Interactions between affect, cognition, and information behavior in the context of fibromyalgia

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Abstract
It is widely recognized that affect and cognition can have a profound influence on information behavior. However, how these factors affect information behavior in the context of chronic, stigmatized conditions is less clear. This study employed a qualitative approach to explore the interrelatedness of affect, cognition, and information behavior among persons with fibromyalgia. Persons with fibromyalgia were recruited using multiple recruitment strategies (e.g., listservs and social media) for an interview study. The interview guided participants to tell their story as they drew a timeline. Data were analyzed using qualitative data analysis methods based on the Grounded Theory Methodology. Participants’ narratives illustrated that affect and cognition had diverse effects on participants’ information and health behaviors: uncertainty and negative affect promoted information seeking; affect and information facilitated reconceptualization and self-growth; and online venues facilitated venting, gave rise to validating experiences, and provided opportunities to help others. This study’s findings contribute to extant knowledge by connecting affect, cognition, and action in long-term health management. The study also provides recommendations for practice: a need to focus on practical management strategies in information provision, develop information resources to address the needs of diverse populations, and promote empathy and awareness concerning invisible conditions.

1 | INTRODUCTION

Emotion and cognition can play important roles in people’s interactions with information. For example, Wilson’s (1997) model of information behavior depicts information needs as arising out of a person’s physiological, affective, and cognitive states. Kuhlthau’s Information Search Process (ISP) explains information search as being comprised of three realms of activity—physical (actions taken), affective (feelings experienced), and cognitive (thoughts), occurring over a series of stages (Kuhlthau, 1991, 1993). Emotions are associated with aspects of the information search process; anxiety and uncertainty can provoke searches, and people can have emotional reactions to search results (Lopatovska & Arapakis, 2011). Emotion and perceived relevance following searches can also predict attitudes and behavior, including decision making (Chi et al., 2020; Myrick, 2017).

People may exhibit different tendencies in how they approach information, including avoiding, receiving, asking, seeking, and verifying (Costello & Veinot, 2020). In addition, people’s information behaviors may relate to their perception of health threats. Some may engage in monitoring (attending to, scanning for, or amplification of
threating cues) or blunting (avoidance of threatening cues) (Case et al., 2005; Miller, 1995; Rood et al., 2015). Worry and perceived risk can increase perceived information need, information seeking intent, and information seeking (Kahlor, 2010; Lee & Hawkins, 2016; Van Stee & Yang, 2018). When self-efficacy is low, negative emotions can be inversely associated with information seeking (Lee et al., 2008). However, people can also become aware of the negative emotional consequences of online information seeking and avoid such information (Synnot et al., 2016).

The idea that emotion, cognition, and information behavior are linked is not new. Information seeking and use are inherently situated, and emotion and information behavior vary across time and space (Dervin & Reinhard, 2007). However, there is a need for research examining how they are related in the context of long-term health management. In a longitudinal mixed-methods study of persons with diabetes, St. Jean (2017) observed that affective and cognitive factors both motivated and demotivated information seeking. The number of information needs a cancer survivor has may be inversely associated with mental well-being (Kent et al., 2012). However, even with conditions such as cancer for which substantive research on information seeking exists, much existing evidence is based on cross-sectional studies of patients’ information behaviors at particular points in time (Germen et al., 2015). Thus, there is a need for additional research on affective and cognitive factors in health information behavior in the context of chronic conditions.

2 | FIBROMYALGIA AND INFORMATION BEHAVIOR

Fibromyalgia is a disorder in which people experience a variety of symptoms including chronic widespread pain, stiffness, fatigue, sleep disturbance, cognitive dysfunction, anxiety, and depression (Goldenberg, 2009). The condition is controversial due to a lack of clarity about its etiology (Bellato et al., 2012; Häuser & Wolfe, 2012). Diagnosis is difficult; people often see several healthcare providers over multiple years before receiving a diagnosis of fibromyalgia (Choy et al., 2010), and recommended practices for diagnosis have changed even in recent years (Bellato et al., 2012; Häuser & Wolfe, 2012).

Early criteria for the diagnosis of fibromyalgia were established by the American College of Rheumatology in 1990 (Wolfe et al., 1990). This assessment, involving the counting of “tender points,” was performed differently by healthcare providers; the criteria also overlooked important aspects of the condition such as fatigue, cognitive symptoms, and the extent of somatic symptoms, thus resulting in a revision of the criteria in 2010 (Wolfe et al., 2010). However, diagnosis and assessment of fibromyalgia remain contested due to the diversity of symptoms, the tendency of symptoms to evolve over time, patient and physician interactions, continued difficulties in diagnostic practices, the role of psychosocial factors, and the illusory constructs of the diagnostic criteria (Bidari et al., 2018). Even after diagnosis, treatment of fibromyalgia is a challenge due to significant variability in the symptoms and other conditions persons with fibromyalgia experience (Arnold & Clauw, 2017). Current guidelines recommend a stepwise approach to symptom-based management, as there is no standardized algorithm for treatment selection.

Because the symptoms of fibromyalgia are not clearly visible and there is no clear medical explanation, persons with fibromyalgia often experience disbelief, lack of understanding, discounting and stigmatization by family, coworkers, the healthcare system, and society (Barker, 2008; Kool et al., 2009; Kool et al., 2010). Many come to avoid communication or social contact (Armentor, 2015). Persons with fibromyalgia also face other difficulties, including uncertainty about the meaning of the condition and its effect on their lives (Madden & Sim, 2006). Even after diagnosis, they can continue to experience a lack of understanding and resolution, and struggle to cope and achieve legitimacy (Sim & Madden, 2008).

Those with fibromyalgia experience a variety of information needs along phases of their “illness journey,” which often includes four main features: onset, progression toward diagnosis, acceptance, and development of an effective management strategy (Chen, 2016). They utilize a diverse range of information sources (Bennett et al., 2007), their information needs change over time (Chen, 2012b), and their information use can affect their sense of control, even years later (Chen, 2015). However, despite evidence that negative affect such as anxiety, worry, and fear play a salient role in the lives of persons with fibromyalgia (Ricci et al., 2016; Sallinen et al., 2012), how affect and cognition influence information behavior over the long-term remains unclear, both in relation to fibromyalgia specifically, as well as chronic condition management more broadly. Thus, a qualitative interview study was conducted to examine how affect, cognition, and information behavior are related in the context of fibromyalgia.

3 | METHODS

3.1 | Sample and recruitment

This study employed multiple strategies to recruit participants, including a university listserv, an email contact list from a previous study (Chen, 2012b), online discussion forums, Twitter, and face-to-face support groups. Extant
literature was used to select dimensions for observing a range of behaviors concerning change in health-related information behavior over time: age, illness duration, and social media participation. First, age-related differences exist in the use of coping mechanisms (e.g., Molton et al., 2008). Second, reconceptualization of illness and redefinition of the self are essential to effective coping (e.g., Charmaz, 1991; Mishel, 1999), and pain acceptance is a process of realizations and acknowledgments (LaChapelle et al., 2008). As these phenomena require time, illness duration was included in the sampling strategy. The last dimension was social media participation style. Lurkers, posters, and infrequent posters are terms that have been used in previous research on online communities (e.g., Chen, 2015; Nonnecke et al., 2004; Ridings et al., 2006). The sample included participants who varied in the extent they engaged with social media in the following ways: “nonusers” (no usage at all in terms of reading or writing posts), “lurkers” (reads social media, but does not post or create any content), “infrequent poster” (posts once in a while, but primarily reads), and “frequent poster” (reading and authoring content on a routine basis). A target sample size of 20–30 participants with participant characteristics spread out over the dimensions was set to ensure variability on each of the dimensions. Nonusers and lurkers were considered together as one level of participation style, such that there were three participation levels.

3.2 | Data collection

This study employed semistructured interviews focused on the evolution of participants’ health management and information behavior over time. Almost all interviews were conducted in person. Participants were interviewed either once or twice depending on their engagement with social media and geographic proximity. If participants did not participate in social media or had limited participation, they were generally only interviewed once. If participants lived far away from the researcher, the questions from the second interview were integrated into the first and only interview. Interviews took place at locations selected by participants (e.g., home, restaurant, workplace).

The first interview focused on participant characteristics, health history, information use, and health management. This interview session also included the drawing of a timeline to facilitate participants’ reflections. Participants were asked to verbalize what they were drawing, which can help the researcher understand people’s cognitions as they occur (Jaspers, 2009), and in this case, afforded insight into participants’ perspectives of their past experience. Last, participants were asked to complete the Fibromyalgia Impact Questionnaire—Revised version (FIQR) (Bennett et al., 2009), a general assessment of the impact of fibromyalgia.

The second session was focused on participants’ engagement with social media and other online information. The researcher asked participants who engaged in social media production to provide usernames so that social media content could be included in the study. The researcher wrote code to automatically download content from Facebook, Twitter, Reddit, and other social media platforms. This content was discussed in the interviews, and a portion of the data collected was included in the qualitative data analysis to be described.

A total of 37 interviews were conducted with the 23 participants. The mean total interview time per participant was 2 hr and 26 min; the mean times for the first and second interviews were 1 hr 42 min and 1 hr 11 min, respectively. Participants were not provided incentives to participate. The interviews were recorded and transcribed verbatim prior to analysis. The study protocol was approved by the Institutional Review Board at University of Washington.

3.3 | Data analysis

3.3.1 | Descriptive statistics

Aggregate statistics are reported concerning the sample characteristics, including age, gender, race/ethnicity, education, employment status, and whether or not they received disability. In addition, descriptive statistics concerning participants’ health histories, namely, fibromyalgia onset year, duration, and comorbidities were presented. Illness severity was assessed using the FIQR (Bennett et al., 2009).

3.3.2 | Qualitative analysis

This study involved a qualitative analysis of the interview content and a purposively sampled subset of social media content authored by participants. To protect participant identities, each was assigned an identification number. The 23 participants in the study will be referred to as P05-P27 (the numbers P01-P04 were assigned to pilot participants who were not included in the analysis).

Though Facebook, Twitter, and other forms of social media content were also collected, the social media analysis focused on the health-related discussion forum data because it had the richest content about health management. Because some participants were prolific in their social media content production, a subset of posts were selected that provided a sense of the diversity of each
participant’s social media production. Seven participants had discussion forum data, and the number of artifacts analyzed for each participant ranged from 4 to 20. The posts that participants authored were analyzed in the context of the threads, or discussions, in which posts were embedded. The interview and social media content were analyzed using Atlas.ti qualitative data analysis software (ATLAS.ti, n.d. [Version 8]).

This study employed a qualitative approach to data analysis that draws from constructivist grounded theory and Interpretative Phenomenological Analysis (IPA). This study draws from both IPA and grounded theory in the sense of being concerned with both the meaning of lived experience, as well as social processes. Primary aims of IPA are to depict how participants make sense of their world and produce an interpretive account that situates this depiction in a wider social and cultural context (Larkin et al., 2006; Smith & Osborn, 2008). This focus on meaning and conceptualization of the person as being embedded in a larger context was considered during the code development process.

Grounded theory, originally developed by (Glaser & Strauss, 1967), is used to inductively generate theoretical explanations of social and psychosocial processes (Charmaz, 1990). Grounded theory was employed as the basis for the analytic procedure. Grounded theory begins with line-by-line coding (Charmaz, 2008), then is followed by focused coding, when the researcher selects from the initial codes the ones that make the most analytic sense (Charmaz, 2008). The next step involves raising focused codes to relevant conceptual categories. While raising codes to concepts, the researcher creates an explanation, organization, and representation of the data, taking an active and dialectical stance in shaping conceptual categories (Charmaz, 1990). This process involves constant comparisons (of data with data, category with category, category with data, category with concept, and concept with concept) and continued questioning. This article focuses on themes having to do with affect and cognition that were also related to information and communicative behaviors.

4 | RESULTS

4.1 | Sample

The sample comprised 23 individuals who self-reported that they had fibromyalgia (Table 1). Consistent with previous surveys of fibromyalgia patients in the United States (Bennett et al., 2007; Wolfe et al., 1995), the majority of the sample comprised White women.

There was substantial variability in participants’ ages, symptom onset, and condition severity as measured using the Revised Fibromyalgia Impact Questionnaire (FIQR) (Table 2). The average age was 48.1 years ($SD = 16.0$), and participants had experienced symptoms for 17.7 ($SD = 14.7$) years, on average. For most participants the path to diagnosis was long, involving numerous lab tests and multiple healthcare practitioners. The mean FIQR score was 47.2 ($SD = 14.4$), and the minimum and maximum were 14 and 80 (out of 100), with higher scores indicating greater condition severity.

4.2 | Themes

Four themes emerged that showed how affect, cognition, and information behavior were interwoven in the lives of persons with fibromyalgia: uncertainty, negative affect, and information behavior; affect and information in the reconceptualization of the self and life; online engagement, decreased isolation, and validation; and acceptance and sharing to facilitate understanding.

4.2.1 | Uncertainty, negative affect, and information behavior

In this sample, uncertainty was associated with negative affect, including fear and worry, which in turn was associated with information seeking and online engagement. Early on in their experience of symptoms, participants often worried due to the uncertainty of experiencing pain and not knowing the cause. Over time, the lack of answers heightened concern: “I was scared because I didn’t have any answers, and as time went on, it seemed like the potential for it to be something really serious increased?” (P09) In a Reddit post, P11 expressed her doubts: “How can this not be killing me? For months I was certain that there was no way one could feel this bad and not be dying.”

Prolonged uncertainty in clinical encounters provoked continued frustrations. The gradual elimination of conditions perceived as more severe, such as arthritis or lupus, provoked constant mental re-adjustment. On the one hand, there was relief, but on the other, frustration because participants were no closer to an answer:

I came out of the nerve conduction study and they told me all right, everything looks great, I walked out and my dad was sitting there in the waiting room and I just burst into tears. He goes like, “What happened?”
Frustration with the lack of progress toward a diagnosis and perceived lack of control of their health situation led participants to continue searching for information and solutions. P13 said: “They either thought I was being a hypochondriac or just didn’t believe me at all. So, that was a bit frustrating, but I kept persisting, and tried different doctors…” Fear also led to greater receptivity and trust in information sources than participants might have had otherwise:

I was getting sicker and sicker … I was afraid I was not going to be able to have a career, let alone the personal life that I wanted, and I was really grasping at straws. And I think very, very gullible and susceptible to any and every hoaxy solution … it’s embarrassing for me to say this stuff now, but I had people give me crystals, and be like, “Put this in your window. You’ll feel better!” And I’m like, “Really?” (P19)

As participants made progress in their health management, such as learning food triggers and negotiating successfully with employers for work accommodations, confidence grew incrementally. Participants realized that they “could research and learn and access things that were good for me” (P19). Thus, greater knowledge of fibromyalgia, management strategies, and health in general paved the way for improved management. P26 equated information to hope:

Once you have that knowledge and you have information, then you can equate that to hope … when I asked [my doctor] how long do I have to live, in my mind I had already decided that whatever this was, it certainly had to kill me because I felt so bad, and I
couldn't imagine living a lifetime like that. There was a hopelessness to that, but then there was hope in the information, the knowledge of what it was and then the information of what you actually can do, because it's not like you're sitting here totally subjected to your illness. There are things you can do to help yourself. (P26)

For most participants, progress was painfully arduous and included many episodes of noninformative test results and disbelief. Some participants reached a point where they had had enough with the uncertainty and made decisions to embark upon new directions involving the use of information. For example, P15 said: 

“I was not getting where I wanted to get with the doctors and all that, so I thought, ‘Well, what would you do differently if you had the diagnosis? What would you do differently? ... Whatever that is, you need to start doing it now.’” She started researching and trying health management strategies, such as elimination diets, on her own. Similarly, P22 became fed up with her lack of progress with providers, and made an appointment with a provider that she trusted to break the cycle. She indicated the problem and her monumental step to resolve it by drawing a cyclone on the timeline:

I decide that I’ve had enough of these suggestions from my physicians about what to do ... I have to figure out what’s going to work or not work and what’s wrong because I’m obviously getting no place ... I want to move on. I either want to be better or at least understand what the problem is and what can be done about it, not this holding pattern where everything seems to be just piling up, and we’re getting nowhere ... there’s a lot of confusion, a lot of information coming and going, and nothing is happening. (P22)

Participants’ concerns were not limited to obtaining a diagnosis, but how they could effectively manage their condition and its impacts over the long term and in different aspects of their lives. Some participants were concerned about how they would manage at work: “I didn’t know that my health would enable me to have a job. I was not able to keep up with my work; I was not able to have the life that I wanted to have” (P19). Participants also worried about the future: “there’s times that I’m afraid. Because when I start feeling really bad, I’m like—okay, you can’t go much ... I can’t go up much further for the Lyrica” (P20).

Motivations for information seeking lessened dramatically once fears were alleviated: “The symptoms fit the diagnosis, and while it’s frustrating to have that diagnosis and I don’t like it, and I wish it were something that were curable, I’ve mostly stopped [seeking information], um, because the current treatment regimen is helping” (P09). Over time, participants developed heuristics for judging information, becoming wary of those who promised cures or life-changing solutions: “I don’t trust anyone that’s, like, this will change your life” (P11).

Participants also interacted with others online to express frustrations. P14, who kept a blog on Tumblr, said that for a while she and her husband were having difficulties interacting due to her condition, and then she engaged a lot in online spaces: “I had a lot of frustration with communicating with him about my illness... that provoked a lot of writing on my end.”

Another participant remarked on Reddit, “Make no mistake, I’m not giving up on my life. I have a pretty great one all the venting aside. I just needed to get it out so I wasn’t unnecessarily cranky at the people who are around” (P09).
In summary, participants experienced prolonged uncertainty about their health status and future, frustrations with daily living, and hopelessness. These affects and cognitions were associated with increased information seeking and use. The information that participants encountered eventually led to adoption of health management strategies, greater understanding, or perhaps both. These incremental successes led to greater perceived control and abatement of information seeking. Participants also engaged in online social venues to express their frustrations.

4.2.2 | Affect and information in the reconceptualization of the self and life

As participants came to realize that they could not do all the things that they used to, they experienced disappointment, sadness, and depression. Two key aspects of participants’ reconceptualization process emerged: participants often had to come to terms with their own expectations for themselves and adjust their lifestyles to suit their current health situations.

For some, coming to terms with these expectations included reconceptualization of their identities, and this could be very daunting. For P15, it involved grieving the loss of the “old me.” P05 said: “It was just too overwhelming, and I was just like, I can’t do it. I feel like I’m never going to be able to live some kind of an independent life...” She sought out stories to find out how others had addressed the challenges that she faced: “How are people living with it?”, “What are the stories out there?”, and “What are people doing?” P21 also saw her adjustment as a fundamental reconceptualization of her identity: “Most of my younger life I was very independent, could do whatever I wanted, whenever I wanted, didn’t have to rely on anybody, but I had to let that go...” Information she encountered on her own and at work helped:

I read a lot of books ... I would go to a wellness conference in Wisconsin, it’s a national wellness conference for my job ... [I] just finally came to the realization, well I can be miserable with this mindset or I can just change my mindset. You know, learning how to change and adapt is hard for most people; change is always stressful, but just finally coming to the realization, how do you want to live the rest of your life, like this or do you want to change and adapt and be the best you can and change some of your goals? (P21)

Some participants sought information from others who had similar backgrounds and experienced varying degrees of success. P20 said she would ask if there were others in the military in the online support groups that she visited; she had previously also thought about starting a Facebook group for persons with fibromyalgia. P05 had trouble finding stories of those she perceived as similar. She said of face-to-face support groups: “they were nice, but imagine, they were all... older women. Older White women... we don’t even have a shared experience.” She felt that part of the reason she had not met as many Black women with fibromyalgia was most likely due to differences in the extent to which racial/ethnic groups may speak about the condition: “When it comes to fibromyalgia, I have not met a lot of Black women... I know it has to do with how people perceive and talk about illness. Especially in Black communities... fibromyalgia’s one of those where... how people perceive it... affects how people are going to talk about it.” P27 did not feel that she had trouble connecting with others with the same condition and background, and she affirmed the value of having access to information from those with similar experiences: “being able to share information or just talk about what it’s like to be a person of color diagnosed with fibromyalgia by a medical system, that we’re like slightly distrustful of in general, like that’s been really empowering.”

These participants’ reflections showed that health-related experiences were often associated with sadness and disappointment due to the inability to reconcile their health status with their expectations. Coming to terms with one’s health situation involved reconceptualization, a cognitive act that was highly emotional, and information could play an important part. Participants relied on a variety of different resources, and some felt more satisfied than others in the information that they used.

4.2.3 | Online engagement, decreased isolation, and validation

Interacting with others online provided validation and mitigated the feeling that participants were alone in the challenges they faced. P14 said of online media, particularly the social support she found in Facebook support groups: “I think anybody with chronic illness who uses it would say that it really helps us to not feel so isolated.” Even those who felt supported by family recognized the unique value of empathy by those with similar experiences:

Even just commiserating, saying I understand how you feel and sending you gentle hugs. Cheesy little sentiments like that really
do mean a lot when you’re sitting there miserable or it’s three o’clock in the morning and you can’t sleep and you’re scrolling through Twitter or Instagram and see that other people are up and having the same problem and they’re in pain, too ... My friends and family can say I’m so sorry you’re going through this and I understand what you’re going through, but you don’t. You haven’t had this pain. You haven’t had this fatigue. You haven’t had to say no to all your plans that you’ve been offered in a two-week span. I appreciate the sympathy, but through Twitter and Instagram and Facebook, you get that empathy more. (P24)

Participants experienced this validation whether or not they themselves participated in the discussion. P08, who did not post in discussion forums, remarked, “I will go to either a place where I know I’ll be able to find similar people or read about people’s shared experiences and like, I’m not alone in this.” The feeling of validation might also come from healthcare providers, friends, family, co-workers, and even government entities. P14, who had had social security disability benefits denied several times and then obtained them, spoke of “this amazing sense of joy and like, at least somebody believes me now. Somebody gets it. The government gets it. It wasn’t even really about the money for me, I think it was just about, quit telling me I’m crazy ....”

Thus, these examples showed that participants’ experiences with the condition led to a need for validation. Through various communications in online spaces and otherwise, participants realized that they were not alone and received recognition for their condition, which led to a sense of validation.

4.2.4 | Acceptance and sharing to facilitate understanding

As participants came to understand and accept their health situation, a subset of participants described engaging in acts of disclosure, sharing, or awareness raising to promote understanding among friends, family and others. A few participants shared their stories via email, blogs, or social platforms such as Facebook. P05 said she wanted to become “an advocate for fibromyalgia.” P24 said that on National Fibromyalgia Awareness Day:

I encouraged my friends, my family and my co-workers/coworkers, encouraged everyone to wear purple on that day as awareness ... People kept sending me pictures and so that was really kind of an eye-opener for me, that I can make a difference with this and take something that is awful and has changed my life and try to help maybe change other peoples’ lives in a positive way.

A few participants made efforts to provide useful information to other members in various ways: directing them to forums that would be of use to them, recommending content to read or products to try, or trying to fill in information gaps that others had. P22 tried to provide information and answer questions because “I just feel doctors don’t do a very good job communicating ... people have to be educated and if the doctors aren’t going to do it, somebody’s got to do it ...” There is both empathy and a sense of perspective:

I think that it gives me a better perspective on my own situation because I can look at somebody else and go, “Well, thank God, that isn’t me”—at least not today. It gives me some degree of pleasure to be able to share information and help someone who is really struggling, and I just think it gives me a sense of balance because I can see where other people are at, and I know where I’m at ...” (P22)

In summary, once participants started to feel that they had begun to grasp their health situation, they made various efforts to reach out to others, either in the form of disclosing their condition or to help others who were struggling with it. There was diversity in participants’ approaches. Some reached out primarily to their personal networks via email. Some helped others one-on-one by answering questions on discussion forums, while a few blogged and tweeted about their experiences.

5 | DISCUSSION

This study examined how affect and cognition are related to information behaviors in the context of fibromyalgia. Four main themes were identified: the connections between uncertainty, negative affect, and information behaviors; affect and information in the reconceptualization of the self and life; the role of online engagement in reducing isolation and providing validation, and disclosure of health status to facilitate understanding by others. Affect and cognition were often intertwined and played important roles as triggers, products, and contingencies of information behavior. Emotions were not merely experienced in isolation, but tied
Figure 1 depicts the inter-relatedness of affect, cognition, and information behavior through the lens of Wilson’s conceptualization of the “person-in-context” in information behavior (Wilson, 1999). In Wilson’s model, a person, with their physiological, affective, and cognitive states, is conceptualized as playing a social role while to cognitions.
being embedded in their surrounding environment. This is the context in which information needs arise, and they engage in various information seeking behaviors to satisfy this need, confronting barriers they encounter. Figure 1 illustrates, for each of the themes reported in this study, the interplay between affect, cognition, and behavior within the frame of the affective and cognitive states of this person-in-context.

Extant literature in information behavior has shown that affective, cognition, and behavior can both influence as well as result from searches for information (Lopatovska & Arapakis, 2011; Myrick, 2017), and moreover, that they can be associated with information seeking more broadly (Kuhlthau, 1991). This study expands on our understanding by analyzing the interplay of affect, cognition, and behavior over a larger time scale and in a health-related context.

Examining Figure 1, we see that in many cases, cognitive and affective states serve as the backdrop or context of subsequent happenings. In addition, in many cases, affective states lead to subsequent information behaviors, notably information seeking or communication with others. The products of information seeking—information—often led to altered cognitive states such as conceptualization, greater perceived control, and acceptance. Uncertainty, acceptance, and validation have been indicated as being both cognitive and affective because each is associated with a cognition that may be tightly coupled with its corresponding affective counterpart.

These findings both support and elaborate on prior studies of the relationships between affect, cognition, and information behavior in health management. Extant research on the questions posed in Yahoo! Answers has observed that negative psychological aspects and symptoms activate information seeking (Park et al., 2020). The findings of the first two themes support and extend Mishel (1999), which argues that uncertainty in chronic conditions spread throughout a person’s life, undermining the meaning that they ascribe to everyday events, and successful coping arises not from eliminating uncertainty, but rather, integrating it into a new worldview. In this study, participants engaged extensively in information seeking due to uncertainty. Eventually, participants’ information seeking abated as they found tenable health management solutions or reconciled themselves to the situation. Similar to Mishel (1999), participants ended up with a drastically different worldview and lifestyle. This study provides insight into the role that information plays in this process. Though not what participants originally envisioned for themselves, participants came to accept the new reality because information facilitated an alternate vision of what life could be. Previous literature has also observed that people who experience health disruptions experience a breakdown in their sense of normalcy, which can be replaced by a socially constructed new normal through interactions with others with similar experiences (Genuis & Bronstein, 2017).

Though extant literature has reported that information seeking is associated with increased knowledge and decreased worry (Lee & Hawkins, 2016), others have observed that information does not always lead to uncertainty reduction (Brashers & Hogan, 2013), and this was the case here. In this study, participants generally experienced a prolonged period of uncertainty—first, in the uncertainty of the diagnosis, and even after diagnosis, in terms of symptom management. This may be partly due to the lack of a standard treatment protocol for fibromyalgia; current treatment guidelines call for individualized treatment based on patient symptoms, comorbid conditions, and prior response to therapy (Arnold & Clauw, 2017).

In this study, the information that participants encountered eventually led to increases in their sense of control through the mechanism of self-efficacy, or confidence that they would be able to manage their condition effectively. Thus, while understanding the nature of one’s condition may be important, providing people solutions can perhaps be even more so—to help them see a way forward. Multiple types of information may be helpful. On the one hand, concrete how-to information can help them address day-to-day health management issues. On the other hand, information addressing higher level questions such as the conceptualization of self can also be crucial.

The third and fourth themes focused on online interactions in the context of affective and cognitive aspects of long-term health management. The sense of invalidation that participants experienced was salient. Lack of understanding and disbelief has been widely reported in the context of fibromyalgia (Armentor, 2015; Barker, 2008; Kool et al., 2009). In the face of invalidation, online interactions and positive interactions with the government systems such as the approval of disability benefits took on an additional significance as a form of validation. Thus, affective factors in information and communicative behaviors may perhaps be particularly salient due to the nature of fibromyalgia as a stigmatized condition.

There is considerable literature on the role that online support groups play in long-term health management. Online support groups can be an invaluable resource to those with chronic conditions by providing information and facilitating collaborative problem solving about day-to-day condition management (Chen, 2012a; Huh & Ackerman, 2012). They can be associated with various empowering outcomes, including feeling more informed, and increased acceptance, confidence, optimism, self-esteem, and social well-being (Bartlett & Coulson, 2011).
Those who experience stigmatized conditions are able to discuss their experiences while remaining anonymous (Allen et al., 2016). Online communities can also facilitate illness-related identity work, social support and connectivity, and collective voice and mobilization (Kingod et al., 2017).

This study provides further insight into the functions that online support groups serve in the context of a stigmatized condition such as fibromyalgia. Given its status, many choose not to disclose or discuss it. As such, people may be unaware of others with the condition, and miss out on opportunities for information exchange and support. Online communities can partially compensate for this missed interaction and fill gaps even for those who have strong offline support networks by providing empathy for participants’ health-related experiences. Participants seemed particularly cognizant of the societal need for greater awareness and understanding of the condition. A few expressed an interest in doing their part to promote this awareness by sharing with their social circles and sought opportunities to participate in larger efforts, but this enthusiasm did not appear to result in a larger impact due to a lack of awareness of efforts that they could contribute to. If efforts to channel these energies through volunteering and/or writing were developed and made available on a larger scale, these programs could improve both public and individual experiences of fibromyalgia.

5.1 Implications for practice

The findings of this study suggest that there are leverage points through which information could play a role in mitigating challenges that persons with fibromyalgia face. First, participants experienced negative affect, including frustration and hopelessness; they were able to improve their situations incrementally through the use of practical symptom management information. Presenting information directly, in the form of strategies to solve concrete problems, could increase self-efficacy and mitigate frustration. Participants’ needs were pragmatic—and after a certain point, they simply wanted to “get on with life”; their information seeking revolved around finding ways to do that. Clarity of information presentation could also be important for persons with fibromyalgia because the complexity of symptoms makes it difficult to make sense of them and develop a coherent health management strategy (Chen, 2016).

Second, with regard to “invisible” conditions, there is a need to increase felt empathy and resonance, both in information intended to help people with health management, and in our information environment. There were times when participants perceived a need for information from those who shared their background and experiences, but experienced varying degrees of success in their searches. There is a need to develop online information resources that include diverse voices and perspectives. In addition, some study participants developed an interest in helping others. Connecting the desire to help to this need could be synergistic.

Lastly, though there is awareness in extant literature of the invalidation that persons with “invisible” conditions face, there is a need to for broader societal awareness and development of a more empathetic environment. Efforts to facilitate this could take multiple forms, including media campaigns to promote awareness, as well as policy-level changes, which not only provide structural support, but also recognition, of the challenges faced.

5.2 Limitations and future directions

This study had a number of limitations. First, this study employed retrospective recall. There may have been instances in which participants’ recollections were not accurate, and their view of events may also have changed over time. Second, the sample size was limited and primarily comprised White women with a high level of education. As such, the phenomena observed may not reflect those experienced by persons with fibromyalgia of different genders, racial/ethnic background, and education level, and there is a need for additional research to understand how affect and cognition may affect information behaviors in a more diverse sample.

This study raises questions concerning the role of fear or worry in the assessment and use of online health information. Existing models of web credibility assessment consider user characteristics including demographics, user involvement, and technology proficiency (Choi & Stvilia, 2015), fear promotes the acceptance of persuasive messages (Meijnders et al., 2001), and laboratory experiments have shown mood can affect judgment of information (Zhang & Jansen, 2009). However, there is limited research on the influence that health-related anxiety can have on a person’s assessment of, intention to act upon, and actual use of, health information.

In the context of management of chronic conditions, patients can develop their own ways of assessing information about complementary and integrative therapies (Chen et al., 2020). Though there is value in patient-generated discussion (Chen, 2012a; Hartzler & Pratt, 2011), we are also increasingly aware of the potential danger of misinformation (Wang et al., 2019). Given these concerns, additional research to understand how affect and
cognitions influence information processing and use is particularly important.

6 | CONCLUSION

This study employed a qualitative approach to explore the influence of affect and cognition in information behaviors among persons with fibromyalgia. Participants’ narratives illustrated the two were often intertwined and had diverse effects on participants’ information behaviors. Uncertainty and negative affect such as fear and worry promoted information seeking; disappointment prompted information seeking and use; the cognitive process of reconceptualization, and ultimately, acceptance; and online venues facilitated venting, gave rise to validating experiences, and provided opportunities for people to reach out to others. The findings of this study contribute to extant knowledge by connecting affect, cognition, and information behavior in the context of long-term health management. In addition, the study provides recommendations for practice, including a focus on day-to-day symptom management strategies to mitigate negative affect, developing information resources to address the needs of diverse populations, and promoting empathy and awareness concerning invisible conditions such as fibromyalgia.

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