Uncertain and Anxiously Searching for Answers: The Roles of Negative Healthcare Experiences

and Medical Mistrust in Intentions to Seek Information from Online Spaces

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Abstract

While online sources of information, like support groups and wellness influencers, can be beneficial for those seeking additional information about their health conditions, these sources can also contain detrimental information. As misinformation and even conspiracies like QAnon proliferate in wellness discourse, particularly in online support groups and on the accounts of wellness influencers, it becomes increasingly important to understand what may contribute to individuals seeking information from these sources. Based on uncertainty in illness theory and theory of motivated information management, we conducted a cross-sectional survey ($N = 544$) to test the role of negative healthcare experiences and medical mistrust in uncertainty and information seeking from online support groups and wellness influencers across those with chronic and acute health concerns. Results indicated that negative healthcare experiences had an indirect effect on information seeking from both online support groups and wellness influencers. This indirect effect, however, operated through uncertainty anxiety but not uncertainty discrepancy. For those with chronic conditions, the indirect effect also included medical mistrust. Implications and future extensions of the results are discussed.

Keywords: negative healthcare experiences, medical mistrust, uncertainty, information seeking

Uncertain and Anxiously Searching for Answers: The Roles of Negative Healthcare

Experiences and Medical Mistrust in Intentions to Seek Information from Online Spaces

What might prompt a person to ignore medical advice and, instead, resort to unproven advice from the Internet by "doing their own research" (see: Baker, 2022b)? Previous studies have suggested it may be due to a preexisting conspiracy mindset, mistrust of authority, or simply better alignment with their values and beliefs (Astin, 1998; Lamberty & Imhoff, 2018; Lobera & Rogero-García, 2021). However, anecdotal evidence suggests that dismissal by healthcare professionals and other negative healthcare experiences may actually account for information seeking from alternative sources; these connections have been echoed in a recent meta-analysis (Hintz, 2022). Thus, it may be the case that turning to these alternative sources fulfills a desire for decreased uncertainty around medical diagnoses and solutions – certainty that may have been eroded by negative health care experiences and mistrust of the medical establishment. Though these connections may be more pronounced for individuals with chronic and less understood health conditions (e.g., Hintz, 2022), this may be a process that occurs for individuals regardless of health condition. Understanding how negative healthcare experiences may result in medical uncertainty and, in turn, result in an increased willingness to seek online information may provide a more nuanced understanding of what may lead to patients choosing to seek information from online sources, where, along with helpful information, they may encounter mis- and disinformation, in lieu of medical advice.

The current study utilizes the uncertainty in illness theory (Mishel, 1988) and theory of motivated information management (Afifi & Weiner, 2004) to examine the relationships between

negative healthcare experiences, medical mistrust, uncertainty, and information seeking

intentions. In addition to explicitly connecting these theories, we move the literature forward in

three ways. First, we explicitly test negative healthcare experiences and medical mistrust as

contributors to medical uncertainty. Despite qualitative work suggesting the connections between

these concepts, to our knowledge, little to no work has quantitatively, explicitly examined these

relationships. Next, we extend insights from media studies on health information seeking and

answer calls for examinations into the relationships between uncertainty and information seeking

in computer-mediated contexts (Afifi, 2016). Finally, we bring this into the context of wellness

influencers, sources increasingly coming under scrutiny for the convergence of wellness

misinformation and far-right ideology in their discourse (see: Baker, 2022a, 2022b).

Seeking Information from Online Spaces

While there are opportunities for patient advocacy and education, the proliferation of

"medical populism" within online illness support groups moderated by laypeople with similar

conditions and unvetted wellness influencers can also increase the risk of misinformation and

negative health outcomes (Lasco & Curato, 2019). This raises questions about not only what

causes this divergence but what leads people to seek information from informal online sources to

begin with, particularly from online support groups and wellness influencers, which have risen in

use and popularity (Rueger et al., 2021; Baker 2022b). Online support groups serve as a source

for information sharing, especially around the management of uncertainty and anxiety about a

given illness or condition and often when trust in clinicians is low (Bell et al., 2011). While

research has been conducted to study the ways in which online support groups formed around

specific chronic conditions create space for the management of anxiety related to uncertainty

(e.g., Delaney & Basinger, 2021), there is a dearth of research that explores negative healthcare

experiences as related to uncertainty anxiety and information seeking in these spaces, regardless of the particular health condition.

In comparison to online support groups, there is much less available information about the impact of wellness influencers on uncertainty management and information seeking. A wellness influencer is either a regular person who has made a career of blogging, posting, or sharing about their health conditions, wellness journey, or other health related issues or a medical professional who makes a private career by posting about their medical expertise online (see: Kuznia et al., 2021; Baker, 2022a). Lay people may seek out wellness influencers after experiences of discrimination or dismissal in the traditional healthcare system (e.g., Cohen, 2018); however, there is little research that explores this phenomenon.

Theoretical Background

As uncertainty has been implicated in the utilization of online sources (Kanter et al., 2019), uncertainty theories provide an avenue for investigating what sort of interactions and communicative experiences result in people seeking information from these online sources. This study utilizes Mishel's (1988) uncertainty in illness theory and Afifi and Weiner's (2004) theory of motivated information management, focusing on the role of medical uncertainty - the inability to identify the causes of symptoms or trajectory of illness (Brashers, 2001). Medical uncertainty is the primary cause of uncertainty across a variety of domains (e.g., cancer, Donovan et al., 2015; type 2 diabetes, Middleton, et al., 2012) and has been implicated in the processes changing perceptions of providers and seeking information from others sources (Hintz, 2022). Specifically, we conceptualize medical uncertainty as medical uncertainty discrepancy, as scholars have asserted that uncertainty motivates action when there is a discrepancy (Afifi & Weiner, 2004).

Uncertainty in Illness

Mishel's (1988) uncertainty in illness theory (UIT) explains how individuals process and make sense of illness-related events, providing insight into what precedes uncertainty. According to UIT, uncertainty occurs when individuals are unable to form a cognitive schema around the illness event and ascribe meaning (Mishel, 1988). Healthcare professionals are one resource for interpreting the illness event. As a credible authority, they can potentially reduce uncertainty by providing information about the causes and effects of symptoms (i.e., a diagnosis) or supplying context that allows events to be recognizable and more congruent with expectations (Mishel, 1988). Positive experiences with a clinician can set expectations for a patient about how their condition may progress or treatment will transpire; these positive (e.g., highly patient-centered) experiences have been found to decrease uncertainty (Wanzer et al., 2004). Negative experiences, on the other hand, may disrupt the ability to set expectations for how their illness-related event will play out. This inability to set expectations or view clinicians as credible authorities that can help ascribe meaning would lead to increased actual uncertainty (Kerr et al., 2019), in turn causing a larger discrepancy between actual and desired uncertainty.

H1: Negative healthcare experiences are positively related to uncertainty discrepancy.

Negative healthcare experiences may not only influence medical uncertainty directly, but also indirectly through mistrust. Previous work has found that negative healthcare experiences, conceptualized as low patient-centeredness, play a substantial role in medical mistrust (Hammond 2010, Williamson, 2023). UIT only explicitly discusses the role of trust in providers, where trust and confidence are associated with a lower level of uncertainty (Mishel, 1988). While trust and mistrust are related, they are distinct concepts with differing impacts on outcomes (e.g., Pellowski et al., 2017). Medical mistrust, beliefs that clinicians have negative motives and might actively work against patients' best interests (Jaiswal & Halkitis, 2019),

would result in the perception that clinicians cannot provide a structure or meaning to events

(Brashers et al., 2006), increasing uncertainty. In fact, recent work indicates that negative

encounters shape these perceptions and are related to medical uncertainty (Hintz, 2022).

> *H2: Negative healthcare experiences are positively related to medical mistrust.*

> *H3: Medical mistrust is positively related to uncertainty discrepancy.*

> *H4: Medical mistrust mediates the relationship between negative healthcare experiences*
> *and uncertainty.*

According to UIT, uncertainty is then appraised. Positive appraisals are associated with

emotional reactions such hope, while negative appraisals are associated with anxiety and other

negative emotions. Given the hypothesized discrepancy between actual and desired uncertainty,

it is reasonable to expect that the appraisal would be negative. Although scholars have

acknowledged the range of emotions that may result from uncertainty discrepancy, anxiety has

long been considered in uncertainty processes (see Afifi & Weiner, 2004 for discussion). As the

interest is in general patterns across health conditions and associations exist across various

contexts (see Kuang & Wilson, 2017), the present study focuses on uncertainty anxiety.

> *H5: Uncertainty discrepancy is positively associated with uncertainty anxiety.*

While UIT can provide an explanation as to what can lead to information seeking generally, it is

unable to provide a full picture of what happens between the appraisal of the uncertainty and the

decision to seek information or why a particular source may be sought out.

Theory of Motivated Information Management

The TMIM (Afifi & Weiner, 2004) provides a causal chain through which uncertainty

leads to information seeking; it posits that responses to uncertainty occur in three phases:

interpretation, evaluation, and decision. In the interpretation phase, which overlaps with the

processes described by uncertainty in illness theory, individuals recognize the uncertainty

discrepancy, which induces an emotional response (e.g., uncertainty anxiety). This emotional

response, in turn, influences the assessment of factors related to potential information seeking

during the evaluation phase. One of assessments made in this phase involves the likely costs and

benefits of engaging in information seeking, or outcome expectancies. The other assessment is

considerations of efficacy beliefs, which reflect perceptions of the ability of the target to

successfully produce a particular outcome (Afifi & Weiner, 2004).

Previous work has supported a negative relationship between anxiety and outcome

expectancy (see Kuang & Wilson, 2021). This work, however, focused on information seeking in

the same context (e.g., uncertainty about talking to and information seeking from parents).

However, when medical uncertainty stems from negative healthcare experiences and mistrust of

the medical establishment, individuals may make different evaluations and seek information

elsewhere, such as online spaces. For example, women who have experienced disenfranchising

talk may engage in acts of resistance and advocacy (Hintz, 2022). Thus, rather than causing an

anxiety that interferes with perceptions of outcomes and efficacy, negative experiences may

make individuals feel as though sources outside of "the medical system" will be more beneficial

for making sense of their health concern. Thus, we hypothesize:

> *H6: Uncertainty anxiety is positively related to outcome expectancies for a) online*
>
> *support groups and b) wellness influencers.*

Similarly, anxiety caused by interactions with a healthcare professional may increase

perceptions that other sources will be more efficacious. The literature has advanced three

different efficacy assessments: communication efficacy, coping efficacy, and target efficacy

(Afifi & Weiner, 2004; Fowler & Afifi, 2011). Given the study context and particular interest in these online sources, we focus on the target efficacy.

> *H7: Uncertainty anxiety is positively related to target efficacy around a) online support groups and b) wellness influencers.*

According to the TMIM, outcome expectancies also contribute to perceptions of efficacy (Fowler & Afifi, 2011).

> *H8: Outcome expectancies are positively related to target efficacy for both a) online support groups and b) wellness influencers.*

The last phase of the process, the decision phase, posits that individuals then decide whether to engage in information seeking. If outcome expectancies are positive and efficacy judgments are high, individuals will engage in information seeking (Afifi & Weiner, 2004). TMIM suggests that efficacy beliefs directly impact information seeking and mediate the influence of outcome expectancies (Afifi & Weiner, 2004). We posit that in the case of information seeking from online support groups and wellness influencers, outcome expectancy also directly influences information seeking. Particularly in the context of information about a health concern individuals associate with negative clinician experiences, the anticipated outcome (e.g., there being more positives than negatives) may directly influence willingness to seek information from these sources.

> *H9: Efficacy is positively related intentions to seek information from a) online support groups and b) wellness influencers.*

> *H10: Outcome expectancies are positively related to intentions to seek information from a) online support groups and b) wellness influencers.*

As our interest is in not only the individual relationships, we also propose that these theoretical constructs may result in an indirect effect of negative healthcare experiences on willingness to seek information. The full model to be tested is presented in Figure 1.

> *H11: Negative healthcare experiences indirectly influence intentions to information seek from a) online support groups and b) wellness influences through medical mistrust, uncertainty discrepancy, uncertainty anxiety, outcome expectancy, and efficacy.*

Chronic Illness

While uncertainty and information seeking around health after a negative healthcare experience may occur regardless of the acuteness of a health condition (Li et al., 2014), the relationships we examine may be particularly salient for individuals with chronic illnesses. Individuals with a chronic illness report higher levels of invalidation (i.e., negative healthcare experiences) (see: Hintz, 2022) and may be likely to experience uncertainty, as there may be delays in diagnosis. The connections between having a chronic illness and facing difficulties with clinicians and medical diagnoses persist across a range of conditions, including type 2 diabetes (Middleton et al., 2012), endometriosis (Osborn et al., 2020), and chronic fatigue syndrome (McManimen et al., 2019). Thus, the relationship between negative healthcare experiences, mistrust, and uncertainty may be stronger for individuals with chronic conditions than those with acute conditions. Additionally, given that decreased confidence in one source of information may correspond to heightened confidence in another (Lee et al., 2018) it is possible that the increased likelihood of negative healthcare experiences also results in better assessments of the information target. As a result, we look specifically at whether and how chronic illness may play a role in information seeking from online sources.

> *RQ1: Do these relationships differ for those with and without chronic conditions?*

Methods

Participants

Participants ($N = 544$) were recruited in February 2022 via Qualtrics, which recruits from a variety of sources (e.g., target email lists, social media) and sends potential participants an email invitation for the survey. Adults over the age of 18 who lived in the United States were eligible for participation. Participants were asked, "Do you have a chronic condition (for example, diabetes, asthma, endometriosis)?" and quotas were set so the sample population reflected the prevalence of chronic conditions in the United States. In the final sample, 342 individuals reported having a chronic condition (62.9%) while 202 individuals reported having an acute condition (37.1%). Participants ranged in age from 18 to 85 with an average of 48.90 (SD = 17.31). A majority of sample was White (65.8%); the remainder of the sample was Black/African American (9.2%), Hispanic/Latinx (7.2%), Asian (4.4%), American Indian/Native American (.7%), Native Hawaiian/Pacific Islander (.6%), Middle Eastern/North African or Southwest Asian/North African (.4%), and multiracial (9.9%). Over half of the participants were women (51.3%) and were primarily cisgender (98.7%) and heterosexual (86.4%). Approximately two-thirds of participants reported not having a bachelor's degree (33.8%) and slightly more than half reported making less than $50,000 (58.3%).

Procedures

Upon approval from the Institutional Review Board at the University of Wisconsin-Madison (Protocol 2021-1492), participants were invited to complete an online survey. After reading the consent information and consenting to the study by clicking "I Agree," participants were asked to think of a specific health concern they have had; this health concern was carried forward, and questions were asked in regard to that specific health concern. The current study

focuses solely on those individuals who reported having had a specific concern; 140 individuals were removed from analysis because they reported never having had a health concern, leaving 544 cases. Participants were then presented with items for the constructs of interest. To prevent order effects, the presentation of sections and constructs were randomized.

Measures

Below, the measures for the current study are presented. Unless otherwise indicated, participants answered on a relevant scale from 1 (e.g., strongly disagree, completely uncertain) to 5 (e.g., strongly agree, completely certain).

Negative Healthcare Experiences

Consistent with previous work (e.g., Hammond, 2010; Jiang & Street, 2017), negative healthcare experiences were operationalized as low patient-centeredness. This was assessed using Jiang and Street's (2017) measure, which asks individuals the frequency of their clinician engaging in seven patient-centered behaviors (e.g., "Give attention to your feelings and emotions") from 0 (never) to 4 (always). Responses were recoded so that higher values indicated more negative healthcare experiences. The five items formed a reliable scale, $\alpha = .94$.

Medical Mistrust

Medical mistrust was assessed using a modified version of the Medical Mistrust Index (LaVeist, Isaac, & Williams, 2009). The items ask individuals to rate their level of agreement with several statements about healthcare providers (e.g., "Patients have sometimes been deceived or misled by healthcare providers"). For the current study, the items formed a reliable scale, $\alpha = .88$.

Medical Uncertainty Discrepancy

Uncertainty discrepancy was a composite measure created by subtracting *desired* medical uncertainty from *actual* medical uncertainty. Both types of uncertainty were assessed using four items from Rains and Tukachinsky (2015). These measures ask individuals how certain they currently feel (actual uncertainty) and how certain they want to feel (desired uncertainty) about the causes, symptoms, detection, and treatment of their condition (e.g., "How certain do you currently/want to feel about the causes of your [insert concern]?") Responses were coded such that higher scores reflect a greater desire for certainty.

Anxiety

Anxiety about uncertainty discrepancy was assessed utilizing items from Afifi & Afifi (2009). This measure consists of three items that asks participants to indicate how much anxiety they feel or how anxiety-producing thinking about the difference between current desired uncertainty around their health concern is (e.g., "How anxious does it make you to think about how much/how little you know about your [insert concern]?") from 0 (not at all) to 4 (extremely). The items formed a reliable measure α= .93.

Outcome Expectancy

Three items from Fowler and Afifi (2011) were used to assess outcome expectancy. For each item, participants were asked about their outcome expectancy as it relates to both online support groups and a wellness influencer (e.g., "Reading commentary from a wellness influencer about their beliefs about [insert concern] would produce _____.") Participants responded about the positives versus negatives expected outcomes from seeking information from the given source (e.g., "more positives than negatives"). The items formed a reliable scale for both wellness influencers (α = .92) and online support groups (α = .92).

Target Efficacy

For the current study, we focus on components of target efficacy: target ability and target honesty, utilizing items from Fowler & Afifi (2011). Target ability was measured with three items reflecting beliefs about the target's ability to provide information about the health concern (e.g., "Online support groups are knowledgeable about [my concern]"). The items formed a reliable scale for both wellness influencers (α = .92) and online support groups (α = .88). Target honesty was measured with four items capturing the extent to which participants believe the target of their information seeking would be truthful (e.g., "A wellness influencer would be completely honest about [my concern]"). The items formed a reliable scale for wellness influencers (α = .92) and online support groups (α = .91).

Information Seeking Intentions

Three items assessed information seeking for both online support groups and wellness influencers based on traditional items modeled on Fishbein & Ajzen (2011), which ask individuals their level with agreement with the statements that they plan to, intend to, and will seek information from this source (e.g., "The next time I seek health information about my [insert concern] I will go to a wellness influencer"). The items formed a reliable scale for both wellness influencers (α = .96) and online support groups (α = .95).

Analytic Procedures

Structural equation modeling multiple group analysis was performed using Mplus Version 8.4 (Muthén & Muthén, 2017). Separate models were tested for online social support groups and wellness influencers. For each set of models, those with chronic and acute concerns were tested as the groups of interest. Measurement invariance was assessed by comparing successive models for configural, metric, and scalar invariance. Once measurement invariance was established, structural invariance was assessed. To determine the partial structural invariant

model, pathways were sequentially constrained. For both measurement and structural invariance, significant changes in chi-square were indicative of non-invariance. As a pathway being invariant across groups only speaks to whether the pathway could be constrained, Wald's chi-square tests were conducted to assess whether invariant pathways were statistically different. A significant result rejects the null hypothesis that the pathways are equivalent.

In assessing model fit, the chi-square statistic (χ^2) is reported alongside the comparative fit index (CFI), root mean-squared error of approximation (RMSEA), and standardized root-mean squared residual (SRMR) (Kline, 2016). A CFI greater than .90, a SRMR at or below .09, and a RMSEA at or below .06 served as indicators of good fit (Hu & Bentler, 1999). Additionally, indirect effects were evaluated by examining 95% confidence intervals based on 5,000 bootstrap samples. If the confidence interval for the indirect did not contain zero, this was taken as evidence of an indirect effect (Hayes, 2009).

Results

Confirmatory Factor Analysis

The hypothesized model for online support groups consisted of six latent variables: negative healthcare experiences, medical mistrust, uncertainty anxiety, outcome expectancy, efficacy, and intentions to seek information from online support groups; efficacy had target honesty and target ability as indicators. Uncertainty discrepancy was also included in the model as an observed variable. The initial model provided adequate fit for those without chronic conditions, χ^2(260, $n = 202$) = 555.41, $p < .001$, $CFI = .922$, $RMSEA = .075$ (90% CI = .066, .084), $SRMR = .056$. The model also provided good fit for those with chronic conditions, χ^2(260, $n = 342$) = 526.08, $p < .001$, $CFI = .959$, $RMSEA = .055$ (90% CI = .048, .061), $SRMR = .041$.

As with the online social support groups model, the hypothesized model for wellness influencers consisted of six latent variables and one observed variable (see above). The initial model provided adequate fit for those with acute conditions, $\chi^2(260, n = 202) = 504.87$, $p < .001$, *CFI* = .934, *RMSEA* = .068 (90% CI = .059, .077), *SRMR* = .056. The model also provided good fit for those with chronic conditions, $\chi^2(260, n = 342) = 513.03$, $p < .001$, *CFI* = .964, *RMSEA* = .053 (90% CI = .047, .060), *SRMR* = .042.

Measurement Invariance

Configural invariance, which assesses whether the same variables measure the same constructs across groups, was tested first. The configural model for *online support groups* indicated adequate fit, $\chi^2(520, N = 544) = 1081.49$, $p < .001$, *CFI* = .945, *RMSEA* = .063 (90% CI = .058, .068), *SRMR* = .047. Metric invariance was then examined to determine whether the factor loadings for each construct could be considered equivalent across those with and without chronic conditions. The model produced a non-significant change in chi-square indicating metric invariance, $\chi^2(539, N = 544) = 1101.23$, $p < .001$, *CFI* = .945, *RMSEA* = .062 (90% CI = .057, .067), *SRMR* = .050. Finally, scalar invariance was examined by setting item intercepts as equivalent across groups. The resulting model did not produce a significant change in chi-square, $\chi^2(558, N = 544) = 1119.07$, $p < .001$, *CFI* = .945, *RMSEA* = .061 (90% CI = .056, .066), *SRMR* = .050. Thus, the model was invariant.

The configural model for *wellness influencers* provided adequate fit, $\chi^2(520, N = 544) = 1017.89$, $p < .001$, *CFI* = .953, *RMSEA* = .059 (90% CI = .054, .065), *SRMR* = .048. The metric model produced a non-significant change in chi-square, meeting the indicator of invariance, $\chi^2(539, N = 544) = 1033.81$, $p < .001$, *CFI* = .954, *RMSEA* = .058 (90% CI = .053, .063), *SRMR* = .051. Finally, the model for scalar invariance did not produce a significant change in chi-

square, χ^2(558, N = 544) = 1052.77, p < .001, CFI = .954, $RMSEA$ = .057 (90% CI = .052, .062), $SRMR$ = .051. The absence of a change in chi-square suggests the model is invariant. The constrained measurement models were used for subsequent structural analyses.

Structural Invariance

The baseline model for *online support groups* showed adequate fit, χ^2(596, N = 544) = 1166.19, p < .001, CFI = .944, $RMSEA$ = .059 (90% CI = .054, .064), $SRMR$ = .049. The full constrained model produced a significant change in chi-square, χ^2(617, N = 544) = 1201.10, p < .001, CFI = .944, $RMSEA$ = .059 (90% CI = .054, .064), $SRMR$ = .061. This indicates that at least one pathway should be freed. Beginning with the baseline model, models were sequentially tested to determine which pathways could be constrained. The final model freed four primary pathways of interest between: a) negative healthcare experiences and medical mistrust, b) uncertainty discrepancy and uncertainty anxiety, c) outcome expectancy and efficacy, and d) efficacy and intentions to seek information from online social support groups. This final model demonstrated good fit, χ^2(612, N = 544) = 1186.27, p < .001, CFI = .944, $RMSEA$ = .059 (90% CI = .054, .064), $SRMR$ = .055.

The baseline model for *wellness influencers* provided good fit, χ^2(596, N = 544) = 1088.47, p < .001, CFI = .954, $RMSEA$ = .055 (90% CI = .050, .060), $SRMR$ = .050. The fully constrained model produced a significant change in chi-square, χ^2(617, N = 544) = 1121.05, p < .001, CFI = .953, $RMSEA$ = .055 (90% CI = .051, .060), $SRMR$ = .062. The significant change in chi-square indicates that at least one pathway needed to be freed. Pathways were again sequentially constrained until the final model was produced. The final model freed two primary pathways, a) between negative healthcare experiences and medical mistrust and b) between

uncertainty discrepancy and uncertainty anxiety and provided good fit, χ^2(614, $N = 544$) =

1107.45, $p < .001$, $CFI = .954$, $RMSEA = .054$ (90% $CI = .049, .060$), $SRMR = .053$.

Main Analyses

As the front end of both models are identical, these relationships are only presented once

(i.e., negative healthcare experiences, medical mistrust, uncertainty discrepancy, and uncertainty

anxiety); the difference in online source did not substantially change parameter estimates. Then,

relationships for each online source are discussed (i.e., outcome expectancy, efficacy, and

intentions to seek information from wellness influencers). Full parameter estimates and related

information can be found for online support groups in Table 2 and wellness influencers in Table

3. The standardized path coefficients for both those with chronic and acute conditions are

depicted in Figure 2 (online support groups) and Figure 3 (wellness influencers). Below,

standardized coefficients are reported for both those with chronic conditions (β_C) and those with

acute conditions (β_A); due to differences in the samples (e.g., variance), standardized coefficients

for invariant pathways may differ.

Negative healthcare experiences were positively associated with medical mistrust (β_A =

.21, β_C = .42, p = .01). Negative healthcare experiences were also positively associated with

uncertainty discrepancy (β_A = .15, β_C = .16. p = .01). There was, however, no significant

relationship between medical mistrust and uncertainty discrepancy (β_A = .05, β_C = .06, p = .24).

For those with chronic conditions, uncertainty discrepancy was positively associated with

uncertainty anxiety (β_A = .19, p = .01) for those with acute conditions, but for those with chronic

conditions there was no significant relationship (β_C = .01, p = .86).

For the *online support group* model, as hypothesized, there was a positive relationship

between uncertainty anxiety and outcome expectancy (β_A = .27, β_C = .31, p < .001). There was

no significant relationship between uncertainty anxiety and efficacy (β_A = .11, β_C = .10, p = .05).

Additionally, there was a significant relationship between outcome expectancy and efficacy for

those with chronic (β_C = .73, p < .001) and acute conditions. (β_A = .75, p < .001). Outcome

expectancy was not associated with intentions (β_A = .11, β_C = .10, p = .20). Finally, efficacy was

associated with intentions for both chronic (β_C = .62, p < .001) and acute (β_A = .71, p < .001)

conditions.

As hypothesized, for *the wellness influencers* model, there was a positive relationship

between uncertainty anxiety and outcome expectancy (β_A = .31, β_C = .30, p < .001). There was

also a significant relationship between uncertainty anxiety and efficacy (β_A = .12, β_C = .12, p =

.004), as well as between outcome expectancy and efficacy (β_A = .72, β_C = .76, p < .001).

Additionally, outcome expectancy was not associated with intentions (β_A = .03, β_C = .04, p =

.61). Finally, efficacy was associated with intentions (β_A = .72, β_C = .70, p < .001).

Differences Between Chronic and Acute Health Concerns

RQ1 asked whether there are differences in the model for those with chronic and acute

health concerns. For both online support groups and wellness influencer models, there was a

non-invariant pathway between negative healthcare experiences and medical mistrust. Wald's

test indicated that there was a significant difference across groups, χ^2 (1, N = 544) = 5.55, p =

.02, indicating that this relationship was stronger for those with chronic health concerns.

Additionally, for both models, the path from uncertainty discrepancy to uncertainty anxiety was

non-invariant and statistically different, χ^2 (1, N = 544) = 54.08, p = .04. This relationship only

existed for those with acute conditions, but not those with chronic conditions. Finally, for the

online support group model, there were two additional non-invariant pathways. Although the

pathway from outcome expectancy to efficacy was structurally non-invariant, the parameters

were not significantly different, χ^2 (1, $N = 544$) = 2.87, $p = .09$. The pathway from efficacy to

intentions to seek information was not only structurally non-invariant but also significantly

different based on a Wald's test, χ^2 (1, $N = 544$) = 5.22, $p = .01$, indicating the relationship was

stronger for those with acute conditions.

Indirect Effects

For the *online support group* model, there was no indirect effect of negative healthcare

experiences on uncertainty discrepancy through medical mistrust for those with chronic (95% CI:

-.02, .07) or acute conditions (95% CI: -.01, .04). Based on the regression coefficients, a post-hoc

indirect effect including medical mistrust, but not uncertainty discrepancy was examined. An

indirect effect existed for those with chronic conditions such that negative healthcare experiences

influenced intentions through medical mistrust, uncertainty anxiety, outcome expectancy, and

efficacy (95% CI: .01, .03), but not for those with acute conditions (95% CI: 0.00, .02). As the

pathway between negative healthcare experiences and mistrust was non-invariant, post-hoc

indirect effects were also examined omitting mistrust. Negative healthcare experiences had an

indirect effect on intentions through uncertainty anxiety, outcome expectancy, and efficacy for

both those with chronic (95% CI: .02, .09) and acute (95% CI: .03, .10) conditions.

There was no indirect effect on negative healthcare experiences on intentions via medical

mistrust, uncertainty discrepancy, uncertainty anxiety, outcome expectancy, and efficacy for

those with chronic (95% CI: -.001, 0.001) or acute (95% CI: -.001, .002) conditions for the

wellness influencers model. The post-hoc examination without uncertainty discrepancy found no

evidence of an indirect effect for those with chronic conditions (95% CI: 0.00, .02) or acute

conditions (95% CI: .00, .02). Similar to the pattern found for online support groups, there was

an indirect effect of negative healthcare experiences on intentions via uncertainty anxiety,

outcome expectancy, and efficacy. This existed for both with chronic (95% CI: .03, .11) and acute (95% CI: .03, .11) conditions.

Discussion

Online support groups and wellness influencers are increasingly becoming sources for the circulation of not only health, but also political misinformation (Baker 2022b). The current study tested the utility of uncertainty theories in exploring what leads individuals, across health conditions, to seek information from these online sources. In doing so, we tested negative healthcare experiences and medical mistrust as precursors to uncertainty and intentions to seek information from both online support groups and wellness influencers. The model suggested by uncertainty in illness (Mishel, 1988) and TMIM (Afifi & Weiner, 2004) fit the data, indicating this is a useful basis for examining these relationships. Across both those with acute and chronic conditions, there were few differences between the groups.

More specifically, negative healthcare experiences were found to be associated with uncertainty discrepancy; this relationship existed for both those with chronic and acute conditions. Despite Mishel's (1998) discussion of healthcare experiences as part of how individuals interpret illness experiences, there has been little quantitative work examining the role of negative healthcare experiences in uncertainty processes; however, qualitative work has highlighted the role of negative healthcare experiences in uncertainty, particularly for individuals with chronic conditions, like endometriosis (Denny, 2009). The findings of the present study provide additional support for this previous work and suggest that these relationships exist across health conditions. Thus, negative healthcare experiences, and its various conceptualizations, should be examined as a factor contributing to these processes.

Consistent with previous work (Hammond, 2010; Williamson, 2023), negative healthcare experiences were related to medical mistrust. This association was present for those both with chronic and acute conditions; however, the relationship was stronger for those with chronic conditions. Individuals with chronic conditions may experience negative healthcare experiences more frequently or in more egregious ways, contributing to this difference. Additional work will be needed to fully understand why negative healthcare experiences have a stronger association with medical mistrust for individuals with chronic conditions than those without. Although negative healthcare experiences were related to medical mistrust, there was not an indirect effect on uncertainty discrepancy through medical mistrust. This is likely due to uncertainty discrepancy not being associated with anticipated constructs.

Recent meta-analyses have found that uncertainty discrepancy was related to uncertainty anxiety (Kuang & Wilson, 2017) but suggested there might be moderators of this relationship (Kuang & Wilson, 2021). In the present study, the relationship between uncertainty discrepancy and uncertainty anxiety was only found for those with acute conditions suggesting that experiencing a chronic condition could be one of those moderators. The experience of chronic conditions may result in different, or a wider array of, appraisals. There are a range of appraisals individuals might make in regard to uncertainty (Afifi & Morse, 2009); perhaps for individuals with chronic conditions, having more uncertainty than desired is either part of a new normal or is appraised positively (Brashers, 2001; Mishel, 1988), neither of which would produce anxiety.

Another possibility is that uncertainty discrepancy and its relationships with other variables alongside this information seeking process is simply too condition-specific. For example, certain chronic conditions are associated with or experienced only by people assigned female at birth, and those conditions may be dismissed or invalidated more frequently by

medical professionals (Hintz, 2022) but have flourishing wellness communities available for

support, versus a chronic condition that has more established avenues for medical care or a

condition that is rare enough to warrant fewer online resources. Alternatively, the issue may have

been the representation of uncertainty as uncertainty discrepancy (see Kuang & Wilson, 2017).

Our data suggested that uncertainty anxiety was the key uncertainty outcome. Negative

healthcare experiences influenced information seeking indirectly by way of uncertainty anxiety.

As our goal was to examine large scale general patterns, the findings do suggest that at a general

level, the anxiety associated with the difference in actual and desired uncertainty, as opposed to

the magnitude of that difference, drives information seeking regardless of health concern. This is

consistent with the proposition that it is anxiety, not the discrepancy, that motivates individuals

to engage in information management (Afifi, & Weiner, 2004).

Relationships between uncertainty anxiety, outcome expectancy, efficacy, and intentions

to seek information were present for both wellness influencers and online support groups. The

models were largely similar for both online sources and in some cases for those with chronic and

acute conditions. Consistent with theoretical indications, outcome expectancy only exerted

indirect effects on intentions to seek information via efficacy assessment. There was, however,

no relationship between uncertainty anxiety and efficacy assessment; this may be due to the

anxiety and efficacy regarding different entities – the medical establishment and sources outside

of the establishment, respectively. In the case of support groups, efficacy was related to

intentions for those with and without chronic conditions, but the pathway was statistically

different, suggesting this may be stronger for those without chronic conditions. Individuals with

chronic conditions may be more familiar with support groups (Kingod et al., 2017). As a result,

they may have a frame of reference and thus, have expectations for online support groups built

on experience; this may not be the case for wellness influencers. These expectations or previous experiences, particularly if they were associated with mixed or negative outcomes, may result in less strong relationship between efficacy and intentions. Subsequent studies should account for the frequency and quality of previous engagement with online sources.

Implications and Future Directions

The present study suggests there can be value in thinking about the uncertainty in illness theory and theory of motivated information management in tandem. Doing so may capture the downstream impact of healthcare experiences as they lead to information seeking outside of a professional healthcare setting. Individually, the theory of uncertainty in illness chronicles how uncertainty arises and is interpreted when health concerns emerge, whereas the theory of motivated information management provides the deliberation that occurs in information seeking. Pairing related theories like UIT and TMIM may allow scholars to chronicle longer processes of how health-related information seeking unfolds. The present findings suggest that this may be a useful way of looking at general patterns around relationships between uncertainty and information seeking. By considering these theories in conjunction with one another, health communicators are able to consider and examine longer, broader processes and connect what happens inside and outside of a clinical encounter.

More explicit work understanding the role of chronic illness is necessary. Experiences of chronic illness might function as a boundary condition, influencing how these relationships play out. Previous work has suggested a strong relationship between uncertainty discrepancy and uncertainty anxiety (Kuang et al., 2021); this was not found consistently in the present study. The type of condition could be an internal, hard boundary (Holbert et al., 2022), one that only applies to a portion of the model but is significantly different from zero for one level of the moderator

(i.e., acute conditions) but not others (i.e., chronic conditions). It is also possible that "chronic conditions" homogenizes inherently different illness experiences. Participants in our study focused on a range of health concerns from allergies and acid reflux to B-cell lymphoma and schizophrenia. The actual magnitude of the difference between desired and actual uncertainty may be relevant for some, but not all, health concerns.

Our study suggests it would be beneficial to put resources into longitudinal data to establish causal relationships and explore potential moderators (e.g., age; Kuang & Wilson, 2017) or mediators (e.g., source credibility). The lay perception is that individuals with existing fringe ideas about medicine are those who wind up seeking information from these sources (e.g., Tolentino, 2016). The current study suggests we should more carefully study whether this is the case. This may be particularly important for wellness sources that have received less attention. Individuals who have negative healthcare experiences with clinicians may simply turn to alternative sources of information. Thus, it is necessary to ensure we are able to arm individuals with the skills to discern trustworthy information. Additionally, it may behoove clinicians to be aware of the downstream impact of their interactions with patients. If this is the case, it is possible that by improving individuals' experiences with clinicians, individuals may be less prone to seeking information sources known to contain health mis- and even disinformation. As some wellness influencers are former or current medical professionals, individuals may distinguish between medical professionals who are part of the "mainstream" and those railing against the medical establishment (Kuznia et al., 2021). If those espousing views counter to the medical establishment are seen as more credible, this may affect efficacy assessment and expectations of what may come from engaging with this online source.

The current study is intended to be a starting point for considering what leads up to individuals seeking information from these online spaces. There are several aspects, particularly around conceptualization, that are natural next steps. Vicarious negative healthcare experiences can also influence perceptions of healthcare professionals (Williamson, 2023); thus, others' negative healthcare experiences may contribute to uncertainty and information seeking. Additionally, patient-centeredness is only one conceptualization of negative healthcare experiences, other conceptualizations (e.g., invalidation, disenfranchisement) may have stronger effects. Uncertainty around health concerns does not exist only in terms of the interpretation of physical symptoms, diagnosis, and treatment (i.e., medical uncertainty), but also how the condition may affect interpersonal relationships (i.e., relational uncertainty) or self-concept and ability to pay for treatment and care related to the condition (i.e., personal uncertainty) (Brashers, 2001). Investigating this tripartite model of uncertainty may provide a more holistic view of the ways in which uncertainty leads to information seeking.

Limitations

The current study relied on theoretical assumptions for the order of constructs. In some ways this was necessary to garner evidence that these relationships may exist across experiences related to a variety of health concerns. The cross-sectional nature of the data, however, precludes causal claims. Additionally, our findings could be a product of the study's cross-sectional design; Kuang and Wilson (2021) found that support for the TMIM varied by study design, with cross-sectional studies providing support but less so for longitudinal studies. In the present study, the primary outcome of interest was intentions to seek information from these spaces; we did not measure actual behavior. Intentions, though a significant predictor, do not always translate to actual behavior (e.g., Albarracín et al., 2001). Subsequent work would benefit from assessing

whether these constructs impact actual behavior. Negative healthcare experiences and medical uncertainty might open up individuals' willingness to seek information from these online spaces, but does not mean they actually seek information from those spaces. Additionally, the theories used in the present study only go up until the point of information seeking. It does not directly speak to the uptake of information in these spaces. It may be beneficial to more specifically examine whether, and through what mechanisms, uncertainty is related to endorsement of misinformation or even conspiracy beliefs.

Conclusion

Uncertainty theories have been utilized to examine information seeking for particular conditions or aspects of health (e.g., cancer, sexual health; Kuang & Wilson, 2017); however, health misinformation, unsafe health practices, and conspiracy theories are not relegated to condition-specific online spaces, but rather appear in wellness-related spaces more broadly. Thus, we need to have an idea of what may generally lead individuals to seek information from these spaces. The present study is intended as a first step in examining the role of negative healthcare experiences in these processes. As we consider the reasons individuals enter and absorb information in these spaces, we cannot neglect what may have brought individuals to these spaces and potentially open them up to be more accepting of this information as it may point to upstream points of intervention to decrease the use of unsafe health practices. Additionally, we cannot ignore medical professionals' roles in creating accepting, validating environments for their patients as they navigate illness in the digital age, as their actions in the clinic may play a role in stemming information seeking from questionable sources, beyond that of explicitly combating misinformation.

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Table 1

Correlations, Means, and Standard Deviations

	Mean (SD)		Correlations									
	Acute	Chronic	1	2	3	4	5	6	7	8	9	10
1. Neg. Experiences	3.20 (.83)	3.03 (.85)	---	.37**	.22**	.38**	-.17**	-0.08	.15**	-0.09	-0.10	.11*
2. Medical Mistrust	3.23 (.83)	3.23 (.90)	.19**	---	.12*	.33**	-0.08	-0.03	.15**	-0.07	-0.06	0.10
3. Unc. Discrepancy	0.57 (.92)	0.48 (.95)	0.07	0.07	---	0.10	-.12**	-0.08	-0.11	-0.09	-.14*	-0.10
4. Unc. Anxiety	1.61 (1.10)	1.76 (1.23)	.25**	.24**	.22**	---	.15**	.14*	.40**	.19**	.22**	.40**
5. Out. Expect. (SG)	3.25 (1.00)	3.34 (.96)	-0.14	0.07	0.07	.21**	---	.71**	.54**	.59**	.41**	.36**
6. Efficacy (SG)	3.32 (.83)	3.37 (.91)	-.19**	.19**	0.05	.24**	.60**	---	.64**	.53**	.52**	.42**
7. Intentions (SG)	2.69 (1.22)	2.73 (1.26)	0.20	.14*	-.02	.40**	.64**	.67**	---	.45**	.47**	.56**
8. Out. Expect. (WI)	3.11 (.94)	3.26 (1.01)	-0.02	0.10	.16*	.25**	.60**	.49**	.52**	---	.73**	.62**
9. Efficacy (WI)	3.18 (.98)	3.31 (1.06)	-0.04	.15*	-0.01	.27**	.51**	.56**	.60**	.66**	---	.71**
10. Intentions (WI)	2.69 (1.25)	2.65 (1.33)	0.11	.20**	-0.07	.39**	.42**	.39**	.64**	.53**	.78**	---

Note. Unc. = uncertainty, Out. Expect. = outcome expectancy, SG = support group, WI = wellness influencer. Below the diagonal, values for individuals with acute conditions are presented; above the diagonal, values for individuals with chronic conditions are presented. Independent t-tests indicated that individuals with chronic versus acute conditions did not differ significantly on any study variables except for negative healthcare experiences.

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Table 2

Parameter Estimates for Online Support Group Model

Pathway	Acute Conditions					Chronic Conditions				
	b	B	SE	p	95% CI	b	B	SE	p	95% CI
Negative Healthcare Experiences --> Uncertainty Discrepancy	0.18	0.15	0.06	0.01	[.05, .30]	0.18	0.16	0.06	0.01	[.05, .30]
Negative Healthcare Experiences --> Medical Mistrust	0.18	0.21	0.07	0.01	[.04, .32]	0.39	0.42	0.06	<.001	[.27, .50]
Medical Mistrust --> Uncertainty Discrepancy	0.07	0.05	0.06	0.24	[-.05, .18]	0.07	0.06	0.06	0.24	[-.05, .18]
Uncertainty Discrepancy --> Uncertainty Anxiety	0.22	0.19	0.08	0.01	[.06, .37]	0.01	0.01	0.07	0.86	[-.12, .15]
Uncertainty Anxiety --> Outcome Expectancy	0.24	0.27	0.05	<.001	[.15, .33]	0.24	0.31	0.05	<.001	[.15, .33]
Uncertainty Anxiety --> Efficacy	0.07	0.11	0.03	0.05	[-.001, .13]	0.07	0.10	0.03	0.05	[-.001, .13]
Outcome Expectancy --> Efficacy	0.52	0.75	0.06	<.001	[.41, .62]	0.62	0.73	0.06	<.001	[.49, .74]
Outcome Expectancy --> Intentions	0.13	0.11	0.10	0.20	[-.07, .33]	0.13	0.10	0.10	0.20	[-.07, .33]
Efficacy --> Intentions	1.29	0.71	0.21	<.001	[.88, 1.71]	0.99	0.62	0.16	<.001	[.68, 1.30]

Note. The standard errors and confidence intervals presented are based on the unstandardized coefficients.

Table 3

Parameter Estimates for Wellness Influencer Model

Pathway	Acute Conditions					Chronic Conditions				
	b	B	SE	p	95% CI	b	B	SE	p	95% CI
Negative Healthcare Experiences --> Uncertainty Discrepancy	0.18	0.15	0.06	0.01	[.05, .30]	0.18	0.16	0.06	0.01	[.05, .30]
Negative Healthcare Experiences --> Medical Mistrust	0.19	0.21	0.07	0.01	[.05, .33]	0.39	0.42	0.06	<.001	[.27, .50]
Medical Mistrust --> Uncertainty Discrepancy	0.07	0.05	0.06	0.23	[-.05, .18]	0.07	0.06	0.06	0.23	[-.05, .18]
Uncertainty Discrepancy --> Uncertainty Anxiety	0.22	0.18	0.08	0.01	[.06, .37]	0.01	0.01	0.07	0.84	[-.12, .15]
Uncertainty Anxiety --> Outcome Expectancy	0.25	0.31	0.04	<.001	[.16, .33]	0.25	0.30	0.04	<.001	[.16, .33]
Uncertainty Anxiety --> Efficacy	0.10	0.12	0.03	0.004	[.03, .16]	0.10	0.12	0.03	0.004	[.03, .16]
Outcome Expectancy --> Efficacy	0.72	0.72	0.04	<.001	[.64, .81]	0.72	0.76	0.04	<.001	[.64, .81]
Outcome Expectancy --> Intentions	0.05	0.03	0.09	0.61	[-.13, .23]	0.05	0.04	0.09	0.61	[-.13, .23]
Efficacy --> Intentions	0.99	0.72	0.11	<.001	[.79, 1.20]	0.99	0.70	0.11	<.001	[.79, 1.20]

Note. The standard errors and confidence intervals presented are based on the unstandardized coefficients.
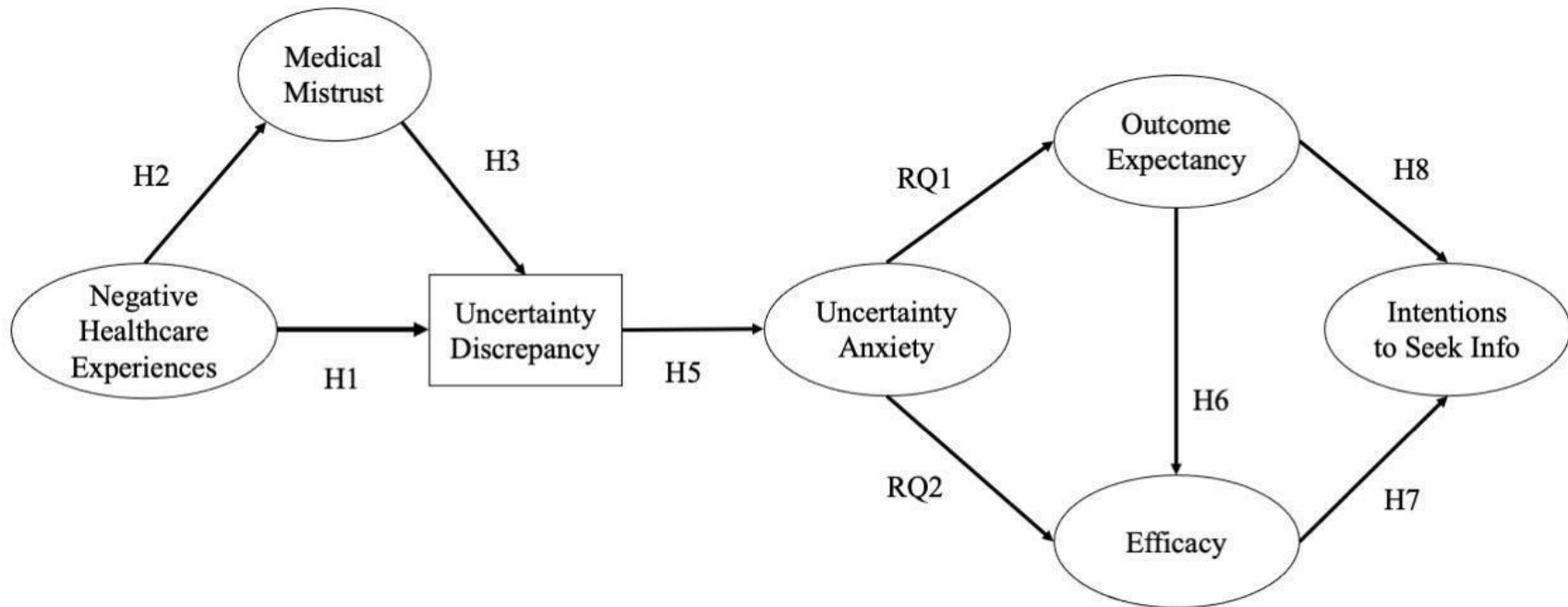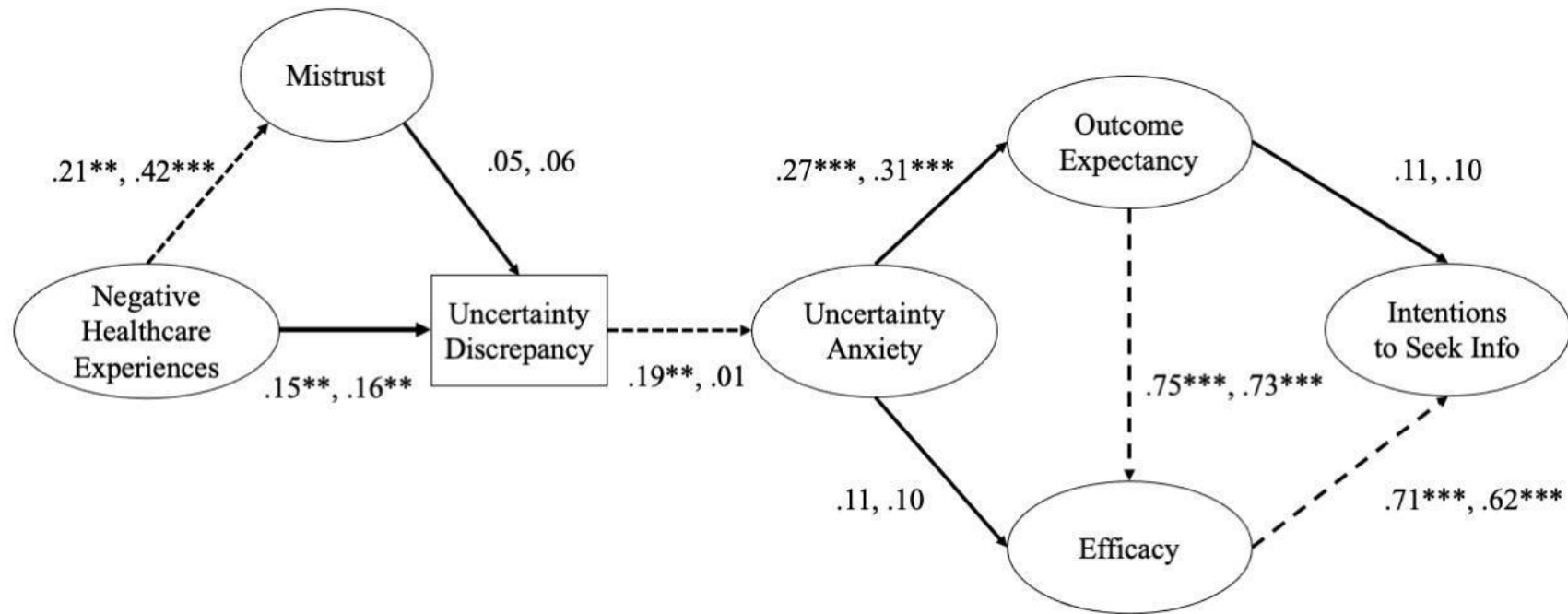
Figure 1. Proposed model

Figure 2. Final structural model pertaining to online support groups. Standardized estimates are presented. For all pathways, the coefficient for those with acute conditions is presented first, followed by the chronic condition sample. Solid lines represent constrained pathways; dotted lines are unconstrained pathways. *p* < .05, **p* <.01, ***p*<.001.
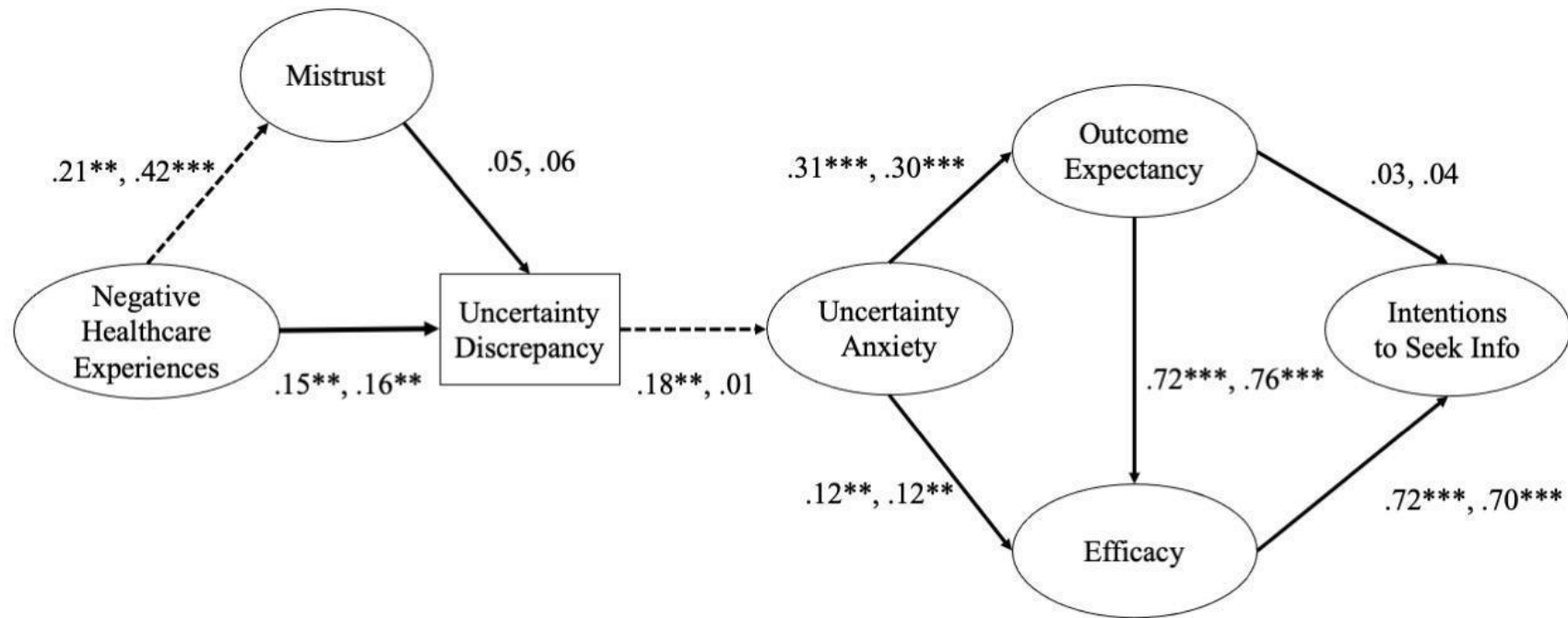
Figure 3. Final structural model pertaining to wellness influencers. Standardized estimates are presented. For all pathways, the coefficient for those with acute conditions is presented first, followed by the chronic condition sample. Solid lines represent constrained pathways; dotted lines are unconstrained pathways. *p* < .05, **p* <.01, ***p*<.001.