . . your blood sugar is rising, or if you feel another way, your blood sugar has dropped. And I’ve actually tried some things and my sugar went up. I said, ‘Well, I can’t do that.’ Then I tried the other, my sugar is fine.” Symptoms were an important source of information for many participants, from before diagnosis through their current attempts to manage the disease. I31, for example, described how her initial symptoms of blurred vision, thirst, insatiable hunger, and a lack of energy first alerted her that something was wrong. I28 described feeling sleepy after eating something as an “indication it’s something I shouldn’t be eating or the portion control wasn’t right.”

Sometimes, however, participants did not experience symptoms even though they were, in fact, having a problem, or they did experience symptoms but were incognizant, remaining unaware of the importance and significance of their symptoms. I24 shared, “Some people . . . feel crappy when their sugar is high . . . they know that from their own physiological meter. . . . But, for me, I never know. . . . I don’t really have this real ill-feeling when I am high or any indicator. . . . I do not have that indicator in my body.” I06 explained, “Most people . . . until they’re diagnosed, they have no clue. You don’t understand the symptoms of high blood sugar or

blurry eyes, going to the bathroom. You don't connect to that, you're not a doctor, you know?" Several participants did not learn they had diabetes until they experienced some major diabetes-related complication, such as having a stroke (I06 and I11), going into a diabetic coma (I28), or developing congestive heart failure (I33). The important information that symptoms can provide was not available to these participants, or only became available at a point in time when it could be of less use to them. I29 cautioned: "That's what is so insidious about diabetes because when you have symptoms, for some people, it's kind of like too far down the road."

Participants learned from their bodies through not only their symptoms but also diagnostic tests and their own journals and logs. I22 rated diagnostic tests as very useful because "you can't lie, you can't sugarcoat things. . . . It's there and it's there." I23 said that the A1C test is the "most important thing of all" because "it tells you how you're doing . . . and whether you have to do something else." Many participants talked about learning from their glucometers: "Testing my sugar is really helpful. . . . I had alcoholic cider . . . and my sugar was really high two hours after and really high the next morning. . . . So that was my last cup of cider" (I09). Some participants kept detailed logs of the foods they ate and their blood sugar levels to assess their progress over time: "The journals help me step aside and see myself, see what I'm doing . . . just objectively see how my behaviors are and how they could be impacting my diabetes. . . . I keep a food diary . . . and I keep up with my exercise diary" (I12). I18 similarly stated, "I have a glucometer that keeps track of my numbers. . . . I want to know what the last couple of weeks has been like. Has there been improvement? Has there been a pattern? Is spaghetti night worse than chicken night?" Some participants attributed a decline in their health, at least in part, to a failure to consistently self-track: "At the time, I did not take the medicine . . . I took the medicine but I didn't take a record of it. I figured I'd . . . do like my Uncle did and exercise and eat right, but I didn't do that, see. So that's probably how and why my diabetes progressed to the point where the endocrinologist said, 'You need to start taking insulin'" (I20). I32 similarly explained, "You watch, you learn, you see patterns. . . . Before, they were bad . . . because I wasn't really monitoring enough to make sure that they didn't lead to this. Now I will."

Motivator. Many participants were motivated to look for and/or use diabetes-related information by their symptoms and/or as a result of their fears and/or hopes regarding their bodies. I18 recounted, "The first time I ever felt what a symptom was is I ate a bag of jellybeans and it felt like my whole body locked up. . . . I had way too much sugar in me. . . . That's how I learned my lesson. . . . I haven't had a spoon of sugar, I haven't had a sip of Kool-Aid, regular pop, nothing. . . . The fence only shocks you one time before you realize not to touch it." Fear of complications was frequently

mentioned as a motivator. I06 explained: "Fear of amputation, fear of death, fear of liver/kidney failure . . . fear of going blind. . . . There's just massive motivation once you're diagnosed. . . . Fear motivated me." The hope for better health motivated many participants to look for and use diabetes-related information. I28 said that he looks for diabetes-related information "because I have it . . . and it will affect the quality of life that I have. Even though I have it, I could still have a decent quality of life if I maintain my blood sugar." I29 described his motivation: "finally understanding that if I wanted to live and not only live, but have a quality of life which I could really embrace, I needed to take care of myself."

Demotivator. Some participants felt that their symptoms or their fear of complications decreased their desire to learn about diabetes and to act on this information. I22 explained, "When none of it works and you're taking your insulin, you're following your diet, and you're doing what you're supposed to be doing and your sugar's just going up and your symptoms are getting worse . . . I do not want to know anymore. What good is it going to do me to know any more?" Some participants found fear of complications to be demotivating. I20 stated, "Diabetes, they go talking about amputation and kidney dialysis and all this other stuff. . . . They feed people with all that fear and fear doesn't do anything but paralyze people. . . . Hope is the thing that makes people get up and want to live and live healthily and do things." Another participant (I14), when asked if anything had ever made him not want to learn about diabetes, responded: "I still don't like hearing about amputees . . . I don't like to hear about those tragedies."

Barrier. Although bodies generally facilitate one's information seeking and use, some participants had developed physical problems that impeded their ability to look for or use diabetes-related information. I01, who had both cataracts and glaucoma, wanted information to prove to her doctor that one's blood sugars increase when they're ill. When asked if she might do some research on this topic, she replied, "If my eyes get real well, where I can read more, I probably will." I22 became unable to record her blood glucose levels in her logbook as a result of developing neuropathy in her hands. She explained how her physical and cognitive difficulties have turned her from an active information seeker into a more passive one: "I like to pick up health tips and I'm not much of a reader anymore because my eyes are bothering me and I shake and I can't concentrate or remember what I read. I hate that crap. So that's the way to do it for me, just listen, keep my ears open." She further noted, "My attention span is not really good right now, my eyesight is not really good. I'd rather watch than read it [information about diabetes] . . . watching Discovery Health Channel, anything. For me, I put it in my TiVo so anything that came up on diabetes, I would tape . . . so I could learn about new techniques." Co-

morbidities, such as breast cancer, bipolar disorder, and depression also impeded some participants' health-related information seeking and use at times. I03 explained, "If I was really depressed, I could care less about having diabetes." I35 described her reaction when a mammogram detected a lump in one of her breasts: "I was just like 'Let me deal with one thing at a time.' Let me deal with this diabetes stuff . . . and I'll deal with that [breast lump] later, since I don't feel nothing."

RQ2: What are the Roles of Other People's Bodies and Experiences in an Individual's Diabetes-Related Information Behavior?

Participants described several different roles that other people's bodies and experiences played in their own diabetes-related information behaviors: (1) Comrades and mentors; (2) Role models (both positive and negative); (3) Galvanizers; (4) Inhibitors; (5) Inspirations; and (6) Potential mentees.

Comrades and mentors. Many participants felt a sense of camaraderie with others who had diabetes, and they described sharing their experiences and tips with one another. I04 stated, "You can talk about your experiences and your problems and these people know what you're talking about. They're there. They've done it. They've been through it. And they can say, 'Well, you know, I tried this, why don't you give this a try? It helped me.' . . . It gives you ideas, it gives you help, and it gives you somebody who knows what you're going through to talk to." I06 shared, "Family members who have diabetes . . . very useful. We compare a lot of notes on what we're doing. . . . And then I give suggestions like, 'Well, I went for a long walk.' And then, 'Oh, I didn't know that. I'll try that.'" I03 said hearing about her husband's experiences with diabetes was useful: "Just because he's lived it, he's close to me, understands about me, the information that I get from him, I trust him. Those kinds of things."

Many participants described seeking advice and receiving useful tips from other people who have diabetes. I31 shared, "I'll tell you, my biggest help, talking to people . . . hearing their experiences, trying some of the things that they say they tried." I14 stated, "It's always good to relate [to] . . . people's experience and their strengths and hope . . . because it is off the beaten path what diabetics go through. . . . I think it's always good to see how other people deal with situations. . . . If suddenly you find yourself in that situation, then you're more comfortable with it because someone else got through it. . . . Got over it or got through it." However, a few participants stressed the importance of being able to relate to and understand the other person. I29, for example, stated, "I find testimonials or case studies helpful . . . the relevance . . . makes the difference. . . . I can say, 'Well, I see myself in there. I'm an old man, late 60s . . . I've had diabetes for X many years. So I'm going to pay attention to that man who

has had those characteristics in his diabetes. . . . It helps me relate to the information.” I21 advised, “Pay attention to what other people have to say. It’s just much easier coming from Joe Blow than it is from the guy in a white coat. . . . I’m not saying that the doctors are lying to you, but they give it to you sometimes in such a way that you don’t understand it real crystal clear.”

Role models. Many participants described learning from other people’s bodies and behaviors either through direct observation or by listening to other people share their experiences. Some participants learned what to do based on observing or hearing about others successfully managing the disease. Many more, however, learned what not to do based on observing or hearing about others who were not so successful. Regarding the former, I01 stated, “My friends have really told me what they’ve been through and what they’ve done and what’s helped them and what’s not helped them.” I31 similarly shared, “I think people and personal experiences was the biggest thing . . . because in talking to them, they showed me the ropes . . . to show me what to do.” Regarding the latter, I19 stated, “Friends who have diabetes, yeah, somewhat useful. They generally tend to be worse off than I am, so I know what not to do.” I08 similarly stated, “Well, the only thing I’ve learned from other people that are not family or friends are people who don’t control their diabetes and they are very useful in showing me what you should never do . . . they make huge mistakes.”

Galvanizers. Many participants were motivated to change their behaviors as a result of seeing or hearing about the positive(/negative) consequences of others’ positive(/poor) health behaviors. A few participants recounted how observing others’ positive health behaviors encouraged them to engage in them, as well. For example, I02 described her sister (who also has type 2 diabetes) and her sister’s friend inviting her to walk with them: “They said, ‘Come on [redacted]! Get your shoes on, get your butt down here.’ . . . They got me walking with them.” Many more participants, however, were spurred to action by observing or hearing about people whose poor health behaviors led to devastating consequences. I06 stated, “I know a lot of diabetics that, they start out losing their toe, losing their foot, losing their leg, losing their life. . . . I could [have] care[d] less about foot care, but now I do. . . . I make sure my feet are dried completely when I get out of the shower and I try to watch them for chapping, and keep my toenails . . . Foot care is very important.” I24 similarly shared, “Seeing the impact on people around me . . . That obviously motivates you to control your diet when you see people who’ve lost their eyesight and basically died early because of diabetes.” I09 said she was motivated to learn about diabetes by “watching my relatives’ lack of compliance and their whole complications.” She stated, “From the very beginning, I just

knew I was not going to walk down the road they did because I've seen what can happen to you. . . . They have classic complications."

Inhibitors. Observing or hearing about other people's poor health behaviors and their negative consequences was demotivating to some participants, and sometimes even led them to engage in poor health behaviors themselves. When asked if there was ever anything that made her not want to learn more about diabetes, I25 responded: "Well, certainly when I was first getting diabetes, they often were talking about ulcers, sores that would not heal and I had no particular desire to learn about that." I20 similarly shared:

When someone is diagnosed . . . there's a whole bunch of emotions that flood 'cause you've heard all the stories. You've seen the people who can't see and that's blind because of diabetes. You've seen people . . . walking around, looking half-crazy because of diabetes. . . . You don't want to hear that. . . . You want to hear positive stuff. . . . Lean toward life instead of death. "Do you know how many people have died from diabetes a year?" "No, I don't even care! I don't want to know!"

This participant went on to emphasize, "You want information that's going to tell you how to get better and where to go from here. . . . Okay, yeah, this could happen. Well, what do you do to keep it from happening? . . . You don't want to hear about this person died . . . this person who don't have no legs. Well, you know that's a possibility, but you don't dwell on that. You dwell on how you can get better." For a few participants, observing other people's poor health behaviors led them to engage in them, as well. I21 described his reaction to his diagnosis: "At that point, I figured I'm not going to worry about it, I'll just do it and do it and do it [drink soda] because I had a couple of friends . . . that had sugar, on construction sites, and they had had it for years. And they never did a thing about it and drank beer like a fish every day. And I'm like, 'Well, there ain't nothing wrong with him.' . . . He's had diabetes for 25 years, ain't nothing wrong with him.' So I figured, 'Hell, I'll just keep doing it, too.'"

Inspirations. Many participants described feeling inspired by the stories of other people who have diabetes. I04 described reading stories in magazines like *Diabetes Management*: "You get a lot of good things in those magazines. They also give inspirational stories . . . Halle Berry . . . is a diabetic, type 2 diabetes. And look how she does. . . . There's a couple of people who did the Tour de France . . . bike racing, that are diabetic. And they give these kinds of stories that says, 'Just because you got it, don't mean you can't do it!' And I like that. I enjoy that." I23 similarly spoke of a magazine called *Diabetes Wellness*: "There are some . . . stories by some athletes that are diabetic and still they are able to do world class athletics. And that's sort of inspirational to read . . . those kinds of stories." I20 stated,

“My uncle... he quickly reversed his [diabetes]. . . . He went on the exercise regimen and he started eating right. . . . He changed his status from type 2 diabetes to normal. . . . So that’s right there in front of my eyes. If he can do it, I can do it.”

Potential mentees. When asked what they would tell a family member or friend who had just been diagnosed with diabetes, several participants said that they would share their own experiences. I29 said, “I would share my experience with diabetes if they wanted to hear about it. . . . And then I would try to give them a little hope in saying that this has become a manageable kind of disease that you can work with your body to reduce the impact of the disease.” This participant said that learning about diabetes has “empowered me to offer the advice that comes from my experience to others with diabetes.” I27 suggested offering various clubs: “You could have a club . . . ‘What complication do you have?’ Maybe you have the blind club and the kidney disease club. . . . I think an information place could have, ‘how do you get a handicap sticker?’—all kinds of little things. And you could have the people who have the illness to be your authorities. . . . You sort of gather the people who’ve got the experience and make them feel good inside by having them be the speakers of ‘this is how you do this.’” Three participants (I09, I11, and I33) mentioned that they are looking into becoming Certified Diabetes Educators.

DISCUSSION

Although seldom explicitly mentioned in information-behavior research, the findings from this study provide strong evidence that a person’s own body and the bodies and experiences of others play a central role in the information behaviors of people with type 2 diabetes. A person’s own body plays the roles of informant, motivator, demotivator, and barrier. In the ideal situation, a person “knows” and regularly “reads” their body, learning through trial and error and paying attention to any clues that may be provided by one’s symptoms; however, people are sometimes incognizant, remaining unaware of the significance of their symptoms or not experiencing any symptoms even though they are, in fact, having a problem. A person’s own body also frequently serves as motivator, propelling them to look for and/or make use of diabetes-related information as a result of their symptoms and/or their hopes and fears regarding their bodies. In addition to informing and motivating a person, one’s body can also demotivate and/or impede one’s information behaviors. Experiencing symptoms, as well as fear of developing complications, serves to demotivate some people’s diabetes-related information seeking and use. Physical disabilities, frequently the very ones brought about by diabetes and/or comorbidities, sometimes pose barriers that prevent or constrain health-related information seeking and use.

Other people's bodies also play important roles in the information behaviors of people with type 2 diabetes. Other people with type 2 diabetes serve as comrades and mentors, role models (both positive and negative), galvanizers, inhibitors, inspirations, and as potential mentees. People who share the type 2 diabetes diagnosis frequently feel a sense of camaraderie and share their experiences and diabetes management tips with one another. They also serve as role models, enabling people to learn from their bodies and behaviors through either observation or listening to their stories. Sometimes role models are positive, showing (or teaching) people what they should do to better manage this disease; however, sometimes they are negative, demonstrating what not to do and the consequences that can befall one who engages in (or does not engage in) certain types of behaviors. Other people also serve as galvanizers, motivating an individual to change their behaviors as a result of observing or hearing about such consequences. Sometimes, however, other people can serve as inhibitors to an individual's diabetes-related information seeking and use. For some people, observing or hearing about others' poor health behaviors and their negative consequences is demotivating—dissuading them from looking for and/or applying diabetes-related information and sometimes even leading them to engage in these poor health behaviors, as well. Other people with diabetes also serve as inspirations, empowering and giving hope to people who may not (yet) themselves be ready for the Tour de France. Finally, other people who have diabetes are sometimes viewed as potential mentees—potential beneficiaries of the expertise one has acquired through their own personal journeys with type 2 diabetes.

While some of the findings from this study are reflected in the existing literature, some of them are novel. The body as an informant is mentioned in some previous literature, with other researchers outlining the same process around individuals learning to use their bodies as a critical source of information to consciously identify their bodies' sensations and reactions through both objective and subjective measures (Chen 2015; Song and Lipman 2008; Wilde and Garvin 2007). The importance of "knowing your body," as mentioned by Paterson and Sloan (1994), was also stressed by our participants. Our findings also echo the importance of learning to body listen through trial and error (Paterson, Thorne, and Dewis 1998; Paterson and Thorne 2000; Price 1993). Our participants described trying out various behaviors and consciously observing their bodies' reactions to make adjustments to their prescribed self-management regimen. They also described maintaining logs of their diet, exercise, and blood glucose measurements, as mentioned by Paterson and Thorne (2000). Unfortunately, our participants also encountered difficulties gaining recognition from their providers as "experts" on their own condition in the context of the information they had carefully collected and assessed through body listening, particularly through subjective measures. However, despite these

challenges, the majority of our participants and those in several related studies (Paterson and Sloan 1994; Paterson and Thorne 2000; Paterson, Thorne, and Dewis 1998; Price 1993; Song and Lipman 2008; Versteeg, te Molder, and Sneijder 2017) still report the motivating factors around taking control of their condition through body listening and actively making the decision to take charge of their own health.

Learning from other people's bodies is another theme mentioned in some of the literature that is supported by our findings. Our participants described engaging in observational learning (Bandura 2002)—learning both what to do and what not to do by observing and hearing about the behaviors and experiences of other people who have type 2 diabetes. This observational learning frequently motivated participants to make positive health behavior changes and to try to manage their diabetes, as reported by Rabin and Pinto (2006) and Walter and Emery (2005, 2006); however, at times, it actually demotivated their diabetes-related information seeking and use, as mentioned in Clark (2005) and St. Jean (2012, 2017). Our participants also described feeling a sense of camaraderie and valued sharing tips and experiences with others who have the same health condition as them, as reported by several other researchers (e.g., Gallant, Spitze, and Prochaska 2007; Johansson et al. 2016; Whelan 2007).

In addition to supporting the findings of earlier studies, our investigation also led to some significant novel findings. One of our major findings is that a person's own body and the bodies of other people with type 2 diabetes can sometimes fuel incognizance (an enduring unawareness that one has a particular information need [St. Jean 2012, 2017]), information avoidance, and information nonuse. However, bodies can also disrupt incognizance, signaling to a person that they have an information need and perhaps providing crucial clues that enable them to work toward specifying and articulating the precise nature of that need and propelling them to actively engage in looking for health-related information and to use it to maintain or improve their health.

Our findings also revealed an opportunity to improve the process of body listening for individuals with type 2 diabetes. Participants described learning from their healthcare providers and other sources how to prevent the occurrence of serious symptoms through diet, exercise, and other behavior changes. They also described learning to recognize serious symptoms, such as numbness or difficulty breathing, through body listening, which was also prevalent in the related literature. However, participants did not seem to have a strong understanding of how to use body listening to recognize more subtle symptoms before they led to a critical point such as numbness. Individuals with type 2 diabetes may need additional support from their healthcare providers on learning to discern the points that can lead to serious symptoms through tailored body listening.

Additionally, participants in past studies (Song and Lipman 2008; Wilde

and Garvin 2007) and our participants described the importance of using both subjective and objective measures to listen to their bodies. However, our participants seemed to introduce an interesting new theme related to this point. They described the process of using the subjective and objective data they collected from their bodies as complementary, intertwined information points, rather than just as separate, parallel data. One participant described checking her food logs to assess spikes in blood glucose readings and then determining how to make changes to her diet based on both sets of information. Although this may be a simple process in some cases, individuals with type 2 diabetes may not always make this connection to more abstract forms of information, such as their mood or degree of tiredness. Tracking this kind of subjective information and comparing it directly with their more objective readings may be a more effective way for individuals with type 2 diabetes to learn how to body listen.

Proposed Model of Body-Related Information Behavior

Figure 1 summarizes our findings in terms of the various roles a person's own body, as well as the bodies and experiences of other people who also have type 2 diabetes, play in an individual's health-related information behavior. The dotted arrows drawn between the two spheres indicate that information about the self and one's own personal experiences are often (though not always) shared among people with type 2 diabetes. For example, the information one obtains about their self through body listening may ultimately be shared as advice to other people who also have type 2 diabetes. Similarly, the information gathered through observational learning may ultimately drive an individual to seek information and/or to apply this information to alter their disease trajectory.

Drawing on our findings, we propose a model of body-related information behavior (Figure 2). The two spheres in Figure 2 represent: 1) the self—the individual's own body and experiences and 2) the bodies and experiences of other people with type 2 diabetes. For each sphere, several of the major components of information behavior—information need identification, information seeking, information management, and information use—are depicted in the small circles along the perimeter of the outer circle. The left sphere depicts the roles played by one's own body and experiences, which not only inform them, but also facilitate or impede and motivate or demotivate their identification of their information needs, as well as their information seeking, management, and use. Arrows are not drawn between these components as there seems to be no consistently reliable order between these nor a guarantee that all will occur. The right sphere shows that the bodies and experiences of other people with type 2 diabetes can inform, support, model, galvanize, and inspire, as well as inhibit and demotivate, the information behaviors of the observing (or listening) individual. These two spheres are connected

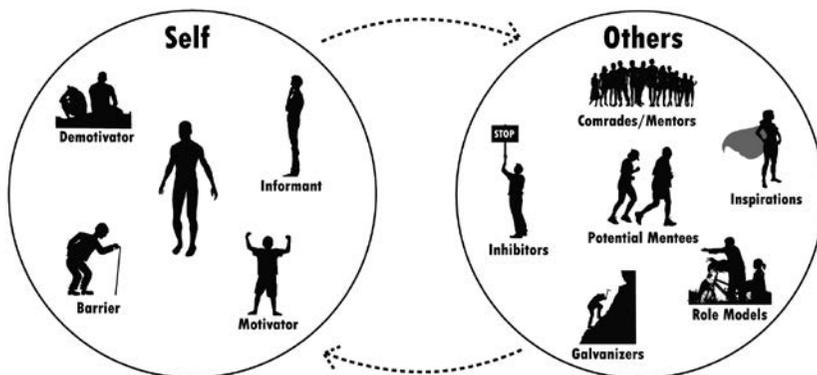


Figure 1. Roles of the Body in the Information Behavior of People with Type 2 Diabetes

as far as the individual and the group share information with one another, experience a sense of camaraderie, and mentor one another.

Limitations

This study has several limitations. First, the findings cannot be generalized beyond our particular set of participants due to the relatively small and biased nature of our sample. Although this study was open to anyone who fit the recruitment criteria, it is very likely that those who chose to participate vary systematically on some central variables of interest, such as how actively they are seeking and/or making use of diabetes-related information. Second, this study relied solely on self-reported data, which

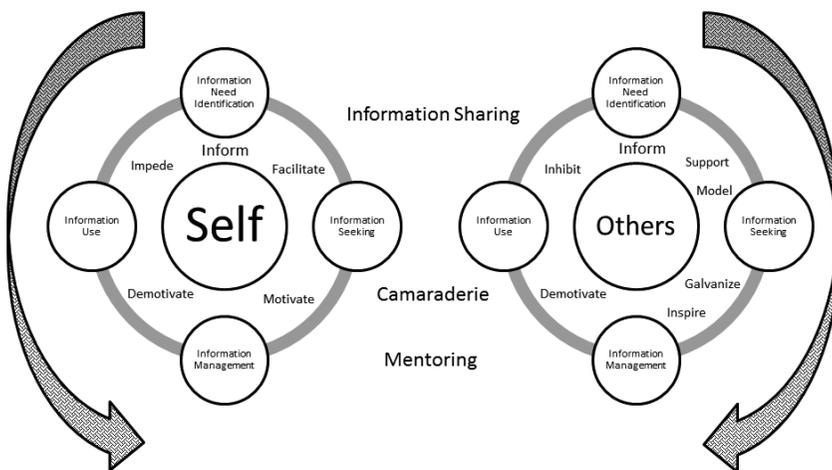


Figure 2. Proposed Model of Body-Related Information Behavior

may be of limited accuracy and comprehensiveness due to factors such as memory limitations and various forms of participant reactivity (e.g., the Hawthorne effect and social desirability bias). Participant reactivity within this study, and in particular the potential benefits that can be brought about by research processes that engender such reactivity, is explored in detail in St. Jean (2013). Mixed methods were used to try to overcome some of the limitations inherent in individual methods. For example, while the interviews enabled the collection of very detailed accounts of participants' thoughts, feelings, and experiences, the card-sorting method proved particularly useful for gathering participants' relative judgements about the usefulness of various types of sources for learning about diabetes. A final limitation of this study pertains specifically to the design of the card-sorting exercises, which were actually what initially alerted us to the centrality of the body in the information behaviors of people who have type 2 diabetes. Through the "Other" cards we provided, we learned that participants learned from themselves and from their bodies, and that they rated the usefulness of these sources quite highly. Similarly, upon asking participants how useful they found "journals" for learning about diabetes, it became clear that most participants were talking not about academic journals, but about their own diaries and logbooks in which they recorded information about their bodies, such as their diet, exercise, and blood glucose readings.

Ideas for Future Research

The fruitfulness of this investigation into the various roles played by one's own body, as well as the bodies of others, in the information behaviors of people with type 2 diabetes suggests that this is an important area for further study. Information behavior research up to this point has largely treated the body, when it has dealt with it at all, in an implicit fashion. However, people do, in fact, view the body (whether implicitly or explicitly) as an information source and as a motivator, and sometimes as a demotivator and barrier, to information seeking and use. Further research is also needed in the area of incognizance. Traditionally, information behavior has been defined as beginning with an awareness that one has an information need, although one may not yet be able to pinpoint or articulate the precise nature of this need (see Belkin's concept of "Anomalous States of Knowledge" [ASK] in Belkin [1980] and in Belkin, Oddy, and Brooks [1982]; and Taylor's [1968] concept of "visceral" information need). However, crucially important information behaviors may (or may not) take place before a person becomes aware that they have a particular information need. Incognizance is both avoidable and remediable, and we need to broaden our definition of information behavior to encompass this earlier state in time. Future studies are needed in order to identify the long-term impacts of incognizance and of having unmet or insufficiently

met information needs on people's health trajectories and ultimate health outcomes. Ideally, such research will lead to the identification of strategies to identify and address incognizance in a timely fashion so that people will have the information they need when it can be of the most use to them.

CONCLUSION

This study has led to the identification of several important roles that a person's own body and that the bodies and experiences of other people with type 2 diabetes play in his/her diabetes-related information behavior. Many information behavior studies overlook the roles of the body and/or fail to recognize that it is inextricably intertwined and just as (perhaps sometimes more) important as the other types of factors (such as affect) we have come to recognize as being important to consider in information behavior studies. However, people fluidly move from source to source, whether doctors, books, the internet, or their own or others' bodies. Their health behaviors drive and inform their information behaviors (e.g., researching why pizza caused their blood sugar to spike), just as their information behaviors drive and inform their health behaviors (e.g., planning a better meal based on their findings from this research).

The present study underscores the importance of recognizing the presence and inextricable enmeshment of the body and the significant roles it may play in one's information behavior. The ways in which these roles play out can influence not only an individual's health-related information behavior but also their health trajectories and their ultimate health outcomes. Participants in this study described learning what to do by observing and listening to the stories of people who were successfully managing this disease; however, far more frequently, they reported learning what not to do by observing and listening to the experiences of people who were not successfully managing this disease and were encountering negative consequences. This finding suggests the possibility that body-related information behaviors may reinforce health disparities within disadvantaged communities, particularly communities in which individuals have lower health literacy levels and less access to important resources, such as medical care, healthy foods, appealing and safe exercise opportunities, sources of credible health information, and other people with type 2 diabetes who are successfully managing the disease. Body-related information behaviors, thus, may play a crucial role in facilitating or impeding health justice. It is imperative that we take action to ensure optimal opportunities for all to benefit from our natural human proclivity to engage in both own- and other-body-related information behaviors. Strategies such as more clearly delineating for people the connections between their everyday health behaviors and their ability to maintain or improve their health and their quality of life, and preventing or combating incognizance by providing newly diagnosed individuals with a mentor who has extensive experience

in successfully managing their diabetes can help us move in the right direction, away from health disparities and toward health justice.

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Beth St. Jean is an assistant professor in the College of Information Studies (<https://ischool.umd.edu/>), the assistant director of the Information Policy and Access Center (iPAC) (<http://ipac.umd.edu/>), and an affiliate faculty member of the Horowitz Center for Health Literacy (<http://sph.umd.edu/center/hchl>), all at the University of Maryland, College Park, USA (<https://www.umd.edu/>). She holds an MLS and a PhD in information from the University of Michigan School of Information (<https://www.si.umich.edu/>). Beth's research aims to improve people's long-term health outlooks by exploring the important interrelationships between their health-related information behaviors, their health literacy, their health-related self-efficacy, and their health behaviors. She has worked with both adults and children, most recently codeveloping the NLM-funded *HackHealth* after-school program (<http://hackhealth.umd.edu/>) to help increase disadvantaged middle-school students' health-related self-efficacy and improve their digital health literacy skills.

Gagan Jindal is a doctoral candidate in the College of Information Studies at the University of Maryland. She holds a Master of Public Health (MPH) in global and community health from George Mason University in Fairfax, Virginia, and a Bachelor of Arts in sociology from the College of William and Mary in Williamsburg, Virginia. Gagan's research interests include the qualitative study of consumer health information behavior, the online information-seeking behaviors of patients with chronic diseases, and patient-generated health information. Her current research focuses on how individuals with chronic diseases find and use online resources to manage their health conditions. More specifically, she investigates how patients and health-care consumers integrate and supplement the information they find online with the information they receive from their healthcare providers, social networks, etc.

Katherine Chan is a graduate of the Master of Library Science program from the University of Maryland. She has a background working in the public health field, social media, and on federal websites as a contractor and federal employee. She received her bachelor's degree in community health from the University of Maryland. She currently works as a librarian for the U.S. National Library of Medicine's (NLM) Web and Information Management Unit, working on web analytics and site search for the main NLM website (www.nlm.nih.gov). Her interests include consumer health information, website analytics and evaluation, and search and discovery of health information online. She can be followed on twitter at @kmchan64.