Care teams misunderstand what most upsets patients about their care

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A B S T R A C T

Background: Negative healthcare delivery experiences can cause lasting patient distress and medical service misuse and disuse. Yet no multi-site study has examined whether care-team members understand what most upsets patients about their care.
Methods: We interviewed 373 patients and 360 care-team members in the medical oncology and ambulatory surgery clinics of 11 major healthcare organizations across six U.S. census regions. Patients deeply upset by a service-related experience ($n = 99$, 27%) answered questions about that experience, while care-team members ($n = 360$) answered questions about their beliefs regarding what most upsets patients. We performed content analysis to identify memorably upsetting care (MUC) themes; a generalized estimating equation to explore whether MUC theme mention frequencies varied by participant role (care-team member vs. patient), specialty (oncology vs. surgery), facility (academic vs. community), and gender; and logistic regressions to investigate the effects of participant characteristics on individual themes.
Results: MUC themes included three *systems issues (inefficiencies, access barriers,* and *facilities problems)* and four *care-team issues (miscommunication, neglect, coldness,* and *incompetence)*. MUC theme frequencies differed by role (all Ps < 0.001), with more patients mentioning care-team coldness (OR = 0.37; 95% CI, 0.23-0.60) and incompetence (OR = 0.17; 95% CI, 0.09-0.31); but more care-team members mentioning system inefficiencies (OR = 7.01; 95% CI, 4.31–11.40) and access barriers (OR, 5.48; 95% CI, 2.81–10.69).
Conclusions: When considering which service experiences most upset patients, care-team members underestimate the impact of their own behaviors and overestimate the impact of systems issues.
Implications: Healthcare systems should reconsider how they collect, interpret, disseminate, and respond to patient service reports.
Level of evidence: Level III.

1. Introduction

The Institute of Medicine's *Crossing the Quality Chasm*[1] prompted closer examination of patients' healthcare service experiences. Positive patient experiences are associated with "patient-centeredness,"[2] which the report defines as "care that is respectful of, and responsive to, individual patient preferences, needs, and values."[1] High patient-centeredness scores, in turn, correlate with a wide range of clinically important consequences, including regimen compliance[3] and functional status.[4]

Although research increasingly documents the benefits of positive

healthcare service experiences, fewer rigorous studies have examined the role of negative experiences. This oversight poses a problem, as people do not equally weight negative and positive experiences.[3,5] Instead, negative experiences typically have greater effects on people's thoughts, feelings, memories, and behaviors than do equally powerful positive experiences.[6] The marketing science literature calls very negative experiences "disgusters," and finds that they impact consumers disproportionately more than do very positive experiences or "delighters."[7]

A small but growing literature suggests negative healthcare service experiences are associated with "doctor shopping,"[8] disuse or misuse of

medical resources,[8,9] medical malpractice suits,[10] lasting patient distress,[11,12] and increased mortality.[13] This literature also shows negative patient experiences include long wait times, systems inefficiencies, inept or substandard care, provider coldness and disrespect, and difficulties with information and communication.[14–17] Yet many of these studies examine single healthcare organizations, involve small samples, or precede the advent of electronic health records, advanced management tools, and public reporting of patient experience scores. Thus their findings may not generalize to other contexts or contemporary healthcare realities.[2,18,19]

A further challenge with understanding negative healthcare service experiences is that most surveys ask patients to rate their overall experience. This methodology can obscure the effects of individual events. For instance, a patient who is upset by a single instance of physician disrespect may nevertheless give a positive overall rating to physician interactions during a care episode.[18–21]

To better understand the frequency and nature of negative healthcare service experiences, we undertook an interview study at 11 highly rated U S. healthcare organizations, asking both patients and care-team members about patients' memorably upsetting care (MUC) experiences during current care at the facility. Our interview methods gave patients the opportunity to describe their MUCs as they felt them, rather than limiting them to *a priori* response options. To represent diverse facilities and geographies, we included six academic and five community-operated healthcare organizations distributed across six U.S. regions. In addition, we interviewed patients receiving ambulatory medical oncology services and ambulatory surgery services so we could study healthcare experiences of different durations.

A parallel aim of this study was to assess whether care-team members accurately perceive which healthcare service experiences most upset their patients.[22] Prior research suggests providers misunderstand patient experiences.[23,24] For instance, surgeons report lower spinal surgery complication rates than do their patients.[25] Yet an accurate understanding of patients' upsetting experiences is necessary for efficiently and effectively resolving them. To explore how well care-team members understand the sources of patient distress, we asked physicians and other patient-facing staff at each site which service experiences most deeply upset their patients.

2. Methods

To learn more about patient and care-team members' views of patients' MUCs, we employed content analysis methods, a common approach in social and behavioral sciences research. We first collected qualitative data and then analyzed it quantitatively.[26] First, using a critical incident technique (CIT) interview, a common tool in health services research,[27] a trained researcher followed a structured protocol to question all eligible patients and care-team members who opted into participation. The interviewer asked patients about the most upsetting healthcare event they had recently experienced at the facility and asked care-team members what they believe most deeply upsets patients about the healthcare provided by their team. Next, we identified the most memorably upsetting care (MUC) themes in participants' interviews. We then calculated MUC theme mention frequencies and used quantitative methods to analyze how these frequencies varied by participant characteristics.

2.1. Participants and settings

From February to July of 2015, we interviewed 373 patients and 360 patient-facing care-team members from the departments of oncology and ambulatory surgery (including general surgery, ophthalmology, plastic surgery, sports medicine, and orthopedic surgery) at 11 U S. healthcare organizations that had received high ratings via multiple national performance rating systems.[28] We sampled one academic and one community hospital from each of six geographic regions. Hospitals

had sufficient patient and personnel volume to achieve 80 total interviews over two days, assuming a 40% decline rate. We initially approached 12 sites, but no Northeast community site agreed to participate. As a result, the final sample included 11 sites.

Hospitals appointed a liaison (typically a charge nurse or clinic manager) in each clinic at each site to facilitate our in-person visits. We aimed to include 80 participants per site (20 care-team members and 20 patients in each of the two specialties), which was the maximum number we could feasibly interview in the allocated time. Eligible patients were English-speakers, 18 years of age and older, who were present on the research team's visit days. Surgical clinic liaisons identified all elective outpatient surgery patients except those recovering from surgery on that day. Oncology clinic liaisons identified all oncology patients except those who were experiencing their first dose of chemotherapy, feeling unwell at the time of interview, or receiving a cancer diagnosis that day. Researchers recruited all eligible, identified patients and allowed patient companions present at the time of the interview to remain; some companions intermittently aided patients in recall and provided additional perspectives.

Eligible care-team interviewees were all personnel with patient-facing responsibilities, including physicians, nurses, medical assistants, social workers, receptionists, and financial advocates present in clinics on visit days. We interviewed occupationally diverse samples at each site, recognizing that each member of a care team may have different experiences with and insights into patients' MUCs.[29]

The institutional review boards of investigator institutions and research sites approved all methods and waived the requirement of signed informed consent.

2.2. Interview questions

Interview questions are included in the supplement. To develop the interview guide, a multi-disciplinary team of healthcare researchers, economists, and sociologists convened and drafted a set of questions reflecting the insight that people disproportionately react to strong negative events. We then cognitively tested the interview questions with a small sample of patients and healthcare providers at a university medical center to ensure that each question was understood and would elicit upsetting events.

For patient interviews, we first asked participants to describe their most upsetting recent care experience at the facility currently providing their care. Our question presumed patients had experienced an upsetting experience to overcome participants' potential reluctance to respond. We did not define "recent," allowing participants to recall egregious events that felt recent even if they had occurred some time ago. We also did not restrict participant responses to just their surgical or oncology care. To reduce interviewer bias and to yield the required volume of responses, the interviewer limited follow-up questions to those of clarification, rather than in-depth probes.

To give participants a structured method to indicate the severity of their experience, we next asked participants to use a 0-to-10 scale (0 = *not at all*, 10 = *very strongly*) to rate how much the experience they described elicited each of seven reactions: fear, anger, anxiety, helplessness, confusion, depression, and feeling disrespected. Applying guidelines from the disgusters and critical incident technique literatures,[7,27] we limited our final, memorably upset sample to participants who gave a rating of 7 or higher on one or more of these negative reactions. We also inquired about patients' age and familiarity with the healthcare organization.

For care-team member interviews, we asked participants what healthcare service experiences they believed most upset their patients. Care-team members also indicated their familiarity with the facility employing them. (We also asked care-team members about what had most upset them in delivering healthcare, and what changes would improve this; these findings are reported in a separate study.[30]) We made no attempt to interview patients and care-team members who had

experienced the same MUC, and so in most cases we assume that patients and care-team members are discussing different events in their interviews.

One of two researchers traveled to each site and conducted the interviews in clinic rooms, conference spaces, break rooms, and infusion sites. Patient interviews lasted from five to 15 min, and care-team member interviews lasted from 15 to 20 min. To preserve privacy, researchers did not collect participant names or identifying information beyond role, clinic, facility type, and gender. Participants received $5 gift cards. Interviews were audio-recorded and transcribed verbatim. Reviews of transcripts confirmed that interviewers did not deviate from the standardized interview protocol.

2.3. Content analysis procedure

To identify MUC themes, we first selected a subsample of patients ($n = 99$) who rated the severity of at least one of the seven negative reactions to their recent service experience at a 7 or higher on a 10-point scale. Examining this subsample's interviews, two researchers used the thematic network method to identify *basic themes* in the upsetting patient experience narratives.[31] Basic themes were not mutually exclusive, meaning an interview could be coded as mentioning all, some, or none of the basic themes. The two researchers next applied the basic-theme codebook to the care-team member interviews, adapting it to account for new response types. Coauthors from diverse disciplines reviewed and refined these themes.

Using ATLAS.ti version 7.5 software, two different researchers next applied the codebook to a random subsample of 20% of the interviews and assessed their inter-rater reliability. The researchers then evenly divided the remaining corpus for final coding. After coding the entire corpus and examining response patterns, researchers aggregated the basic themes into *organizing themes* and *global themes*.

2.4. Data analyses

We used SPSS version 24. All analyses were nonparametric tests and thus did not assume normally distributed data. We set the statistical significance level to $P < .05$, and all hypothesis tests were 2-sided. To assess whether percentages of memorably upset and not-upset patients differed by specialty, facility type, or gender, we used χ^2 tests of independence. We then used χ^2 goodness-of-fit tests to ensure our sample included similar numbers of care-team members across specialties, facility types, and genders.

Next, we calculated the percentage of participants who mentioned each of the seven themes. We then used a generalized estimating equation (GEE) to test whether participant characteristics were associated with frequencies of theme mentions. We then followed up significant GEE effects (i.e., Wald χ^2 $P < .05$) with binary logistic regressions on each of the seven themes, with each regression model including the participant characteristics found to be significant in the GEE. Because higher-order interactions between participant characteristics were not significant, we removed them from final models. Although regressions are often used to test causal relationships, in this research we use them to measure associations between variables, without making claims of causality.

3. Results

3.1. Participant characteristics

The final sample included a total of 360 care-team members and 373 patients, 68% women, with a modal age of 50–59. Care-team members included nurses ($n = 118$), physicians ($n = 76$), medical assistants ($n = 68$), administrative staff such as receptionists and financial advocates ($n = 58$), and other providers, including dieticians, social workers, pharmacists, and therapists ($n = 40$). See the supplement for the distribution

of participants across regions, facility types, specialties, roles, and genders.

Of the 373 patients interviewed, 99 (26.5%) assigned a rating of seven or greater (0–10 scale) to at least one of the seven negative reactions. These 99 participants composed our sample of memorably upset patients. Percentages of memorably upset patients who experienced each of the seven negative reactions to their MUC experience were: anger (20%), helplessness (19%), anxiety (18%), feeling disrespected (13%), fear (12%), confusion (11%), and depression (7%).

Table 1 presents numbers of respondents by role, specialty, facility type, and gender. Percentages of upset and non-upset patients did not significantly differ by specialty or facility type. Yet significantly more women ($n = 66$) than men ($n = 33$) were in the memorably upset patients group, $P < .05$. Nonsignificant χ^2 goodness-of-fit tests showed the sample included similar numbers of care-team members across specialties and facility types, while a significant χ^2 test showed the care-team sample included more women ($n = 273$) than men ($n = 87$), $P < .001$.

3.2. Memorably upsetting care (MUC) themes

As Table 2 shows, the codebook included 11 basic MUC themes, which were collapsed into seven organizing themes and two global themes: *systems issues* and *care-team issues*. Inter-rater reliability tests for basic themes achieved Cohen's kappas ranging from 0.75 to 0.96, indicating "substantial" to "almost perfect" inter-observer agreement.[32]

Collapsing across patient and care-team member data, the most frequently mentioned organizing theme was *inefficiencies,* which 69.1% of participants mentioned. Inefficiencies fell under the global theme of systems issues and included the basic themes *scheduling problems* and *poor flow of care.* "There's no coordination between the different departments, so the left hand doesn't know what the right hand is doing," said a patient citing *poor flow of care.* A care-team member who mentioned *scheduling problems* reported: "There's a lack of letting patients know about appointments. We get in a habit of just scheduling them, and then when they don't come in, we say, 'Well, no one told us.'"

The next most frequent organizing theme was *miscommunication,* which 37.7% of participants mentioned. Miscommunication, a type of care-team issue, included the basic themes of *poor messaging* and *poor patient education.* Oncology miscommunication MUCs including patients not knowing their treatment durations, medications, physician identities, and other care plan details. Surgery patients' most frequent miscommunication MUC was lacking clear discharge instructions.

The third most frequent MUC theme was *access barriers*, a systems issue that 33.1% of participants mentioned. Access barriers included *inconvenience* and *cost/insurance.* As one care-team member explained, "If I'm prescribing a medication that is $6000 a month, and the patient has to pay $2000 out of pocket, it's impossible for the majority of the patient population."

Neglect, a care-team issue, was the fourth most frequent MUC theme, cited by 27.7% of participants. Neglect stories included care-team

Table 1
Participant characteristics: Percentages of memorably upset patients, non-upset patients, care-team members by specialty, facility type, and gender.

		Memorably Upset Patients $n = 99$	Non-upset Patients $n = 274$	Care-team Members $n = 360$
Specialty	Oncology	49 (49%)	137 (50%)	193 (54%)
	Surgery	50 (51%)	137 (50%)	167 (46%)
Facility Type	Academic	58 (59%)	186 (68%)	192 (53%)
	Community	41 (41%)	88 (32%)	168 (47%)
Gender	Female	**66 (67%)***	148 (54%)	**273 (76%)***
	Male	**33 (33%)***	126 (46%)	**87 (24%)***

Note: Bolded cells are significantly different from each other at *$P < .05$, **$P < .01$,* or ***$P < .001$.

Table 2
Memorably upsetting care (MUC) themes and percent of participants mentioning each.

Organizing Themes	% of Participants Mentioning	Basic Themes	Examples of patient experiences
Systems Issues			
Inefficiencies	69.1	Scheduling problems	Encountered glitches in appointments or long wait times
		Poor flow of care	Received rushed or inefficient care because of disorganization
Access Barriers	33.1	Cost/insurance	Had problems with financing, preauthorization, or coverage
		Inconvenience	Could not get care when, where, or how desired
Facilities Problems	11.1	Facilities Problems	Experienced dirtiness, noise, or parking or transportation issues
Care-team Issues			
Miscommunication	37.7	Poor messaging	Received incomplete, late, or false information
		Poor education	Didn't understand diagnosis, prognosis, treatment, or outcomes
Neglect	27.7	Neglect	Felt basic, medical, familial, or social needs were not met
Coldness	22.0	Coldness	Felt disrespected, disregarded, or affronted
Incompetence	12.4	Ineptitude	Perceived team member to be ignorant or unskilled
		Errors and harms	Received wrong diagnosis or treatment; was harmed

members not responding to patients' needs for food, medication, assistance, and other basic, medical, and social needs. Some incidents were quite traumatic: one patient reported requesting water for several hours without receiving it; another could not reach the bathroom; and another reported being ignored while having a panic attack in a magnetic resonance imaging machine.

The fifth most cited MUC theme was *care-team coldness* (22% of participants), which included care-team member rudeness, disrespect, and lack of sympathy. "The doctor thinks he's God," said one surgery patient. "I asked him if it's possible he could have made a mistake, and he went ballistic. I thought he was going to physically attack me."

Incompetence, a care team issue, was the sixth most frequent MUC theme, which 12.4% of participants mentioned. Incompetence included perceived care-team *ineptitude* and *errors and harm*. Most oncology patient mentions of this theme were of incorrect or delayed diagnoses, while most surgery patient mentions were intervention errors (e.g., a procedure on the wrong body part, an incorrectly placed feeding tube). In contrast, most care-team members who mentioned incompetence conjectured that patients are most upset by difficult injections and IV starts.

Although the health services delivery literature suggests that problems with the tangible environment –crowding, dirtiness, noise, and transportation and parking problems – can be memorably upsetting to patients,[33] *facilities problems* was the least-mentioned theme (11.1%) in this study.

3.3. Care-team members and patients have different understandings of MUCs

An initial GEE indicated the percentage of MUC theme mentions significantly differed by participant role (Wald $\chi^2 = 19.44$, $P < .001$) and facility (Wald $\chi^2 = 4.70$, $P = .030$).

As Fig. 1 depicts, significantly more patients than care-team members mentioned care-team coldness (38.6% vs. 48.5%, $P < .001$) and incompetence (31.3% vs. 7.2%, $P < .001$), while significantly more care-team members than patients mentioned inefficiencies (78.6% vs. 34.3%, $P < .001$) and access barriers (39.2% vs. 11.1%, $P < .001$). Binary logistic regressions of participant role and facility on each of the seven themes confirmed significant effects of role on systems inefficiencies (OR = 7.01; 95% CI, 4.31–11.40), access barriers (OR = 5.48; 95% CI, 2.81–10.69) care-team coldness (OR = 0.37; 95% CI, 0.23-0.60) and care-team incompetence (OR = 0.17; 95% CI, 0.09-0.31) (all *P*s < .001).

The effect of facility type was significant only for access barriers (OR, 0.52; 95% CI, 0.34-0.78), with more participants at academic hospitals (38.8%) than at community hospitals (26.3%) mentioning this MUC theme, $P < .01$. This finding is both novel and unpredicted and should be explored in future studies. Associations of participant role with MUC themes remained significant even after excluding facility type from the GEE and regressions.
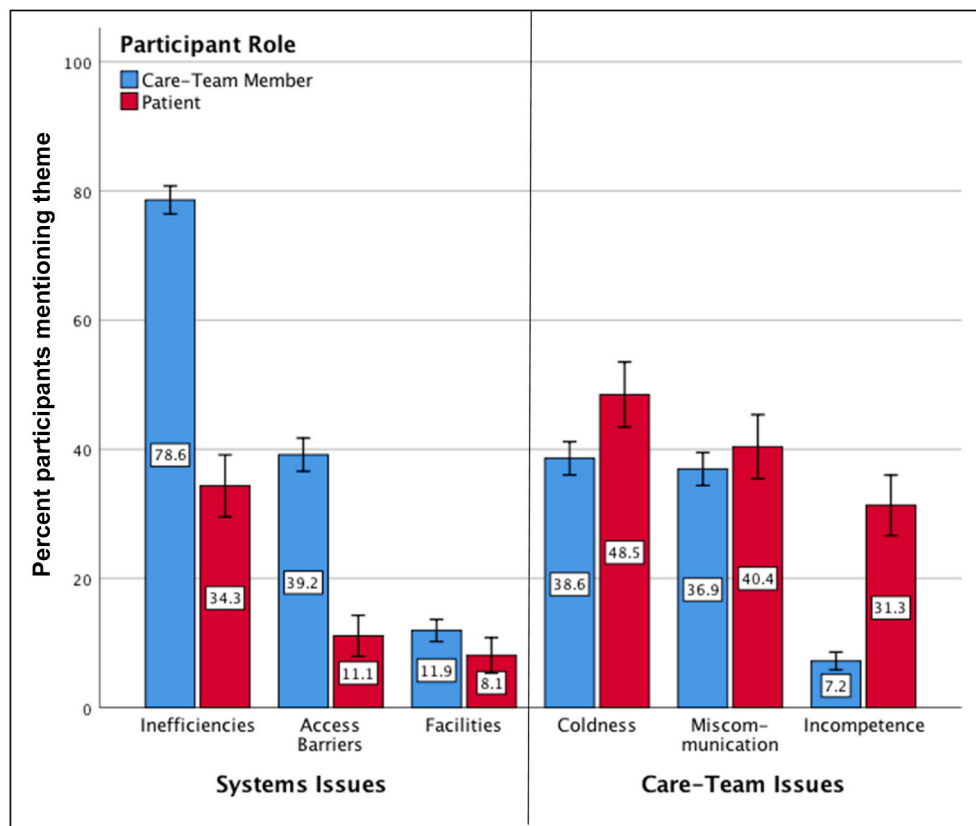
4. Discussion

This study is the first large, multi-site exploration of patient and care-team-member narratives about negative healthcare service events. In a sample of 373 patients at 11 diverse and highly rated U.S. healthcare institutions, more than a quarter (*n* = 99, 27%) reported a memorably upsetting care (MUC) experience, saying that some aspect of their care elicited strong fear, anger, anxiety, helplessness, confusion, depression, or feeling disrespected. This finding signals substantial room for improvement in U.S. healthcare.

Analyses of patient narratives further revealed that patients most often mentioned the care-team issues of *miscommunication* and *coldness*. In addition, almost a third of patients mentioned the care-team issue *incompetence*, while fewer than a tenth of care-team members mentioned this theme. Care-team issues included an anesthesiologist yelling at a patient minutes before surgery, a provider injecting cortisone in the wrong leg despite the patient's warning, and a patient losing toes because emergency department staff dismissed his self-reported medical history. Statistically non-significant relationships with specialty and facility type suggest that care-team issues are similarly prevalent in surgery and oncology, as well as in academic and community healthcare centers.

Meanwhile, nearly four out of five care-team members assumed that patients were most upset by system *inefficiencies,* mentioning this theme significantly more than did patients. About two out of five care-team-members pointed to *access barriers* significantly more than patients' mentions. In light of patients' data, these results suggest that care-team members overestimate the effects of systems issues on patient distress while underestimating the impacts of their interpersonal behaviors.

One reason care-team members may underestimate their role in patient MUC experiences is that most patient surveys do not fully capture the nature or impacts of individual events. Instead, these surveys ask patients about their overall service experiences across general domains. Relatedly, many measurement systems do not explicitly query patients about single instances of care-team incompetence, neglect, coldness,[26] or other negative interpersonal issues.[27] Instead of asking about "your visit" and "your care" in the aggregate, surveys should ask patients about "anything about your visit or care" or "the aspect of the visit or care that felt the most discourteous, unclear, insufficient, or inaccurate." To our knowledge, no post-visit surveys use questions framed in these specific terms. The results of such surveys should be shared openly with care-team members, with accountability and support

Note: Error bars are +/- 1 SE.

Fig. 1. Percentages of care-team members and patients mentioning each MUC theme.

for improvement.

Contemporary focus on average net promoter scores may also obscure individual MUC experiences. More effective management of patient care will require detecting memorably distressing events, even when average ratings are satisfactory.[25]

An additional reason care-team members may misunderstand patient MUC experiences is that patients may not fully disclose these events, because they feel intimidated or fear reprisal.[34] Improving care-team performance may therefore require giving patients more explicit assurances and protections.[28,29]

4.1. Limitations

In interpreting our results, several limitations should be considered. First, although we intentionally selected high-performing hospitals of two types across six census regions to yield conservative assessments of MUCs, our selection of leading hospitals still risks selection bias. Similarly, while we aimed to interview a census of patients and care-team members in two types of clinics, we did not track characteristics of non-respondents, and so we don't know the generalizability of our findings to other populations. We also conducted interviews only in English, and so we don't know whether our findings generalize to non-English-speaking participants, who may be at especially high risk of experiencing care-team issues like miscommunication. Another limitation is the short interview format, which may have limited the types of experiences participants shared. For example, no participant shared a story related to discrimination or bias. Additional research using longer interview protocols could uncover additional themes.

In addition, any study that endeavors to obtain critical accounts will be limited by participants' willingness to share upsetting events and their perceptions of such events. Indeed, a few patients reported events that seemed serious, but they did not report being upset by them. Other

patients reported being very upset by events that they perceived as medical errors, but which may have been routine, e.g., severe bruising following surgery. (N.B. educating patients about appropriate care was beyond the scope of this study.)

To overcome participants' reluctance to criticize care providers, our target question presumed that patients had experienced upsetting healthcare service. To offset the expectancy effects this framing may have introduced, we excluded experiences assigned a severity rating below seven on a 0–10 scale.

A strength and limitation of our care-team sample is its heterogeneity. Though we gained broad perspectives by sampling multiple member roles, how much care-team members misunderstand the causes of patient distress likely varies by role (e.g., doctors may be less accurate than nurses). With small samples for each role, however, we do not have enough data to explore these patterns.

A final limitation is that qualitative data analysis is subject to interpretation bias. Our use of an interdisciplinary research team and highly structured research methods aimed to reduce this risk.

5. Conclusions

Although upsetting service events can undermine patient health, care-team members may not adequately understand their own contributions to patient distress. To optimize health outcomes, healthcare systems may need to refine their approach to collecting, interpreting, disseminating, and responding to negative service event reports. To that end, future research should aim to validate standardized measures of MUC experiences. Studies should also more closely examine relationships between specific MUC experiences, patient reactions, and patient outcomes. Healthcare systems will also need to build infrastructure and offer training to address the problematic health service issues that such research is likely to reveal. In the meantime, healthcare systems should

be circumspect about relying on patient surveys that elicit summative ratings across major domains of service without probing for individual upsetting experiences.

Credit authorship contribution statement

Alana L. Conner: Conceptualization, Data curation, Methodology, Formal analysis, Writing – original draft, Writing – review & editing. **Beatrice V. Podtschaske:** Data curation, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing. **Mary Carol Mazza:** Conceptualization, Data curation, Methodology, Investigation, Formal analysis, Writing – review & editing, Project administration. **Dani L. Zionts:** Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Project administration. **Elizabeth J. Malcolm:** Writing – review & editing, Project administration, Supervision. **Carey C. Thomson:** Writing – review & editing, Project administration, Supervision. **Sara J. Singer:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision. **Arnold Milstein:** Conceptualization, Writing – review & editing, Supervision, Funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.hjdsi.2022.100657.

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