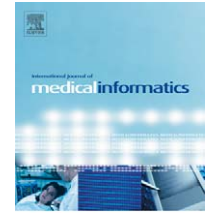




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# Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors

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## ABSTRACT

**Purpose:** Patients have the most to gain from reducing medical errors; yet, little research has been done to investigate the role they could or already do play in detecting and preventing errors in their own health care. The purpose of this study is to examine patient's role in detecting, preventing, and recovering from medical errors in outpatient oncology.

**Methods:** In this paper, we use cognitive work analysis and Rasmussen's taxonomy of human performance to describe five cases of medical errors that occurred in an outpatient, cancer-care setting. We detail the role of the patient in each case, and analyze each role using constructs from previous studies of human behavior and errors.

**Results:** Observational data indicates that patients engage in a range of tasks that identify, prevent, and recover from medical errors in outpatient cancer care. The results of this study point to the importance of considering patients and their work in both the design of patient-care information systems and the structure of clinical-care environments that enable safe and effective health care.

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## 1. Introduction

Patients and providers share a primary goal: to improve the current health of the patient and prevent future medical problems. Medical errors are a major threat to this goal and preventing medical errors is an important objective in clinical practice [1,2]. Because clinicians are responsible for directing, administering, and monitoring treatment, researchers naturally focus on clinicians' work in attempts to understand and prevent medical errors. However, clinicians are not the only actors in health care; patients also play an important role in their own care. Because recent work in error analysis suggests that an effective approach to understanding and preventing medical errors must account for the roles and actions of all actors involved in system processes [3,4], the

patient's work must be examined in our efforts to reduce errors.

In this paper, we explore the patient's role in detecting, preventing, and recovering from medical errors in outpatient cancer care. We begin with background information on how others have studied and modeled human error, both within medicine and in general human activities. Then, we present our study of the patient's role in medical errors, including an analysis of five cases of medical errors. We describe these medical errors from a patient point of view, use error research from human factors and medicine to describe salient factors in these events, and highlight the role that the right information did or could have played in these error situations. This work has led to insights both for the design of patient care information systems, and for the structure of clinical-care environments.

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## 2. Background

Human error is roughly defined as the failure of an action to achieve its intended outcome [5]. Note that this definition is broader than the medico-legal definition, which requires the error to cause actual harm. Errors occur because an actor(s) do not execute tasks correctly (e.g., slips or lapses) or do not implement the appropriate plan to solve a problem (i.e., mistake). Errors may be active errors (i.e., noticeable effects are present at the point of action when the error occurs) or latent (i.e., the actions that produce the error lie dormant within a system for some time before the error actually occurs). In general, latent errors and mistakes are more difficult to detect than active errors because latent errors and mistakes often are de-coupled in space and time from the effects of the error. Consequently, these types of errors are more difficult to study, and researchers know the least about how these errors emerge and what can be done to mitigate their effects.

### 2.1. Error research in medicine

In medicine, our understanding of errors is derived primarily from studies of adverse events in hospital settings. Researchers report the prevalence of adverse events between 2.9% [6] and 3.7% [7] of all hospitalizations. Although researchers disagree on the exact cause of adverse events, they frequently cite preventable clinical errors that occur during diagnosis [8,9] and treatment management [8,9], particularly during medication ordering and administration [10,11]. Researchers emphasize the role that information access and use – or the lack thereof – contribute to medical errors and their resulting adverse events. For example, a study of iatrogenic cardiac arrest found that over half of the arrests leading to death might have been prevented by closer monitoring of patients and their health status information [12]. As a result, many look to computerized systems to reduce errors in clinical care [2]. Ironically, researchers in medical informatics have noted that information technology designed to prevent errors can also produce unintended consequences in clinical care and sometimes actually facilitate medical errors [13].

### 2.2. Taxonomy of human performance

To help model human behavior in complex sociotechnical systems, Rasmussen classifies human performance into three levels: skill, rule, and knowledge-based behavior [14]. At the most basic level, skill-based behavior represents sensory-

motor performance that “rolls along without conscious control or attention.” Examples of skill-based behavior include riding a bicycle, driving a car, or playing the piano. Once we develop these skills, we do not actively attend to individual subtasks, such as moving the pedals, turning the steering wheel, or playing individual notes on a keyboard, and often find it difficult to articulate just exactly how we do them.

At the intermediate level, rule-based behavior represents human performance that is guided by rules of action that an individual has internalized through experience or adopted from an external information resource. The rules take the form: if situation X then take Y action. Each rule maps a known, usually familiar, situation to a plan of action. The planning involved in rule-based behavior is minimal: a person needs only match the particular situation that she encounters to a specific rule.

In contrast, knowledge-based behavior represents human performance that is consciously analytical and goal-oriented. Knowledge-based behavior often occurs in novel situations where people cannot find a well-matched rule, nor can they rely on their sensory-motor skills to solve the problem. A person engaged in knowledge-based behavior formulates an overall goal, analyzes the environment for relevant information, and develops a plan based on her own understanding of the problem space. We summarize this taxonomy of human behavior or action for medical oncology in Table 1.

### 2.3. Errors, medicine, and human performance

Reason shows the efficacy of Rasmussen’s taxonomy of human performance to describe and model error types [5]. For example, skill-based errors occur because actors are either inattentive or over attentive to a particular sensory-motor task. Rule-based errors occur because either actors apply an otherwise sound rule to the wrong situation or they apply an inadvisable, inefficient, or outright faulty rule. Knowledge-based errors occur because actors are limited by bounded rationality and “the fact that knowledge relevant to the problem space is nearly always incomplete and often inaccurate [5].” Extrinsic situational factors heavily influence knowledge-based behavior, and multiple paths can lead to a successful or unsuccessful solution. Consequently, knowledge-based errors are particularly problematic because they are highly variable, hard to detect, and difficult to predict.

In this paper, we use Rasmussen’s taxonomy of human performance and Reason’s subsequent model of error types to analyze five medical errors that occurred in outpatient cancer

**Table 1 – Summary of skill, rule, and knowledge-based action for medical oncology; adapted from [5] and [14]**

	Skill	Rule	Knowledge
Action-based on	Sensory-motor skills	Rules (if → then)	Active analysis of situation
Action description	Minimal conscious attention; action occurs in background	Map familiar situations with appropriate course of action	Formulate goal, analyze environment, generate plan
Example	Physically hanging IV medication	If the flow of IV medication slows unexpectedly, then check for blockage or extravasation	Generating an alternative treatment plan when unforeseen circumstances arise

care. Our goal is to understand these errors in enough depth to provide initial guidance for the design of information and support systems that facilitate effective human performance and thereby minimize errors in outpatient cancer care.

### 3. Methodology

We present data that emerged during phase one of a larger research project to study the tasks that patients perform during outpatient cancer care. We began with the assumption that it takes work to be a cancer patient. During cancer care, all patients navigate the health-care system, communicate with clinicians, and manage information related to their health situation. However, patients' work remains largely invisible [15–17]; we understand little of how patients accomplish their tasks or how existing systems and services relieve or exacerbate the burden of these tasks. In this section, we describe both our theoretical orientation and our methods for studying patients' work.

#### 3.1. Theoretical orientation

The theoretical framework for this study is cognitive work analysis (CWA) [18,19]. CWA is a work-centered, systems approach that was designed to analyze the cognitive work that occurs within a system [20]. The definition of system in this context is consistent with that from general systems theory, which defines a system as a set of interrelated elements that share a common goal or purpose [19]. Applying this definition, outpatient cancer care is a complex, socio-technical system that is defined by its primary purpose to improve the health of the patient and prevent future medical problems. As a system, outpatient cancer care consists of a variety of actors (e.g., patients, their family members, oncologists, surgeons, primary care physicians, nurses, technicians, schedulers) and resources (e.g., diagnostic technologies, treatment devices, medical knowledge, treatment departments, information technologies). Actors use available resources – individually and collaboratively – to perform tasks to improve the health of cancer patients within certain constraints.

CWA emphasizes the role of constraints within a system for two reasons. First, constraints are one of the few predictable characteristics of operational systems. Second, constraints define limits to active work within a system. For example, four constraints are important in outpatient cancer care:

- Patient care is distributed across different clinicians and departments.
- Clinicians have limited time to spend with patients.
- Patients spend the majority of their time during their treatment for cancer away from the treatment center (i.e., they return to home or to work after treatment sessions).
- Patients lack professional expertise in oncology.

Given these constraints, patients and clinicians must find a way to complete their work and minimize errors in outpatient cancer care. We return to these constraints in the discussion below.

#### 3.2. Data collection methods

In phase one of our research, we conducted in-depth interviews with 18 cancer patients between August 2003 and June 2004. Sixteen out of the 18 cancer patients were actively receiving treatment, and 8 out of 18 were actively undergoing chemotherapy. Study participants came from three types of treatment centers: community hospitals, comprehensive cancer centers, and university-based oncology centers. Patients varied in their educational background (e.g., high school to Ph.D.), profession (e.g., blue, white collar, retired, unemployed), and familiarity with the health care system. Eight interviews were conducted in chemotherapy infusion areas. These interviews became significant because we witnessed several of the events that we discuss below. In addition, five family members participated in the interviews. Two of these family members completed full interviews independently of the interviews conducted by the cancer patient. These interviews were helpful to triangulate data and elicit additional detail about events in which spouses participated or witnessed with the patient. When warranted, participants were re-contacted to clarify or supplement the statements they made during the interview.

## 4. Results

In this section, we discuss five cases in which patients identify medical errors, prevent mistakes from occurring, and act to ensure the quality of their care. Our goal is to describe the problems that arise in these cases, draw connections to Rasmussen's taxonomy of human performance, and examine how patients' actions shape the outcome in each situation. All quotations come directly from patients unless otherwise noted.

#### 4.1. Case #1—detecting procedural errors

Patients are careful observers of their own care. Many patients learn treatment protocols and can detect unexpected events that occur out of the bounds of intended treatment procedures. Consider the case of a soft-spoken woman being treated for breast-cancer. During one of her treatment sessions, she alerts staff that her IV drip had finished considerably earlier than usual:

“Cause it's obvious, [the nurse] says ‘this will take twenty minutes.’ But eight minutes later it was beeping [referring to being done]. I'm like [pauses] uh, that's not right. It turned out to be the confusion of the 50 milliliter bag versus a 100 milliliter bag.” After an investigation that verified the incident, clinic managers took steps to prevent this error in the future.

In this case, the infusion nurse made a skill-based error. The error was a slip that occurred when the nurse lost attentional control, likely due to some distraction in her thoughts or the environment. Infusion nurses administer chemotherapy medication through IVs hundreds of times in the course of their work. The procedure is routine and nurses quickly internalize the steps in the process: check the medication instruc-

tions, retrieve the IV bag, hang the bag on the IV, and adjust the flow rate on the infusion device. In this case, however, the nurse retrieved a bag with twice the intended concentration, hung it, and adjusted the flow rate for the lower concentration bag that she thought she had retrieved. The infusion nurse was familiar with this patient and told her – still thinking that she is administered the correct concentration at the correct rate – that the procedure will take the usual 20 min. In actuality, the patient received the chemotherapy medication at twice the concentration in half the recommended time.

Most observers of this situation would focus on the nurse and her actions. After all, the nurse is the one who committed the error. However, the patient was an important actor in this event. In fact, she performed significant work to detect the error which might otherwise have gone unnoticed. This patient was attentive to her environment and she picked up important information about her treatment procedure from the nurses. The information came in the form of a rule: this procedure should take approximately 20 min. When her medication finishes early, she uses this rule in combination with other information from her environment (e.g., empty medication bag hanging in the IV and beeping infusion pump) to detect a potential problem with her treatment. In effect, this patient engaged in rule-based work to detect a skill-based error. The patients' subsequent actions to report the problem enabled clinic staff to investigate the incident and make procedural changes to reduce the likelihood that other nurses would make similar errors in the future.

#### 4.2. Case #2—coordinating treatment tasks

Patients also prevent errors by coordinating tasks distributed across multiple health-care providers. Consider the case of a patient who arrived in the chemotherapy infusion area to get her hemoglobin levels checked. While waiting for the results of the blood test, she correctly aligned the work tasks of her nurses on two occasions: once when she interrupted the nurse's attempts to remove the access to her portocath, and a second time as the nurse attempted to apply an adhesive material over the portocath access area. In the first incident, the infusion nurse was unaware that the patient was part of a clinical trial that required a portocath access for the research nurse to perform additional procedures. When she noticed the infusion nurse's actions, the patient intervened:

“So, so, I said, ‘Wait! [the research nurse] is going to come and she is gonna want a couple of vials [of blood] so let's leave this [access] in until she gets here.’”

In the second incident, the patient correctly prevented the clinician from applying adhesive directly to her skin because – unknown to the nurse – the patient was receiving radiation concurrently in the department of radiation oncology, where the technicians had informed her not to apply adhesive directly to her skin in the area being irradiated:

[interrupting nurse's actions]

“Um, you know, I'm not sure, but I don't think I'm supposed to have, because of my radiation, she said I'm not supposed to have dressing.”

In both these incidents, the nurse engaged in rule-based work; the rules come in the form of well-established procedures governing routine chemotherapy visits. Although this nurse was attentive – for example, he noted that this patient was not scheduled to receive chemotherapy medication during this particular visit to the infusion clinic – the nurse remained unaware of other key aspects of this patients' health situation. Thus, the nurse initiated incorrect action because the rules he used to guide how he routinely cared for patients no longer applied in this situation.

Fortunately, the patient used information to coordinate her treatment and prevent rule-based errors. When the nurse initiated an incorrect action, the patient twice intervened with new information – essentially a new rule – that successfully modified the nurse's planned action. In the first incident, the patient used information to coordinate treatment activities conducted through intra-departmental actors: the research nurse and the infusion nurse. In the second incident, the patient used information to coordinate treatment activities conducted by actors across two of the treatment center's organizational units: radiation oncology and medical oncology.

Patients are particularly attentive to procedural information because they bear the consequences from the lack of coordination of different treatment activities that comprise their care. This patient made this point very dramatically later on in the interview when she again brought up the coordination issues between the infusion nurse and the research nurse:

Interviewer:

“So how do you remember all of these things?”

Patient: [in agitated voice]

“Cause, do you want to get stuck twice? That's how I remember, you know. Because I don't want to get stuck twice and I, I got caught last time. And so that's how I remember, you know.”

In this case, the patient was a crucial information resource in a fragmented care environment. Recall that one of the four main constraints in outpatient cancer care is that patients' care is distributed across multiple clinicians and departments. This patient facilitated the lateral exchange of information between different clinicians and departments. She used information to correct the rule-based work of the infusion nurse and ensured that the quality of her care was not compromised.

#### 4.3. Case #3—maintaining continuity of care

Patients actively maintain the continuity of their care when different clinicians rotate through the clinic. Patients in our study emphasized the importance of seeing their regular nurse in the infusion area. They took action to educate unfamiliar nurses or technicians to the nuances of their health situation, often out of concern for treatment side effects. Consider the case of a breast cancer patient who asked for a specific health status check:

“So, you know, I, I come in [to the infusion clinic] also saying: ‘Would you pay attention to my lungs?’ And that's one of the things about a new nurse. I would have to say: ‘Would you listen to my lungs as well.’ Because I really want to keep

track of that, you know. I, I don't have a spleen. That's part of what they do for Hodgkin's [a diagnosis 10 years earlier], take that out. And I'm at great risk of pneumonia and things like that. You know, I have to really watch out for that."

Like the patient in Case #2, this patient provided important contextual information about her treatment routine and 'filled in' for knowledge that was not transferred from nurse to nurse. The nurse took action based on well-established rules governing routine chemotherapy treatment sessions that do not necessarily include a specific respiratory check every time a patient comes in for chemotherapy infusion. The patient in this example had a simple request, however, and one that was easy to satisfy. When the regular infusion nurse learned of this patient's special needs, she incorporated the respiratory check into her normal routine during this patient's infusion sessions.

The patients' request can be represented as a rule:

if (I receive chemotherapy infusion)

then (I would like to have a nurse examine my lungs)

Unfortunately, this rule was not formally stored in the system. Instead, the rule was informally stored in a shared understanding between two people: the regular infusion nurse and the patient. The continuity of care broke down when this patient was assigned a different infusion nurse, a common occurrence in busy infusion clinics. Without the physical presence of her regular nurse, the information about the patient's care was unavailable. The patient then was responsible for remembering to request this event.

This case illustrates two dilemmas that patients experience in clinical settings. First, patients generally rely on intermediaries to communicate their preferences – often stated in the form of rules – to clinicians. For example, this patient had no formal way to inform the infusion clinic at large about her care preferences. The best she could do was to express her preferences to an individual infusion nurse, whom the patient assumed would communicate this information to the rest of the infusion unit. When this global communication did not occur, the patient became responsible for keeping the infusion clinic staff aware of her needs during each treatment session.

Second, patients seldom receive feedback on who does – or does not – have important information prior to treatment events. In this case, the patient never knew before her treatment session whether she was scheduled to receive care from her regular infusion nurse or from another infusion nurse. Consequently, this patient always felt on edge wondering when she would have to remember to provide important information about her care. Furthermore, this patient worried that other aspects of her care might not be known by different caregivers:

"Oh, there's things like um, I get hives from uh, alcohol. From isopropyl alcohol and so [the regular infusion nurse] remembers it and a new nurse comes in and I make sure that the new nurse isn't going to swab me down with alcohol. Uh, it's that kind of stuff."

In this situation, the patient is responsible for ensuring the continuity of her own care through information that she must

be prepared to provide to clinic staff in every treatment event. In effect, the treatment delivery system relies on this patient to ensure that the patient receives consistent, quality care across treatment sessions.

The error of not performing a patient-requested health-status check almost occurred because the clinic at large has no mechanism for storing important rules about individual patients' preferences or customized care needs. This case illustrates how patients act to prevent knowledge-based errors in the clinic. The informal information space developed between the patient and a single actor within the health-care system is inadequate to prevent these knowledge-based errors because many actors fulfill the same role to provide care for a patient. Thus, the patient needs to ensure that all actors caring for them have the necessary knowledge about their individual needs to provide high-quality care.

#### 4.4. Case #4—health status monitoring

Patients use formal (e.g., systematic recording) and informal (e.g., making mental notes) strategies to monitor their health status when they are away from the treatment center. Consider the case of a patient whose chemotherapy treatment was temporarily halted due to low blood counts and the presence of other side effects. Over the next several weeks, the oncologist experimented with multiple strategies to control these side effects. Eventually, the oncologist decided to continue the patients' chemotherapy treatment, but only at a reduced dose.

The patient was concerned about a possible reduced efficacy of her treatment and began to chart her own health status in relation to the medication that she received. She noticed that her blood counts remained at acceptable levels when she received a particular drug designed to bolster blood counts, specifically neutrophils, during chemotherapy. She used detailed notes to build a case that she could return to a full dose of her chemotherapy regime because her body was particularly responsive to a specific medication that elevates the level of neutrophils in her blood:

"They would've given me the [reduced] dose probably, I don't know, maybe until the end of the treatment. Because they were telling me: 'well, you know, some people just can't tolerate the full dose, and so you should just relax and you're still getting the [reduced] dose and that's OK.' And then I was arguing: 'There's a reason you have a full dose, you know, it's not just a number someone picked out of the air, that's an effective dose. I want the effective dose. And if you give me the right support to go with it, I can tolerate the effective dose.' That was my argument."

In this example, the oncologist detected severe side effects and used a rule – if blood levels are low, then reduce the chemotherapy dose – to manage these side effects. After the oncologists' decision, the patient builds her own model of her health status by charting her blood counts and other side effects in relation to her medication regimen over time.

"I mean, they were just happy to let me have the half dose. I was not happy to have the half dose. I remember that, higher dose then and less recurrence later on. So I wanted

the full dose. And I thought I could have it if I had the right support. So I, on that matrix I put what was my blood count, and like, how many, what GCSF I had had that week, how many doses on what days, you know, so they could sort of look at the frequency. And see how when I had like three GCSF shots my blood count was OK. When I didn't have it my blood count was low. So it [all the information] was all in one place and you could sort of go, see? And I got back to full dose."

This patient engaged in knowledge-based work to build a model of her evolving health status. She asked for information about her blood counts during her visits to the infusion clinic and integrated this quantitative information with qualitative information about other side effects that she detected when at home. She organized the information on a grid, and she used the grid to communicate with her clinicians about her health status. In subsequent meetings, the patient and her oncologist used her information to adjust her treatment plan to reflect her priorities for treatment, and she returned to the full dose of her medication for the duration of her chemotherapy treatment.

In this case, the oncologist used rules to manage the patients' side effects but engaged in knowledge-based work to balance the tradeoffs between the chemotherapy regimen and side effects. From the patients' perspective, a knowledge-based error occurred because the oncologist failed to act on information about this patients' specific response to her treatment over time. In this case, the oncologist appears not to have considered all of the details of the patients' evolving health status in an integrated form. In addition, the oncologists' knowledge of the problem was limited to weekly feedback (e.g., the blood draw) to make adjustments in the patients care. Furthermore, these adjustments were not always done through face-to-face meetings with the patient but rather through information passed through infusion nurses and lab reports. Thus, the patient remained uninformed about the actions – and the justification for those actions – taken by the oncologist.

The patient recovered from this knowledge-based error by performing rule and knowledge-based work. As an informed patient, she believed that a full regimen of chemotherapy was crucial to minimize her chances of recurrence in the future, a basic rule in medical oncology. She was not satisfied to receive the partial dose and she took initiative to chart her health status in response to the different components of her treatment as they were modified over time. Because she was very close to the problem – it was her health situation – the patient recorded detailed information about quantitative as well as qualitative components of her health status at a level of granularity unavailable – or at least unnoticed – to the oncologist. Finally, this patient initiated a specific, targeted discussion of these data points with her oncologist.

#### 4.5. Case #5—obtaining treatment information

A common way that patients participate in their own care is by asking questions. When patients ask questions, they sometimes catch gaps in information flow or treatment planning. Consider the case of a breast cancer patient who was sched-

uled to start chemotherapy within a week. She called her nurse to ask if she should get a flu shot after she heard through the media that supplies of the flu vaccine were running low in the region in which she lives.

"I asked her I said, 'with all this stuff I see in the media should I be getting a flu shot?' [The nurse] said: 'Oh my goodness yes, you're very high risk.'"

This patient wanted to be proactive about her healthcare. Upon hearing this information, she performs a series of tasks to secure a flu shot.

"So I thought: 'OK' so I get on the phone for myself. You have to be your own advocate on part of this. And I called public health and they said that up in the north end they still had some for very high risk patients. And they made an appointment for me that Monday. But then, I heard on the news that Thriftway down on Viewland Avenue was going to have these flu shots on a Sunday. And so I went and stood in line there with my husband for two hours. You know, I'm all weak, you know. Because at the time I was still kind of uh, and stood in line for two hours and paid our \$20 a piece and got our flu shots and I thought: 'Great, I've had my flu shot.'"

Quite proud of herself for being proactive about her health, she attended her first chemotherapy appointment 4 days later. During that appointment, the patient reported the following interaction with an infusion nurse:

"And then when I went in to chemo the following Thursday, this was Sunday after church I had it, I went into chemo Thursday to the nice nurse in the infusion lab and she, she said to me, and this is a different nurse from [her regular nurse]. And she says: 'Now be sure to stay away from people with colds and the flu because you know you are at risk' And I said: 'Oh, I had my flu shot on Sunday.' So I was being real proud of myself. And she says: 'You had it this last Sunday?' And I said: 'Yes' And she said: 'You should have never had it the week you're having chemo.'"

[participant throws up her hands and makes a disgusted face]

You know? And I'm like. She [nurse] said: 'Had you reacted to the flu shot we'd have had a real problem here.'"

In this case, the patient engaged in both rule and knowledge-based behavior to act on her own behalf. Initially, the patient heard a rule: if you are vulnerable to the flu, then get a flu shot immediately before limited supplies run out. She wondered how this information related to her own situation, and she sought information from the nurse to see if this rule applied to her specific situation. After receiving information that the rule did apply to her, she worked to obtain a flu shot.

Recall that an important constraint in outpatient cancer care is that patients lack professional expertise in oncology. The patient formulated a question based on what she knew,

but her knowledge was limited. The patient did not know to include other relevant information that could serve as a cue to the nurse answering the telephone that the general rule (e.g., if you have cancer, then you are at risk for the flu and should get a flu shot) might need to be modified based on procedural information about her treatment plan.

In this situation, we see three errors. The first error occurred when the information about the flu and the flu shot was not conveyed to the patient. Although the patient detected this rule-based error, she was unable to successfully recover from it. In fact, her subsequent actions caused the second error, getting a flu shot without consulting with her oncologist about the timing of the shot with her treatment regimen.

The nurses who interacted with this patient were engaged in this problem at the wrong level of human performance. The first nurse committed the second error, a rule-based error, when she misapplied an otherwise good rule. She gave the patient correct rule-based information – that the patient is at risk and she should consider getting a flu shot – without reasoning about what other information might be relevant for this case (e.g., where is the patient in the treatment process). In all likelihood, the nurse thought that she did her job well; she responded to a patients' inquiry quickly and concisely.

The second nurse committed the third error, a rule-based error, when she applied a wrong rule by giving the patient misleading information. Although the nurse was correct that oncologists try to coordinate additional medication – such as the flu vaccine – with ongoing cancer treatment; receiving chemotherapy does not necessarily prohibit patients from receiving a flu shot. Furthermore, the nurse failed to identify the most crucial error: the lack of communication between her oncologist and the patient. Instead, she blames the patient – albeit inadvertently – by chastising her for following the first nurse's instructions.

This scenario illustrates how patients use clinicians as information resources. Patients ask questions because they have incomplete knowledge of the intricacies of cancer care and the impact of different treatment options on their own health status. Patients value clinicians as an information resource not only because they can field specific questions and give direct responses, but also because they can contextualize information for patients based on their own professional knowledge of cancer care. When patients receive instructions – essentially rules – to perform tasks that could improve their health situation, rule-based errors are likely to occur if these instructions are not contextualized to a particular patients' situation. Rule-based action is particularly problematic when contextualized information is distributed across multiple actors. The root of the problem in this case lies not in individual actors but rather in the ability of these actors to build a shared representation of the problem with enough contextualized information to solve it without creating new downstream problems.

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## 5. Discussion

Patients do important work in outpatient cancer care. Using Rasmussen's taxonomy of human performance, patients do

rule and knowledge-based work to detect procedural errors, coordinate treatment tasks, maintain continuity of care, monitor their health status, and obtain treatment information. Patients do their work at home and at the treatment center. Although patients sometimes work independently, they often work by collaborating with clinicians. As these cases illustrate, an important outcome of patients' work is identifying, preventing, and recovering from medical errors.

As actors in outpatient cancer care, patients are valuable resources for safe and effective cancer treatment systems. Patients are the only actors physically present during every treatment and consultation event in outpatient cancer care. Therefore, patients carry with them important contextualized information as they move through a distributed system of care. To use Strauss' language, patients are uniquely positioned to observe, understand and monitor the overarching disease trajectory as it unfolds over time [15]. Patients use their intimate knowledge of their own evolving health status to intervene when problems arise in their care.

### 5.1. Implications for clinical research and practice

Our results have three implications for clinical research and practice. First, researchers need to examine the invisible work [15–17] that patients perform to ensure positive health outcomes in a distributed system of cancer care. Patients do important work to ensure that they receive quality cancer care, and our study has provided several examples of this work. However, further research is needed. Without a clear understanding of patients' work, we could underestimate their contributions to safe and effective treatment delivery systems and – by extension – the important role that they could play in preventing errors. Such a lack of knowledge could also introduce errors when new operational procedures or information technologies are implemented that affect the patient's work in unknown ways. Patients are rich information resources for researchers tackling the problem of errors in treatment delivery systems, and these valuable resources should not be overlooked.

Second, administrators, researchers, and clinicians need to redraw the boundary of the outpatient cancer care system to include important patient activity, even when it occurs outside the treatment clinics. As Cases #2 and #4 illustrated, much of patients' work revolves around coordinating care between different organizational units in which they receive care. In addition, Cases #4 and #5 demonstrated that patients do important work to try to integrate and communicate health information across the boundaries of home and the treatment center. Thus, when the system is viewed from only a single organizational unit's perspective or when the patient's home setting is ignored, many potential sources for errors are overlooked.

Third, researchers and clinicians need to support patients as key actors who work with others in outpatient cancer care to reduce medical errors. Compared to other actors in outpatient cancer care, patients have few resources to help them obtain, organize, share, and use health information effectively. Without such resources patients cannot work with clinicians to detect and prevent medical errors in their own care. Moreover, an information imbalance emerges in outpatient cancer care. This imbalance impedes system-wide

efforts to reduce medical errors because information does not flow freely between different actors with diverse – yet vitally important – perspectives on the delivery of care services. In complex patient-care environments like oncology, such information triangulation is an essential precursor to error detection, prevention, and correction. If researchers and clinicians would provide adequate resources, patients would increase the robustness of treatment delivery systems in outpatient cancer care.

### 5.2. Implications for the design of information systems

Our research also has implications for the study and design of information systems. One important finding from our study is that both patients and clinicians need better ways to share information about the patient's health situation. Sharing information is particularly problematic because of the constraints present in outpatient cancer care. Despite these constraints, information systems in clinical settings can support information sharing in three ways.

First, information systems can help patients share information with clinicians in a distributed care environment. Currently, patients have no systematic way to share information with multiple clinicians in a formalized way. As Case #3 illustrated, patients are forced to remember to inform and update each individual clinician involved in their care. Information systems can provide a shared information space where patients can push information out toward clinicians at any time of day or night. In this way, information systems could provide a mechanism for patients to directly inform clinicians of their needs, regardless of who actually gives them care at any given time.

Second, information systems can help both patients and clinicians understand patients' health situation, particularly their treatment plan. As a result of increased specialization, outpatient cancer care has become so fragmented that even clinicians have trouble identifying where any given patient is in her treatment plan. Cases #2, #3, and #5 epitomize the importance of contextualizing health status information with procedural information from the treatment plan. Neither patients nor clinicians know exactly what information follows the patients as they move through a distributed system of care. When contingencies arise from misunderstandings of what treatment the patient did, should, or will undergo, errors are likely to occur. By allowing patients and providers to view the same information about the treatment plan and upcoming treatment events, information systems can foster a shared understanding of treatment procedures. Information systems can help clinicians and patients view the same treatment information, and make discrepancies or problems more transparent.

Third, information systems can extend functionality beyond the boundaries of the treatment center or oncology clinic. The very nature of outpatient care requires that clinicians conduct consultations and direct treatment activities away from the treatment center. Therefore, information-at-the-point-of-care no longer means only at the treatment center. Information systems can help patients share information with multiple clinicians from home, work, and other personal spaces to enable effective outpatient care.

## 6. Conclusion

Our study provided several examples of how patients' work helps detect, prevent, and recover from medical errors. However, current clinical information systems do little to support that work. Generally, these systems do not extend functionality to patients, facilitate information sharing between patients and clinicians, or support clinical interactions beyond the treatment center. Consequently, patients have difficulty accessing and using information to participate in their own care. Thus, providers and patients cannot effectively share information. These consequences impede patients' ability to prevent medical errors and could actually encourage errors.

In the past, researchers and clinicians have focused on the fourth constraint – the fact that patients lack professional oncology knowledge – to discount the patients' ability to participate as a partner in outpatient cancer care. Yet, our examples show that patients' actions can be a crucial link that is responsible for identifying, preventing, and recovering medical errors. Furthermore, these examples point to new directions for supporting patients' actions in outpatient cancer care. This research provides us with important insights into the role that patients play in treatment settings, the actions they take to receive appropriate treatment, and the work that patients do to ensure the safe and effective delivery of health-care services.

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