



When Patients and Their Families Feel Like Hostages to Health Care

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Abstract

Patients are often reluctant to assert their interests in the presence of clinicians, whom they see as experts. The higher the stakes of a health decision, the more entrenched the socially sanctioned roles of patient and clinician can become. As a result, many patients are susceptible to “hostage bargaining syndrome” (HBS), whereby they behave as if negotiating for their health from a position of fear and confusion. It may manifest as understating a concern, asking for less than what is desired or needed, or even remaining silent against one’s better judgment. When HBS persists and escalates, a patient may succumb to learned helplessness, making his or her authentic involvement in shared decision making almost impossible. To subvert HBS and prevent learned helplessness, clinicians must aim to be sensitive to the power imbalance inherent in the clinician-patient relationship. They should then actively and mindfully pursue shared decision making by helping patients trust that it is safe to communicate their concerns and priorities, ask questions about the available clinical options, and contribute knowledge of self to clinical decisions about their care. Hostage bargaining syndrome is an insidious psychosocial dynamic that can compromise quality of care, but clinicians often have the power to arrest it and reverse it by appreciating, paradoxically, how patients’ perceptions of their power as experts play a central role in the care they provide.

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When my 6-year-old son was hospitalized for 3 months, I became acutely aware of how my typical consumer experiences differed from my experiences as the parent of a child in a life-threatening situation. If a restaurant were to present my son with food that appeared not to have been cooked properly, I would not have hesitated to assert my right to send the meal back. In a health care setting, in contrast, when my son received poor care (eg, a caregiver did not wash her hands), I hesitated to be assertive for fear of alienating the physicians and nurses whose goodwill we needed to maintain. I felt dependent and powerless, as if my son was a hostage to the care he received and the system that delivered it. It was as though I was compelled to negotiate for his safe release from potential harm.

—Personal communication,
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This story (of a parent whose child is receiving extended inpatient care) could just as easily be that of a 70-year-old man with coronary artery disease who is unsure about the cardiologist’s recommendation for surgery but hesitates to question it, or a 27-year-old woman with cancer who does not express her fear of treatment-related infertility to her oncologist. Patients and families often hold back from openly engaging clinicians in the thorough discussions that true shared decision making (SDM) requires.¹⁻³

We refer to this phenomenon as “hostage bargaining syndrome” (HBS) because, in the presence of clinicians, patients and their families may behave like hostages negotiating, from a position of fear and confusion, for their health. The behavior of adult kidnapped hostages has been categorized as cognitive (eg, confusion and disorientation); emotional (eg, fear and anxiety); and social (eg, withdrawal and avoidance).⁴ Clinicians who



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experience similar behavior in patients are unlikely to want their patients to feel like hostages, and many will actively encourage the patient's involvement in SDM, although this effort may be perceived as time-consuming in the context of competing priorities.^{5,6} Nevertheless, although a medical team actively works to assist, protect, and help make the patient well, many patients and their families still experience HBS and are reluctant to speak up.

Although HBS can arise in any medical context, it is especially seen when serious illness unfolds over the course of multiple, complex, emotionally laden interactions with clinicians. Cancer care and intensive care unit services, for example, each are characterized by a high degree of dependence and powerlessness for patients. To address HBS more effectively in any clinical scenario, from minor to life-threatening, we need to understand it and its causes from the perspective of the patients themselves.

BECOMING A HOSTAGE TO ONE'S CARE

Medical care has recently become more focused on serving patients as consumers, but some distinctions are important. Most commercial services are "want" services: consumers want to dine out, use a smartphone to send text messages to friends, or buy a ticket to attend a sporting event. Medical care is a "need" service that consumers-turned-patients often dread and may delay receiving.⁷ In using most commercial services, the consumer is in charge, deciding what service to buy and where to buy it; in a medical clinic or hospital, clinicians (and health care management) typically have the greater authority. This shift in the balance of power has especially high stakes in cases of serious, life-threatening illness, where anxious patients and their families can become particularly susceptible to HBS.

Hostage bargaining syndrome, which includes a reluctance to challenge people in authority, assert a different point of view, and question decisions that raise concerns, is an adaptive response to authority figures who retain *de facto* control because of attributes such as expertise, prestige, and position. Hostage bargaining syndrome often manifests as a form of compromise, such as understating a concern or asking for less than what is

desired or needed. Hostage bargaining syndrome may be perpetuated by asymmetry of information, an assumed hierarchy, fear of retribution, or fear of jeopardizing an important relationship.⁸ Patients and families who exhibit the symptoms of HBS refrain from questioning their doctors, hesitate to express concern about potential errors or harm, and worry about being perceived as troublemakers or "difficult" for fear that it could affect the quality of care they receive.¹

Hostage bargaining syndrome is an advanced case of "white-coat silence."³ It is especially prevalent when, as clinical conditions deteriorate and the stakes of health decisions rise, patients become more dependent on clinicians and more likely to seek favor from them in a deferential manner. They believe that "the doctor knows best" and conform to a socially sanctioned role of reluctance to assert their interests in the presence of experts.^{1,8}

To be sure, professionals typically do know best. Just as lawyers should draw on their expertise instead of merely reacting to clients' requests, and teachers should use their experience to expertly guide their classes rather than feeling pressured by students' whims, so too must physicians use their knowledge, training, and clinical judgment to steer patients with competence and accuracy. Ultimately, of course, lawyers, teachers, and physicians bear more of the social (and often legal) burden of accountability than do the populations they serve; in short, the pressure on the trained professional is high. But good lawyers also know that justice is served best when clients fully participate in how they access that justice, and good teachers know that getting students to invest themselves in the learning process makes it easier to achieve positive educational outcomes. So, too, do good physicians know that achieving desirable health outcomes is more likely when patients understand and participate in their care.⁹⁻¹³ All professionals face accountability pressures that are very stiff, but the people they serve may be profoundly affected by the outcomes and, therefore, deserve to be intimately involved in how those outcomes are pursued. Part of the professional's expertise is in knowing how to fully bring the person he or she serves into the process; it's a core element of the job.

In medical settings, patients and families are less likely to experience HBS when things are going as well as can be expected. Conversely, worrisome events—concerns about a change in the care plan, a medical error, an unexpected adverse effect, deterioration in the patient's condition, or a clinician's unresponsiveness to input from the patient or family—are likely to intensify HBS and lead to extreme anxiety, stress, and fear.^{1,14,15} Hostage bargaining syndrome may manifest as inner turmoil between speaking up or remaining silent, between assertiveness and inaction. The hesitation may even escalate to fear of saying much of anything at all. This risk is especially great when patients must advocate for themselves. Family members are sometimes better able to muster the courage to confront experts because they are not directly suffering the pain and dysfunction of disease and related treatments. Nevertheless, even family members can succumb to HBS, particularly if they are not well-informed about the patient's condition, which can be a critical loss of support for the patient.

One of us (T.S.D.), after interviewing parents of children who were being treated for cancer, sent this internal communication to the rest of our author team:

One mother told me that when she noticed a subtle change in her child's behavior, she informed a nurse, who promptly performed a routine set of tests that indicated no cause for concern. But the mother's worry lingered, and she lay awake rehearsing what to say to the consultant in the morning. She feared being perceived as disrespectful of the medical team's expertise, or as demanding and overanxious. She worried about saying nothing, but perhaps even more about the consequences of saying something. At times, she even doubted her own eyes and ears, wondering if she'd imagined the subtle change in her child.

Hostage is an unusual, perhaps startling, word in a health care context. We use it because it captures how people may behave when they feel deeply dependent on the health care system. However, unlike hostages whose

captors threaten harm to achieve financial, political, or other gains, the health care hostage is rarely the object of ill intent but, rather, susceptible to the ill effects of poor communication, highly technical processes, and professional precedents.^{1,2,16} We allow our systems to perpetrate this indignity even though almost no one in the system desires it.

LEARNING TO BE HELPLESS

If HBS is permitted to persist and escalate, the result can be learned helplessness, which takes root when people feel powerless to control their own situations.¹⁷ Perceiving repeated aversive events as beyond one's control can make a person expect future events to also be uncontrollable.¹⁷⁻¹⁹ The affected individual may overlook opportunities for relief, escape, or change, in effect simply giving up. Seriously ill patients are especially susceptible to learned helplessness because they routinely face uncontrollable, painful, and otherwise aversive illness events. If clinicians' actions are (inadvertently) disempowering, that behavior can deepen the patients' sense that circumstances are beyond their control.¹⁷

When patients or families believe they lack control over disease, illness events, and health outcomes; feel deficient in self-confidence or emotional capacity to assert themselves; or experience repeated authoritarianism in clinical encounters,¹ their helplessness can lead to passivity, neglect of health maintenance activities, and loneliness and depression.¹⁷ Asking questions, raising concerns, and actively sharing in decision making are effectively blocked. Recognizing HBS, and the potential for learned helplessness to emerge from it, offers the clinical team an early, fork-in-the-road opportunity: either allow HBS to fester or actively try to minimize or eliminate it, thereby preventing learned helplessness.

The true story recounted in the [Appendix](#) illustrates the conceptual distinction between HBS and learned helplessness. The mother of the ill child strongly experienced HBS but did not descend into learned helplessness. In this case, the educated parents had the resources, time, and will to learn the complexities of their son's illness. For many other families, this story could have ended quite differently.

FREEING THE HOSTAGES

When patients feel inhibited to participate in their care, clinicians may misread the behavior as disengagement or lack of interest, thereby eroding trust. This dysfunctional relationship may make patients less likely to adhere to medical recommendations and may contribute to misdiagnoses (because of poor symptom reporting), unnecessary pain and suffering, diminished quality of life and well-being, or even loss of life.²⁰⁻²² Hostage bargaining syndrome may also compromise the validity of patient surveys when, despite promises of anonymity, patients and family members hesitate to provide negative feedback that might adversely affect their future care. Labeled “acquiescence bias,”^{23,24} false-positive survey results about patient experiences hide opportunities for improvement and may lead to undeserved financial rewards for care that is not as good as it is reported to be.

The health care field now emphasizes SDM, whereby clinicians and patients share the best available evidence when faced with making decisions, and patients are supported in voicing their informed preferences.⁹⁻¹¹ Shared decision making re-envision the traditional clinician-patient relationship and, in that vein, is an antidote to HBS. Instead of primarily unidirectional communication from clinician to patient,¹⁶ SDM values and respects the patient’s self-knowledge, values, and lived experience as complementary to the clinician’s expertise, as both parties work toward the desired health outcome.

The evidence in favor of SDM, and its effects on outcomes and costs, is growing. A Cochrane review from 2017 showed that when patients used shared decision aids, there were improvements in their knowledge, understanding of risk, and likelihood of getting care aligned with their values.¹² Multiple studies have shown that SDM often leads to less invasive, less intensive therapeutic options and greater adherence to evidence-based care.⁹⁻¹³

Most clinicians encourage patients to engage in SDM and to have a voice in their treatment journey.²⁵ Similarly, most patients want to discuss options and share their opinions about treatment with their clinicians, and many seek to be involved in clinical

decisions.²⁶ Nevertheless, as a result of longstanding cultural norms and the authority gradient, patients often hesitate to speak up, ask questions, actively participate, or challenge clinicians’ expertise.^{2,8,27,28} Clinicians serve patients best when they frame available medical options in terms of the values and treatment goals that patients and their families articulate.

Despite the advantages of SDM, barriers to it can obstruct clinicians’ ability to deliver it well. Engaging in meaningful dialogue takes time, but clinicians today are able to spend less time with patients largely because of growing demands on them to respond to regulatory, reimbursement, and management requirements.²⁹⁻³² A recent study showed that for each hour doctors in outpatient practice spend delivering direct care to patients, they spend nearly 2 additional hours on electronic health record and other desk work.⁶ Growth in the electronic health record task load correlates with the rise in physician burnout and attrition.^{33,34} And many medical subfields, especially primary care, continue to have physician shortages as the average age of the patient population increases.³⁴ Physicians and nurses also express concerns about short staffing in hospitals, which limits their time for patient interaction.³⁵ In the litigious environment of health care, physicians necessarily prioritize their time toward providing the standard of care to their patients and documenting in the medical record the delivery of that care. Having a preformulated agenda, even a well-intentioned one, can limit physicians’ willingness to truly engage in SDM.

Creating a True Sense of Partnership

Health care is a knowledge- and skill-intensive service involving interactions among clinicians, patients, and patients’ family members. The quality of manufactured goods depends on the producer; service quality, including in health care, often depends (in subtle ways) on both the service purveyor and the consumer because the service is “coproduced.”³⁶ Parties on the supply and demand sides of the service exchange have roles to play and input to offer. For example, consumers advise hair stylists of their preferences and may give real-time feedback during the service, and

weight-loss consumers need to manage their diet and be physically active.

Service coproduction requires a true sense of partnership, whereby both parties feel safe in communicating with each other in a context of mutual trust. Consistently attaining this level of partnership in health care has been elusive,^{1,8,26,36} as the prevailing culture is one of deference to the clinician's expertise and status. This deference arises from the perception that clinical competence is the most vital ingredient in managing a person's illness. When HBS is present in cases of serious illness, it diminishes the patient's (or family's) influence when it is needed most.

A patient we know remembers a clinician who treated him like a true partner. The patient had just undergone open heart surgery for a mitral valve replacement. His primary care physician visited him in the hospital, sitting at his bedside for an extended period to map out a plan for primary care follow-up and to ensure coordination with his heart surgeon and cardiologist. He writes, "My primary care physician had the compassion to show me I would finally get out of the hospital and receive the routine monitoring and care coordination that I needed after discharge." It is that kind of partnership that can hold HBS at bay, not just for one interaction but potentially for the entire duration of the clinician-patient relationship. Such interactions become more difficult, of course, when a patient is cognitively impaired, is debilitated, or has a substance abuse problem. Partnership is a goal, not a blind mandate.

Fostering Trust and Communication

The cultural norm of patients' deference to a health professional is tough to overcome, and demographic and personality differences can play a role. Higher social class has been associated with greater communication with the medical team.³⁷ Educated patients with higher literacy levels receive more diagnostic health education from their doctors, ask more questions, and express themselves more assuredly³⁸⁻⁴⁰; less educated patients engage in less SDM, have a reduced sense of control, and are given less responsibility for their own health maintenance.⁴¹ Nevertheless, even educated and affluent people who are used to being in control often find themselves

without their customary authority, voice, and independence when serious illness strikes.

One of us (R.L.A.A.), a physician who herself became critically ill and witnessed the HBS dynamic, recounts her experience in this way:

Immediately after undergoing major abdominal surgery, I overheard a nurse label me as "difficult" when I refused an attempted blood sample draw until I felt that my pain was more adequately controlled. I sat, wordless, as the surgical team she summoned interrogated me about my home pain regimen (there was none). I felt hopeless as they attributed my pain to an imagined tolerance to opioids. In that bed, in pain, I felt terribly, frighteningly vulnerable, dependent on strangers for my most basic needs in addition to their complex care. I felt powerless in a way that is impossible to imagine when one is in a privileged position of wholeness and well-being. I know this because after that comment, I pathetically tried to ingratiate myself to the care team. I suppressed my fear and sadness, and attempted to make small talk with people who just moments earlier had made me feel belittled and somehow ashamed. I offered compliments and commiserated about burdensome charting responsibilities and unwieldy patient assignments. I believed that I needed to make them like me in order to receive their best care—in effect, to earn pain control through good behavior. I felt I had to prove to them that I was deserving.

Trust is an essential element in giving patients confidence in their relationship with a clinician^{42,43} and, thereby, countering the cultural underpinnings of HBS. Trust especially matters in cases of serious illness because of the duration, intensity, and frequency of interactions with clinicians; the asymmetry and complexity of information; and the vulnerability and uncertainty that patients feel.⁴⁴ Without trust, patients may not disclose all relevant information or even adhere to a clinician's advice and recommendations.⁴³ Trust can manifest externally or internally: Patients may not trust the clinician to welcome

their input and may fear repercussions if they offer it, or patients may not trust themselves and instead assume that the more experienced person is always right.⁴⁵

To gain trust, a cornerstone of SDM,^{23,44,46} clinicians need to demonstrate compassion. Because patients may not be able to gauge competence, compassion may be used by patients as a surrogate marker of competence. Clinicians must also maintain the patient's privacy and confidentiality, be reliable and dependable, have good communication and interpersonal skills, and show interest in the patient as a person.^{42,47,48} Clinical outcomes are best improved when the patient is both "informed and activated."⁴⁹

Educational campaigns, such as the Joint Commission's Speak Up initiative,³ encourage patients to engage in their care and ask questions. Indeed, high-reliability organizations have recognized that to succeed in creating a psychologically safe practice environment, certain high-risk communications should be structured with critical language that effectively allows for all team members to grasp the meaning.⁵⁰ The Agency for Healthcare Research and Quality advocates for empowering all members of the care team, including patients, with escalating assertive statements, easily recalled by the acronym CUS (I am Concerned, I am Uncomfortable, this is a Safety issue).⁵¹ The clinician's response to that engagement is of paramount importance.^{14,52} To elicit SDM and minimize HBS, clinicians should proactively—and repeatedly—invite candor by framing dialogue with patients as bidirectional and stressing that the patient's lived experience matters. Body language and physical positioning—sitting not standing, choosing a place on the same side of a patient's hospital bed as the family, making physical contact with the patient when appropriate, and minimizing distraction and interruption—signal that the clinician values the patient's and family's contributions to the care plan.⁵³⁻⁵⁵

Showing genuine empathy for the patient's situation, not just sympathy for the condition, invites patients and families directly into the conversation. Open-ended questions ("We value your input. What are your concerns about the plan of care that we've discussed?" and "How can we improve the care we're

giving you?") can be especially effective.^{56,57}

Clinicians can also directly invite patients to be critical observers of care, ask questions, and take specific actions. For example, some hospitals have made it possible for patients or family members to call a rapid response team of clinicians to the bedside if they feel that something is not going well clinically.⁵⁸

Elwyn and colleagues⁵⁹ offer a three-step model for how clinicians can achieve SDM in clinical practice. (1) Choice talk makes patients aware that a choice exists, such as saying, "Here are the possibilities. Let's figure out which one is best for you." (2) Option talk provides specific details about the options, including outlining potential risks and benefits in concrete terms for the patient. (3) Decision talk involves asking the patient to identify what outcomes matter most to him or her; examining those preferences in the context of the available clinical options; and, when the patient is ready, arriving at a shared clinical decision.⁵⁹ Incorporating patient and family input into decision making and treatment, when appropriate, strengthens partnerships and weakens HBS. What may seem like a small matter to clinicians can make an important impression, for better or worse, on the patient or family.

We recognize that using SDM to counter HBS is not universally possible because not every patient or clinical scenario allows for it. Exceptional situations include emergency care, when time may be inadequate to engage in more meaningful communications with patients and their surrogates; instances when a patient has cognitive impairment, dementia, or a current problem with substance abuse; and occasions when language or cultural barriers impede communication. Nevertheless, it is possible to lessen these challenges and those posed by time pressures on clinicians by reorganizing how they prioritize their time and tasks in clinical practice and by improving the clarity and efficiency of clinician-patient dialogue using translators and other support staff. In short, structural and systemic solutions can help mitigate some of the obstacles to SDM in clinical practice.

CONCLUSION

It is essential to disentangle precisely how barriers in the clinician-patient relationship

contribute, directly or indirectly, to negative health outcomes. Hostage bargaining syndrome, an insidious psychosocial dynamic whereby patients feel disempowered in relation to the medical experts who care for them, is always depleting and sometimes potentially dangerous. Arresting this phenomenon before it disintegrates into learned helplessness should be an aim of every clinician. Shared decision making achieves its promise only if clinicians understand and actively work against HBS. This essential effort—done with self-awareness, dignity, and grace—is how health care professionals can make collaborative decisions with patients (and their families) who do not fear that openness will undermine the quality of the care they receive.

APPENDIX. BARGAINING FOR MY SON

An example of hostage bargaining syndrome recounted by the mother of a 4-year-old boy with cancer who we call Noah.

My son, Noah, was to follow a specialized, evidence-based treatment protocol for his cancer. It requires 5 rounds of very high-dose chemotherapy. Consolidation, the final phase, is an autologous stem cell (bone marrow) transplant (SCT), which calls for 7 days of conditioning chemotherapy, 72 hours of rest, and then return of the stem cells, a fact I confirmed by reading the published protocol myself and corresponding with its lead author. However, the team at our hospital set Noah's SCT protocol at 48, rather than 72, hours of rest before stem cell return.

Before Noah's hospitalization for this treatment, I raised the inconsistency with the care team in writing but never received a satisfactory answer. The situation was complicated by the fact that the SCT was being performed at a different hospital with a different care team than we had during our induction chemotherapy. Apparently, given Noah's start date for treatment, a 72-hour rest period would have required staff to return on a Saturday (which they prefer not to do) rather than a Friday. The team argued that they had performed many SCTs and always used a 48-hour rest period. I felt very uncomfortable about this but initially relented, thinking "they must know best."

Noah was admitted to the hospital, and during the next few days my worry grew.

Again, I asked specifically how many times the team had used the 3 chemotherapy drugs in Noah's protocol before the stem cell return. They indicated that they had used combinations of 2 of these drugs, but never all 3 before.

Noah's cancer is a 1-in-3-million probability, so although the 3 drugs used in the protocol were all familiar to the team, they had no experience using all 3 in combination, despite their long experience with SCTs in general. My worry deepened, and as the day of stem cell return approached, I spent 2 nights with no sleep rereading the articles and researching other cancer diagnoses where the 3 drugs in Noah's protocol were used together before a stem cell return. The protocol with these drugs was always 72 hours of rest.

Almost in a state of panic, I raised the issue with Noah's care team again. They responded to me in a way that was overtly polite but that bristled with irritation and condescension as they insisted that the schedule was "fine." Fearing I would alienate the people who had to save my son's life during the next 6 weeks, as a last resort I again emailed the protocol author explaining my understanding of the protocol and literature. This was his response:

"There are protocols that wait just 48 hours, and that is likely safe for most patients (but, we all differ in the rate at which we excrete drugs)... However, I chose 72 hours for the reason that we want to be absolutely certain that all marrow-ablative chemotherapy has been excreted from the body when autologous cells are re-infused; otherwise, the re-infused cells could be damaged, and reconstitution of the blood could be delayed or, even worse, fail completely."

It was at this point that I felt most desperate. The clinicians at the hospital were not used to being questioned by parents who do so much research, yet I needed these people on my side during the "dangerous" stem cell return phase, when Noah would have a severely diminished immune system. I worried about speaking up, but I knew that I would never forgive myself if I did nothing and Noah suffered (or worse) as a result.

In the morning, I asked to speak to our consultant but was told they were “in clinic”. My husband then stepped in, as I was an emotional wreck, and emailed the head of the SCT unit, our oncologist from the induction phase of treatment (as we felt we had a good relationship with him, but he was at our former hospital), and the clinical nurse coordinator for our case. Approximately 30 minutes later, the head of the SCT unit and a group of colleagues arrived at the hospital room, whereupon I was given a thorough dressing down. It took all my might to hold my ground, but I am articulate, and I probably knew more about Noah’s protocol than anyone in that room. I also had the protocol author’s email.

Again, I asked for stem cell return after 72 hours of rest, demanding evidence that 48 hours was a safe interval, given the 3 drugs Noah had received. I was told that there was no evidence, there were no controlled trials testing and comparing these return time frames, but that the team had done thousands of SCTs and a 48-hour interval had never caused a problem. I asked again if they had ever used these 3 drugs simultaneously; they again said no but that they were sure a return at 48 hours would not compromise his recovery. I was lectured about how if I could not trust their judgment, Noah’s care might be compromised—as we had to work as a team.

After much back and forth, the team reluctantly agreed to the 72-hour interval, according to the protocol guidelines for using these 3 drugs. This meant getting a specialist team in on overtime, on a Saturday, to “defrost,” prepare, and oversee the stem cell return.

I was worried, not about the decision itself but about whether the team would have the will to do the best for my son given how I had challenged them so vociferously. It was a harrowing experience, but to this day I’m confident we did the right thing. Perhaps 48 hours would have been “fine,” but there was no way I was going to gamble with my child’s life.

—Personal communication, November 15, 2016, used with permission

Abbreviations and Acronyms: HBS = hostage bargaining syndrome; SDM = shared decision making

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