

# USE OF GROUP CONCEPT MAPPING TO IDENTIFY PATIENT DOMAINS OF UNCERTAINTY THAT CONTRIBUTE TO EMERGENCY DEPARTMENT USE



**Authors:** Kristin L. Rising, MD, MSHP, Shannon K. Doyle, MPH, Rhea E. Powell, MD, MPH, Amanda M.B. Doty, MS, Marianna LaNoue, PhD, and Angela M. Gerolamo, PhD, APRN, BC, Philadelphia, PA

**CE** Earn Up to 7.5 Hours. See page 113.

## Contribution to Emergency Nursing Practice

- The current state of scientific knowledge suggests that patient uncertainty related to new or ongoing symptoms is a driver and unmet need of emergency department visits, yet the mechanisms of patient uncertainty have not been described.
- The main finding of this research is that patients identified multiple domains of uncertainty, both intrinsic (self-care and treatment) and extrinsic (alternative care options), that drive their care decisions when experiencing symptoms.
- Key implications for emergency nursing practice include the importance for providers to understand patient drivers of ED use and needs during ED visits. Further exploration of domains of uncertainty can inform development of targeted interventions to deliver more patient-centered care in the emergency department.

## Abstract

**Introduction:** Prior research suggests that uncertainty related to symptoms is a driver of emergency department (ED) use, and that patients often leave the ED with uncertainty not being addressed. Our objective was to engage patients to identify domains that contribute to feelings of uncertainty and decisions to use the ED.

**Methods:** We used Group Concept Mapping, a quasi-qualitative/quasi-quantitative method, to elicit patients' views on how uncertainty related to experiencing symptoms contributes to decisions to access the ED. Purposive sampling was used to recruit participants who either sought treatment at the ED twice within a 30-day period, or visited both the ED and a primary care provider at least once within the past year.

**Results:** Thirty-four participants engaged in two rounds of Group Concept Mapping during which participants participated in structured brainstorming of ideas, followed by ranking and clustering of ideas into domains. The first round generated 47 idea statements reflecting uncertainty about consequences, severity, emergency room services, primary care options, finances, and psychologic concerns. The second round generated 52 idea statements reflecting uncertainty about self-management, causation, diagnosis and treatment plan, trust in the provider and institution, accessibility, and alternative care options.

**Discussion:** Factors that contribute to uncertainty and decision-making about ED use are both intrinsic (ie, cause, symptom severity) and extrinsic (ie, finances, accessibility). These domains can inform approaches to measure the uncertainty that patients experience, and to design and test interventions for nurses and other providers to help manage patient uncertainty during acute illness.

**Key words:** Emergency department use; Patient uncertainty; Emergency nursing; Quality of health care

Kristin L. Rising is Associate Professor and Director of Acute Care Transitions, Department of Emergency Medicine, Thomas Jefferson University, Philadelphia, PA.

Shannon K. Doyle is in the Department of Emergency Medicine, Thomas Jefferson University, Philadelphia, PA.

Rhea E. Powell is Assistant Professor, Department of Internal Medicine, Thomas Jefferson University, Philadelphia, PA.

Amanda M.B. Doty is in the Department of Emergency Medicine, Thomas Jefferson University, Philadelphia, PA.

Marianna LaNoue is Research Associate Professor, Department of Family and Community Medicine, Thomas Jefferson University, Philadelphia, PA.

Angela M. Gerolamo is Associate Professor, College of Nursing, Thomas Jefferson University, Philadelphia, PA.

For correspondence, write: Angela M. Gerolamo, PhD, APRN, BC, College of Nursing, Thomas Jefferson University, 130 South 9th Street, Suite 846, Philadelphia, PA 19107; E-mail: [angela.gerolamo@jefferson.edu](mailto:angela.gerolamo@jefferson.edu).

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## Introduction

Cost-containment efforts and changes in reimbursement models have led hospital administrators, researchers, and policymakers to focus on reducing use of the emergency department (ED) for nonemergent conditions.<sup>1</sup> Historically, research regarding system- and patient-level factors associated with ED use has been done primarily with retrospective review of medical records rather than obtaining patients' perspectives.<sup>2-4</sup> System-level factors that have been identified as reasons patients seek ED care for nonemergent conditions focus largely on issues of access to care and other logistical concerns such as financial barriers or transportation limitations.<sup>2</sup> Patient-level factors are attributed to psychosocial concerns including chronic poverty, mental illness, social isolation, and cultural norms as well as patients' beliefs about their own health and the health care system.<sup>3-6</sup>

In more recent research, patients were engaged directly to identify motivators for seeking unscheduled acute care. Findings suggest that patient uncertainty related to symptoms is a primary motivator for seeking care in the emergency department and ongoing uncertainty related to symptoms is an unmet need at the time of ED discharge.<sup>7,8</sup> In contrast to many of the factors identified by retrospective medical record review (financial concerns, social isolation) that providers may have limited ability to address, patient uncertainty is a factor that providers can address directly. To do so, however, we must first define the types, or domains, of uncertainty that patients experience to ultimately inform the development of targeted interventions to address the various domains of uncertainty.

Our objective was to engage patients to conceptualize the domains of uncertainty that potentially contribute to decisions to seek care in the emergency department. Findings from this research were used to inform development of a scale to measure patient uncertainty during an ED visit: the "Uncertainty Scale" (U-Scale).<sup>9</sup> We hypothesize that interventions designed to help manage patient uncertainty during an acute care encounter may improve patient outcomes. Thus, the ultimate goal of this research is to develop a means of identifying and intervening upon patients who are experiencing heightened levels of uncertainty during an ED encounter.

## Methods

### DESIGN

We used group concept mapping (GCM), a quasiquantitative/quasiqualitative method, to engage participants to describe how uncertainty related to new or ongoing symptoms con-

tributes to decisions to access health care in the emergency department. GCM is a method of "structured conceptualization," in which a group of stakeholders, defined by a common characteristic or goal, work together to define the meaning and boundaries of a difficult or complex concept through a sequential process of (1) brainstorming, (2) sorting, and (3) refining a set of ideas.<sup>10</sup> Ideas are generated in response to a focused prompt meant to elicit the features of the concept (qualitative), with final organization of the results performed through multivariate analyses (quantitative). GCM has been used widely across other disciplines for program planning and evaluation,<sup>11-16</sup> yet its application in health care has been much more limited.<sup>10,17</sup>

### SETTING AND SAMPLE

This study was conducted with patients at 1 of 2 hospitals within the same health system in the United States. One hospital is an urban academic teaching hospital with an annual ED census of 60,000 visits, and the second hospital is a university-affiliated community hospital with an annual ED census of 43,000 visits.

We purposively sampled 2 distinct populations to identify individuals who recently sought ED-based care that did not result in hospital admission, suggesting that factors other than strict medical acuity contributed to their decision to go to the emergency department. Purposive sampling is used to identify individuals who are knowledgeable about the topic being examined and will most benefit the study.<sup>18</sup> The first population included individuals who were ED patients at either of the 2 hospitals twice within the previous 30 days, with the more recent visit occurring within 3 weeks of the GCM session. The second population included individuals who were ED patients at either of the 2 hospitals within 3 weeks of the GCM session and had visited a hospital-affiliated primary care practice at least once within the previous year. Patients who presented to the emergency department for evaluation of an injury, requesting a medication refill, or with primary alcohol- or substance-use problems were excluded. We also excluded patients who were admitted to the hospital as a result of the ED visit, patients with significant psychiatric problems or other cognitive impairment potentially limiting their ability to participate in a group brainstorming session, incarcerated patients, pregnant women, and children (under 18 years of age). Eligibility criteria were purposefully broad to allow for recruitment of a diverse sample.

Based on guidance in the literature suggesting an optimal group size of 10 to 20 participants,<sup>19</sup> we aimed to schedule 30 patients per group for a target of 15 to 18

participants, accounting for up to a 50% no-show rate. We recruited 2 groups of participants for 2 separate rounds of GCM.

### PROTECTION OF HUMAN SUBJECTS

The study was approved by the university's Institutional Review Board (IRB). A member of the research team obtained written informed consent from each participant before the first GCM session. Standard measures were used to protect patient confidentiality, including use of a study-specific ID number to link patient identification to study materials, storage of all study materials in locked files, and use of a password-protected research database with access limited to key personnel. Participants were compensated upon completion of each GCM session, as follows: session 1 = \$50, session 2 = \$25, and session 3 = \$50. Funding was provided by the Emergency Medicine Foundation and the Emergency Nurses Association.

### PROCEDURES

We implemented GCM following standard guidance based on previous practice.<sup>20,21</sup> Each GCM iteration included 3 sessions on 2 separate days. In addition to participating in GCM activities, each participant completed a demographic survey that included age, gender, race/ethnicity, education, whether they had a primary care provider, level of education, household income, social support, use of health care services, and chronic medical conditions.

The first session was group brainstorming or idea generation. Participants were asked to respond to the prompt: "When experiencing symptoms, people might go to the emergency department when they feel uncertain about..." The prompt was developed by the research team and was pilot tested with a patient advisory panel with which the research team works closely. The prompt was reworded to ensure clarity and understandability after pilot testing. Members of the research team served as GCM facilitators to ensure that each participant had a chance to contribute ideas and that the group had exhausted all ideas by the end of the brainstorming session. If an idea posed by a participant was not consistent with the probe, the research team asked for further clarification of the idea's meaning. This approach ensured that the idea statement was relevant to the topic and conformed to the participant's intended idea, ultimately establishing confirmability of the data. This session lasted approximately 1 hour. Idea statements were projected on a screen in front of the participants' group in real time. Participants were encouraged to brainstorm out

loud in the group setting, but they also had the option to write ideas and give them to a facilitator during or at the end of the session.

At the conclusion of the first session, team members refined wording of the idea statements to ensure that they were all of a similar structure and tense (all in present tense, all starting with a verb). This was done to minimize differences in sorting (performed in session 2) due to differences in grammar as opposed to differences in ideas. The list of idea statements were then uploaded into the concept mapping software, CS Global MAX (Concept Systems Incorporated, Ithaca, New York),<sup>22</sup> in preparation for session 2. This software was used to perform all remaining data collection and analyses.

Session 2, "sorting," was completed independently by each participant on a computer using the CS Global MAX web-based software. Participants were asked to sort the idea statements into groups by dragging and dropping each idea statement into a "pile" of similar ideas and to name each pile based on the theme of the pile. After session 2, the participants' sorting data were processed by the software (see analysis details below) to generate a visual map ("concept map") representing the relatedness of each idea to the other ideas. On the map, each idea is represented by a point, with ideas that were almost always sorted together displayed next to each other on the map and ideas that were almost never sorted together displayed on opposite sides of the map. The computer then used mathematical modeling to suggest "clusters" of ideas that belong together.

Participants convened again 2 days later for the final session, in which they reviewed the concept map and the clusters that were generated by the software from their individual sorting data. During this session, participants were asked whether the final groupings (clusters) of idea statements were logical to them and whether there were any ideas contained within 1 cluster that belonged better in another cluster. Then they were asked to decide as a group the name for each cluster. This member checking ensured the credibility of the data. The final clusters were interpreted to represent patient-important domains that contribute to a person's feelings of uncertainty during acute illness.

### DATA ANALYSIS

Descriptive statistics were used to describe the demographic characteristics of the sample. Analysis of the sorting data was performed by the CS Global Max software.<sup>22</sup> For the first step, nonmetric multidimensional scaling (MDS) analysis was used to assign a location to each idea statement in a 2-dimensional space based on how often items were sorted

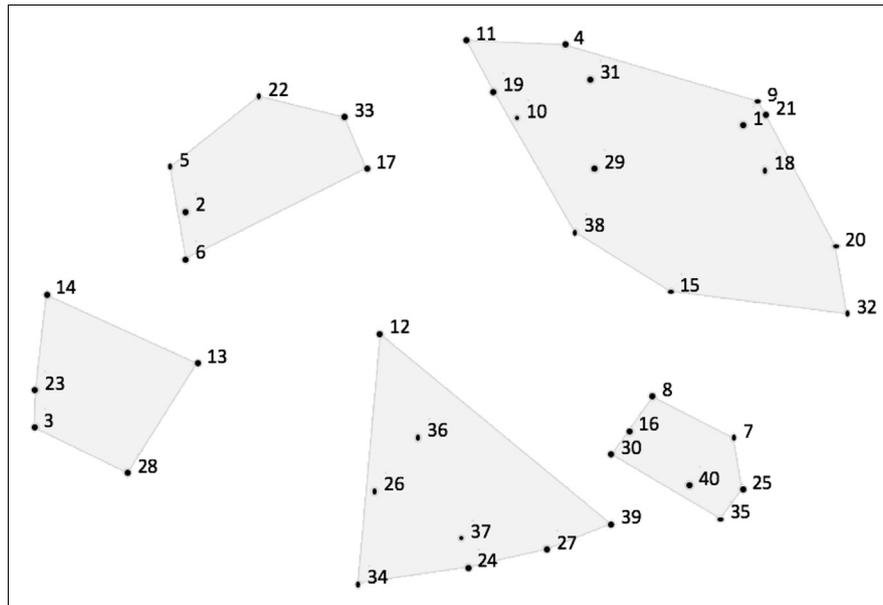


FIGURE 1  
Five-Cluster Map Generated by Group 1.

together. To do this, a distance matrix was created between all statements, which transformed the number of times statements were grouped together in a pile into a distance measure (the more often they appear together, the smaller the distance). Results from participants were aggregated for each item pairing. The 2-dimensional map (referred to as a point map) created from this process thus visually represents the similarity between 2 items.

In the second phase of analysis, a hierarchical cluster analysis was performed on the results of the nonmetric MDS analysis. The software grouped the items into clusters, producing multiple potential “cluster maps” (ranging from 2 to 15 clusters) for review (Figs 1 and 2). The research team reviewed each cluster map to determine adequacy and selected those thought to be most interpretable for review with the participant group. The participant group then selected the final cluster map during session 3, based on how well they thought the layout of clusters reflected similarity of idea statements.

## Results

### PARTICIPANTS

We conducted 2 GCM groups with a total of 34 participants. The first occurred July 9 to 11, 2016, and had a 49% “show” rate (13/29) to the first 2 sessions, with 77%

(10/13) returning the second day for session 3. The second group occurred August 8 to 10, 2016, and had a 60% “show” rate (21/35) to the first 2 sessions, with 76% (16/21) returning the second day for session 3.

Participants had a mean age of 47 years (range 23 to 78, standard deviation [SD] = 15.31), 65% were female, 68% were black, more than two-thirds (68%) had the equivalent of a high school education or less, and more than half (59%) reported a household income of less than \$25,000. Regarding their health, hypertension was the most commonly reported chronic condition (41%), although 21% of participants reported having no chronic conditions. The majority (85%) had primary care providers. Participants most commonly reported zero hospitalizations (38%) and 1 to 2 ED or urgent-care visits (47%) over the past year (Table 1).

### GCM RESULTS

The first group generated 40 statements during brainstorming. The research team and participants selected the 5-cluster map to be the best fit for the data based on conceptual interpretability. During session 3, the participants added 7 more idea statements not produced during the brainstorming sessions (for a total of 47 idea statements) and created a sixth cluster, later labeled psychological concerns. The final 6 clusters (domains) names identified by the group were consequences,

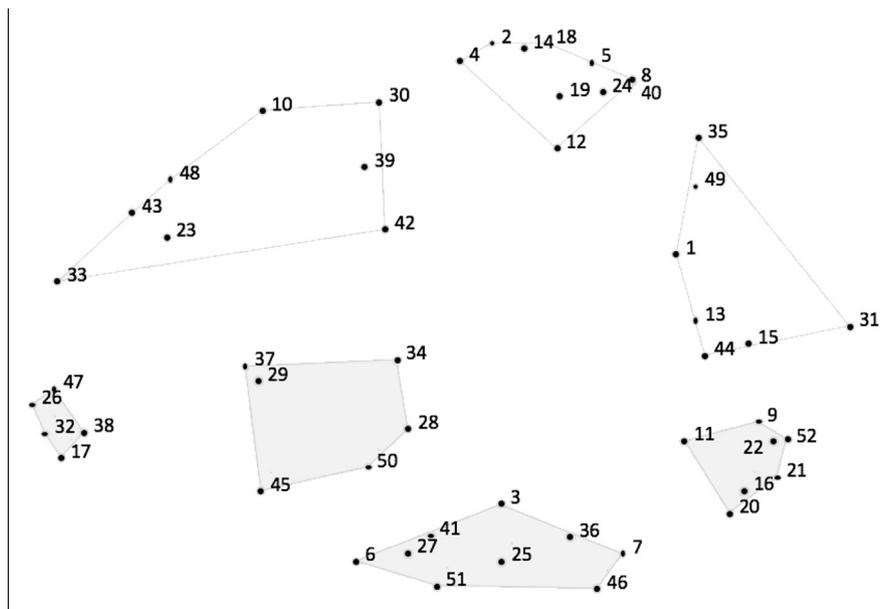


FIGURE 2  
Seven-Cluster Map Generated by Group 2.

severity, ED services, primary care options, finances, and psychological concerns.

The second group generated 52 statements during brainstorming. A 7-cluster solution was chosen as the best fit by the research team and participants. Unlike the first GCM round, no new idea statements were added during session 3. The final cluster (domain) names identified by the group were self-care and treatment, causation, diagnosis and treatment plan, trust in provider and institution, accessibility, financial considerations, and alternative care options. [Table 2](#) provides illustrative idea statements organized by domain for both groups.

## Discussion

We conducted GCM to elicit and organize patients' ideas about the domains of uncertainty that may contribute to decisions to seek health care in the emergency department when they experience new or ongoing symptoms. Patients identified 13 domains of uncertainty: ED services, primary care options, finances, trust in provider and institution, accessibility, alternative care options, consequences, severity, psychological concerns, self-care and treatment, causation, diagnosis and treatment plan. There was clear overlap in some of the domains identified by the 2 concept-mapping groups (finances vs. financial concerns

and alternative care options vs. primary care options), reinforcing the importance of many of these domains in contributing to patient uncertainty about symptoms. There was also unique contribution of domains from each group, suggesting that conceptualization of the construct of uncertainty related to experiencing symptoms as performed within these two GCM sessions may be incomplete, thus supporting future work to further explore this construct.

To facilitate interpretation, the team organized the domains into the following 2 broad categories: external factors (ED services, primary care options, finances, trust in provider and institution, accessibility, alternative care options) and internal factors (consequences, severity, psychological concerns, self-care and treatment, causation, diagnosis and treatment plan). This organization allowed for merging of thematically related domains and subsequent development of scale items for the "Uncertainty Scale."<sup>9</sup> It will also help inform development of interventions to manage patient uncertainty related to experiencing symptoms, as external versus internal domains of uncertainty likely require different types of intervention.

When comparing our findings to previous work, some of the domains we identified (for example, "severity" and "alternative care options") map to domains already in use within published conceptual models of emergency care use ("perceived severity" and "beliefs and knowledge about alternatives").<sup>2</sup> Other domains from this work, such as

TABLE 1  
Participant demographics (N = 34)

Characteristic	N (%)
Age, years - mean (range)	45 (21–76)
Female	22 (64.7)
Race	
Black	23 (67.6)
White	7 (20.6)
Other	4 (11.8)
Highest Level of Education Completed	
Less than High School Degree	1 (2.9)
High School/GED	22 (64.7)
College Degree	8 (23.5)
Postgraduate Degree	3 (8.8)
Annual Household Income	
<\$10,000	13 (38.2)
\$10,000–\$24,999	7 (20.6)
\$25,000–\$49,999	8 (23.5)
\$50,000+	3 (8.8)
Top Chronic Conditions	
High blood pressure	14 (41.2)
High cholesterol	10 (11.1)
Depression or anxiety	9 (26.5)
Blood clots	7 (20.6)
COPD, emphysema, or chronic bronchitis	7 (20.6)
None	7 (20.6)
Has a primary care doctor	29 (85.3)
Number of hospital admissions in last year	
0	13 (38.2)
1–2	11 (32.3)
3–4	8 (23.5)
> 5	2 (5.9)
Number of ED/urgent care visits in last year	
0	2 (5.9)
1–2	16 (47.0)
3–4	8 (23.5)
> 5	3 (8.8)

COPD, chronic obstructive pulmonary disease; GED, General Education Development tests certifying high school equivalency

“psychological concerns,” are novel and suggest potentially unexplored drivers of ED use, warranting further exploration in future work.

## Limitations

This study has several limitations. The study was conducted at 2 emergency departments within the same health system in an urban setting, so findings may not be generalizable to other health systems in different geographic locations. Our sample was composed of predominately African Americans (68%) and those with a low annual household income (59% with less than \$25,000 annually and more than one third with less than \$10,000). This sample is not representative of the overall US populations, as demonstrated by comparison with the 2015 US Census Bureau statistics<sup>23</sup> that shows a population that is 13% black or African American with a national median household income of \$53,899. However, the composition of the sample reflects the low-income predominantly African American population served by the 2 emergency departments in the study.

In addition, participants all likely had recall bias, as they were engaged in this activity after previous health events. We chose to engage participants with GCM to capitalize on the power of the group dynamic for brainstorming, although further work is warranted to explore this topic with patients during an ED visit to assess differences that may arise from patients who are currently experiencing symptoms and have just experienced health care encounters. Also, although the method of GCM has many strengths, the process requires the cognitive capacity to understand the question stem and to sort the ideas. Two participants had significant difficulty understanding and completing the tasks required, and despite assistance from the research team, they were unable to contribute to the sorting component of GCM. Finally, we are unable to comment on when and why these domains of uncertainty trigger patients to seek acute care, as we were seeking to describe the concept of uncertainty related to symptoms as a first step in understanding how uncertainty influences acute care use. Future work should be conducted with a larger, broadly representative sample of people who seek ED care across the US, both through similar GCM methods as well as individually during an ED encounter, to further conceptualize uncertainty related to symptoms that drive care-seeking behavior and to explore why and how these domains influence care-seeking behaviors.

## Implications for Emergency Nursing

This study contributes to the understanding of how and why uncertainty related to the experience of new or ongoing symptoms contributed to ED use. The domains of uncertainty provide a foundation for development of conceptual

TABLE 2

**Domains and illustrative idea statements for both groups**

Group 1	Group 2
<b>Consequences</b> <i>What might happen to you in the future?</i> <i>What will happen to you if you do not go?</i>	<b>Self-Care and Treatment</b> <i>What home remedies can treat your symptoms?</i> <i>Can you get the help needed if you stay home?</i>
<b>Severity</b> <i>Do the symptoms indicate a more serious problem?</i> <i>What is the severity of the symptoms?</i>	<b>Causation</b> <i>Are your symptoms related to a new condition?</i> <i>Are your symptoms caused by medicines you are taking?</i>
<b>Emergency Room Services</b> <i>How you will be treated based on previous experiences in the emergency department?</i> <i>What will be the wait time at the emergency department?</i>	<b>Diagnosis and Treatment Plan</b> <i>Will your treatments consider all your conditions instead of only your current symptoms?</i> <i>What side effects you will have from treatments you are given?</i>
<b>Primary Care Options</b> <i>How long you can wait for answers?</i> <i>Where else to go if you don't have a primary care doctor?</i>	<b>Trust in Provider and Institution</b> <i>How you will be treated in the emergency room?</i> <i>What hospital is best for treating each illness/symptom?</i>
<b>Finances</b> <i>What the bill will be?</i> <i>Where else to go if you do not have insurance?</i>	<b>Accessibility</b> <i>Will you will be sent to the emergency department by your doctor anyway?</i> <i>Will you will be able to get an appointment with your doctor at a convenient time?</i>
<b>Psychological Concerns</b> <i>Another means of escaping life situations</i> <i>How else to receive needed care from others?</i>	<b>Financial Considerations</b> <i>Can you afford to miss work?</i> <i>Will you get a bill for something that wasn't expected?</i>
	<b>Alternative Care Options</b> <i>Will the facilities closest to your home be able to give you adequate care?</i> <i>Is okay to wait until the next day to contact your doctor?</i>

models exploring uncertainty as it relates to the experience of new and ongoing symptoms and the role of uncertainty in influencing decisions to seek health care. In addition, these domains can inform development of targeted interventions for use by nurses and other providers. Such interventions may include enhanced discharge discussions with patients who are experiencing uncertainty in the “trust in provider and institution” or “diagnosis and treatment plan” domains, telephone calls or options for asynchronous messaging with patients in the postdischarge period for patients with uncertainty regarding “psychological concerns” or “self-care and treatment,” or printed information to better address common patient questions across all domains. The ultimate goal of this work is to facilitate and improve patients’ experiences with care transitions and reduce subsequent use of health care.

## Conclusion

Although previous research has described illness uncertainty related to a specific health condition,<sup>24–26</sup> to our knowledge, this is the first study focusing on assessing uncertainty experienced by patients related to symptoms not yet

linked to a specific health condition. The domains of uncertainty identified have already informed the development of a scale to measure patient uncertainty during acute illness, the “Uncertainty Scale” (U-Scale). Future work should focus on developing interventions targeted to these uncertainty domains for use by nurses and other providers to help patients with heightened levels of uncertainty during ED visits.

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