


Piecing the Patient Story Back Together: Why the Patient and Caregiver Contribution Matters

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Abstract

Clinicians make decisions based on a large and complex patient information space in time pressured situations. Through continuity, experience, and privileged knowledge, the patient and caregiver(s) are in a position to support clinician decisionmaking through information delivery. For example, they may make salient relevant information or provide an integrated patient story to help clinicians overcome challenges of making decisions based on incomplete information. Recommendations of engaging patient/caregiver(s) include fostering a culture of listening by clinicians, speaking up by patient/caregiver(s), effective patient education and health information technology, and family-centered rounding and hand-offs. Using a lived experience, I illustrate the value of the potential impact of caregiver's informational contribution to patient safety.

Keywords

patient safety, critical care, decision making, communication

The clinical picture of a complex patient is like a puzzle whose pieces have been scattered. Long conceived as a story or as a narrative, the patient's clinical picture becomes fragmented across numerous clinician roles and technologies as a function of the care continuum. Despite its intent, clinicians report that the electronic health record (EHR) fragments the connections between patient data resulting in data that are not integrated, despite being collocated within the same system. Thus, no consistent continuity of information exists on the clinician side. In the current article, I discuss that through continuity, the patient and/or the informal caregiver may have some of these puzzle pieces and the connections between them. Using a lived experience anecdote (1), I illustrate the value of the potential impact of caregiver's informational contribution to safe and quality patient care.

My father, who had multiple myeloma, experienced kidney failure when doctors in the intensive care unit took him off intravenous hydration. He was also in the middle of a course of Vancomycin, a powerful antibiotic to treat Methicillin-resistant *Staphylococcus aureus* (MRSA). Vancomycin clears through the kidneys. I read in its Federal Drug Administration description—hydration has to be carefully monitored otherwise the patient will experience apparent kidney failure, which can be resolved with rehydration. The nephrologist, new to the team, concluded that the cancer was taking his kidneys and insisted on dialysis.

Patients and Families are an Underutilized Resource

Traditionally, health care research puts the clinician at the center of the work system. A recent research thrust in human factors has begun to focus on the active role of the patient within health care. This work has highlighted the need to understand patient work defined by context, cognition, and behaviors as well as skills and opportunities associated with health management activities on the part of the patient and caregiver(s) (2). Thus, recognition exists that patients are active participants in their care through activities including self-care management, patient-clinician communication, and decision making regarding treatment. More importantly is that through these activities, patients acquire (a) continuity across the care continuum, (b) experience with their health, along with (c) privileged knowledge regarding their condition. All of these elements are essential and potentially unique (unknown to clinicians) components

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of the patient story. In a way, they are the glue that binds together the patient data and information represented in the EHR and distributed across clinicians. Below, I describe the relevance of each component.

Continuity

As part of their *Patients for Patient Safety* program, the World Health Organization (WHO) aims to incorporate the patient and caregiver's voice into "all levels of health care through engagement and empowerment" (3). In 2007, the WHO stated that "the patient and family are the only constant and are thus in a position to play a critical role in ensuring continuity of care" (4). Although recognition exists of the patient's role in filling information gaps, research has not caught up to understanding the problem space around these opportunities, and operations have yet to create formal processes to support them. The limited studies that do exist suggest that not only can patients provide relevant information, but that this information is integral to patient safety. A 2017 study found that families reliably reported an additional 16% and 10%, respectively, of errors and adverse events above the clinicians (5,6). According to Khan et al (6), patients and families are an underutilized resource for monitoring patient safety and quality. Given their continuity across transitions and hand-offs, they are in a unique and important position to observe deviations in the processes of care. An example of a care deviation described by Khan et al of a parent-reported instance of a 12-hour delay in treatment of a patient with fluid accumulation in the lungs, despite parent reports of respiratory symptoms; among other examples are medication errors and missed diagnoses. Studies spanning multiple clinical environments (pediatrics, adult ambulatory surgery, and adult invasive cardiology) (5,6) suggest that not only are patients and caregivers' safety concerns valid, they are also unique. Thus, research in inpatient settings suggests that patients and families are in a position to report safety events that are undetected and undocumented by clinicians in adult (7,8) and pediatric care.

Experience

Given that the day-to-day responsibilities of disease management fall to the patient, they may develop a deeper level of understanding of their disease over time. Research findings suggest that patients who conduct day-to-day responsibilities of managing chronic illness or patient work, may develop deeper knowledge about their condition as a function of experience (9). This point is particularly relevant to patients with chronic conditions and long-term illness such as diabetes or cancer, primarily seen in outpatient settings with the majority of their self-care taking place in the home. For example, experienced diabetes patients are able to engage more meaningfully with their physicians during encounters by delivering relevant information compared to patients with less experience (10). The patient may come to this knowledge as a function of

necessity to manage their condition effectively, rather than through intent. Further, recognition of caregiver expertise (rather than just experience) is salient in domains, where the patient may not be legally and/or physically able to care for themselves like pediatrics and gerontology. These research areas highlight the need to further examine the patient and caregiver's role as an active participant who possesses experience (and potentially, expertise) through patient work.

Privileged Knowledge

Patient and caregiver have possession of knowledge regarding the patient status that includes history, routines, symptoms and potentially, an altered baseline. Lippa et al. (11) call this knowledge, *privileged*, to include phenomenology of symptoms and case history. It is particularly so in chronic illness. Holman and Lorig (12) discuss the patient role in the management of acute versus chronic illness. They suggest that unlike in acute illness where the onset of symptoms is sudden and the patient is inexperienced, for chronic illness that unfolds over time, the knowledge of the patient and the clinicians are reciprocal. The patient thus has privileged, and potentially, tacit knowledge about the unfolding complexity. Through interpretation and reporting of symptoms, they may play an active role in selecting management directions. This knowledge may or may not be shared or become part of the EHR but is potentially primed by a given situation as need arises. Research in situated cognition argues that it is situations in complex real-world environments that drive our cognition (13). Thus, in dynamic and fast-paced clinical environments such as emergency departments or critical care, situations define and potentially prime what information is relevant and may be need to be delivered by the patient or caregiver.

Why it Matters

Health care has long recognized that medical error is a significant problem. According to Makary and Daniel (14), medical error is the third leading cause of death in the United States. It is not included on death certificates or in rankings of cause of death. The additional complexity in medical error is that it can range from being nonconsequential to expediting an imminent death and to ending the life of someone who is has a long-life expectancy. Complex patients who are very sick and fragile are at more risk for medical error. For instance, overly aggressive treatment in critical care causes 30,000 deaths among Medicare patients and unnecessary interventions account for 10% to 30% of spending on health care in the US (~\$250bn-\$800bn) (15). Aggressive critical care protocols involving multiple complex interventions may be inappropriate for fragile patients and result in iatrogenic injuries. For example, a study by Rothschild et al reported that of 120 adverse events in 79 patients, 54 (45%) were preventable (16). Given that individuals with complex illnesses may be living with altered baselines, they

are particularly at risk for poor outcomes if the essential information is not communicated. Given that research suggests that (a) errors are often a function of ineffective communication across providers during handoffs within and transitions across environments, and (b) physicians make decisions based on incomplete information—patients and families are in a position to bridge these gaps through bringing relevant content to the surface (if buried in the EHR) and/or delivering brand new information.

Each of the above-described factors provide insight into the role of patient and/or caregiver as partner in providing safe and quality patient care. Below are summary statements regarding the significance of each factor:

- *Continuity*—patient/caregiver are in a position to fill in information gaps given they are the only ones that have continuity across the care continuum.
- *Experience*—patient/caregiver may develop deep knowledge regarding their condition allowing them to assess status change or deviation from baseline, which is potentially clinically relevant.
- *Privileged Knowledge*—clinically relevant knowledge (e.g., history, routines, symptoms, etc.) will remain privileged, resulting in an incomplete clinical picture, unless elicited by clinicians or delivered unprompted by patient/caregiver.

Revisiting my Father’s Story

Clinicians make medical decisions based on a large and distributed information space with information distributed across multiple individuals, technologies, and artifacts. On an outpatient basis, my father was seeing multiple physicians. In addition, he experienced multiple ER visits and hospital stays. When he experienced yet another acute event and landed in a teaching hospital, care became even more fragmented across the clinicians within the critical care setting. With each visit and event, the amount of patient data grows resulting in a large, complex, and fragmented information space—making it impossible for clinicians to consider all of the relevant information when making decisions.

In the case of my father’s kidney failure, in the face of copious patient data and time pressure, the nephrologist attributed it to the cancer. There may have been several factors at play contributing to his misdiagnosis: (a) he was new to the patient care team, consulted when kidney decline of a patient with cancer occurred, and (b) under time pressure, he collected information that he considered relevant. His intended treatment plan was kidney dialysis, an unnecessary and inappropriate course of action bringing with it additional complexity to my father’s already fragile condition. In this example, I had continuity across the critical care stay along with experience with his cancer, as well as privileged knowledge about the cancer trajectory. Table 1 represents the information that the nephrologist told us he considered, along with the

Table 1. Information Considered by the Nephrologist Versus Delivered by Patient’s Caregiver.

	Information Considered by Nephrologist	Information Delivered by Caregiver
<i>Cancer Status</i>	<ul style="list-style-type: none"> • 6 years since diagnosis • Cancer in advanced stage impacts kidneys • Recovering from sepsis after chemo 	<ul style="list-style-type: none"> • Cancer is stable and under control • Cancer has not metastasized
<i>Changes over last few days</i>	<ul style="list-style-type: none"> • No information 	<ul style="list-style-type: none"> • Taken off IV fluids in the last few days • Having trouble drinking thickened liquids after trach removed • Continuing Vancomycin

information that I delivered. Simply, hydration status fell through the cracks and was not considered by the nephrologist in making his treatment decision—an example of confirmation bias. Confirmation bias, or the tendency to seek out information consistent with one’s hypothesis and disregard the rest, is ubiquitous in many domains such as intelligence analysis and medicine alike (17). Research suggests that confirmation bias plays a role misdiagnosis, particularly for novice physicians. For instance, in the case of a patient with a complex illness, physicians may attribute symptoms of decline to the underlying condition rather than exploring other potential reasons such as drug interactions, side effects of medications, or effects of aggressive treatments. Experts in real world environments employ these decision making heuristics in the face of uncertainty and ambiguity because they save time, are adaptive, and work most of the time. An informed hypothesis by an expert physician is often correct, except when it is not. In this situation, by delivering clinically relevant information, I prevented an unnecessary treatment based on a misdiagnosis.

Conclusion and Recommendations

In this article, I described how the patient and/or caregiver are in a position to support physician decision making through information delivery as a function continuity, experience, and privileged knowledge. Thus, patients and caregivers can make salient clinically relevant information to help clinicians overcome challenges associated with making timely decisions based on a large and complex information space. I used a personal example to illustrate how through continuity in a critical care setting, caregivers can help support an integrated patient story integral to making an appropriate diagnosis and treatment plan. Several recommendations can help engage patients/caregivers in supporting patient safety and care quality including the following:

- *Culture of listening by clinicians*—listening to and creating information sharing opportunities for patients/caregivers
- *Culture of speaking up by patient/caregiver*—fostering a culture in which patients/caregivers can speak up with questions, concerns, and potential safety issues
- *Patient-centered education*—developing and implementing patient-centered education aimed at effectively navigating health care settings, signs and symptoms of concerns to watch for, effective communication strategies including when and how to speak up
- *Clinician- and patient-centered Health Information Technology (HIT)*—using human factors principles and methods, developing and implementing HIT that are both clinician- and patient-centered to support information sharing between clinicians and patients
- *Family-centered rounding and hand-offs*—engaging patients/caregivers in rounding and hand-offs to not only ask questions and voice concerns, but to also to potentially deliver clinically relevant information at a time when the patient care team is co-located

Authors' Note

Elizabeth Papautsky solely conceived of the idea and prepared the manuscript.

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Author Biography

Elizabeth Lerner Papautsky's research is focused on patient-centered care. She uses methods such as naturalistic observations, cognitive task analysis interviews, and artifact review. She applies findings to user-centered solutions such as interfaces, work flows, education and training, with the goal of improving patient safety and care quality.