A "Narcotics Contract" for a Patient With Sickle Cell Disease and Chronic Pain

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ABBREVIATIONS
SCD—sickle cell disease
ED—emergency department

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For many physicians, the treatment of chronic pain is one of the most difficult clinical and ethical challenges that they encounter. Patients with chronic pain can be demanding, frustrating, and mystifying. In pediatrics, sickle cell disease (SCD) is a common cause of chronic pain. In this issue's "Ethics Rounds," we present the case of a patient with SCD and ask 2 experts on pain management to discuss the clinical and ethical issues. Carlton Dampier is a professor of pediatrics and assistant dean for clinical research at the Emory University School of Medicine; Carlton Haywood Jr is an assistant professor of medicine and core faculty in bioethics at the Johns Hopkins University.

CLINICAL ETHICS CASE REPORT: PART I

C.K. is an 18-year-old woman with SCD who has had dozens of hospital admissions and numerous visits to a clinic and the emergency department (ED) for pain crises. Over the previous year she often presented to the ED for treatment of her pain without having first called her hematologists. They have recommended—and stressed—that it would be better to call them first, because they know her and her disease and might be able to manage her pain at home and prevent the need for an ED visit. C.K. has generally listened attentively and promised to call the hematologists before going to the ED, but she then shows up at the ED unannounced.

In the ED, and on the wards when admitted, C.K.'s subjective evaluations of her degree of pain were often at odds with objective parameters such as vital signs and demeanor. Many times she experienced virtually no significant improvement with intravenous ketorolac or hydromorphone dispensed through a patient-controlled analgesia pump. Even an exchange transfusion did not diminish her reported pain despite a postexchange hemoglobin S percentage of zero.

Her doctors recommended psychotherapy. She initially refused to see a mental health clinician because "only crazy people see a psychiatrist, and I'm not crazy." After repeated discussions with doctors and social workers, she changed her mind. A psychiatrist diagnosed depression, and she prescribed mirtazapine.

On more than one occasion, C.K.'s physicians directly broached their concern that she exhibited drug-seeking behavior. Clinicians met several times with C.K. and her mother, step-father, and best friend to develop a more effective care plan. C.K. acknowledged that she had a lot of stress in her life and that narcotics relieved this stress.

An ethics consultation was requested by the hematologists to discuss the appropriateness of a "contract" for C.K. by which they would only continue to provide care for her if she agreed not to use the ED unless she first called her hematologists. If she failed to comply with the terms of the contract, her care would be transferred to an adult

hematology program. C.K. stated strongly that she wanted to remain with the pediatric hematology team and did not want her care transferred.

Question: Is Such a Contract Appropriate in This Case?

Carlton Dampier

This scenario is not uncommon and presents a number of important issues, for both the provider and the patient. Among patients with SCD in the United States, 5% to 10% account for >80% of the acute care visits and hospitalizations for SCD-related problems. These visits are almost always for pain. Considerable empathy and a high degree of therapeutic wisdom and skill are required to deal with patients such as C.K. The frequent admissions can be frustrating and can lead to mistrust between a patient and his or her provider. Each of them may blame the other for the apparent therapeutic failure. These complex cases often require a lot of time and resources, which adds to the frustration level.

Medical management of persistent pain often requires multiple medications that act on a variety of neurochemical pathways. Comorbid mental health issues such as depression or anxiety must be addressed, and a variety of cognitive-behavioral and complementary and alternative medicine techniques can be helpful adjuncts to pharmacologic management of stress, anxiety, or pain.

The clinicians apparently concluded that C.K.'s continued pain despite hypertransfusion indicated that her pain was factitious. This conclusion is incorrect. Pain can be experienced long after tissue injury has resolved. Permanent neuronal changes that enhance the sensitivity of the peripheral and central nervous systems are believed to underlie much of the experience of chronic pain.

Drug-seeking is frequently assumed to be the cause of the excessive use of narcotics, yet true addiction is relatively uncommon in pediatric SCD populations. Hyperalgesia from repeated opioid withdrawal or excessive opioid use are more likely medical explanations. These patients are often not drug-seeking but, rather, care-seeking because of poor psychosocial support, poor coping skills, and inappropriate therapeutic expectations. Assessing C.K.'s motivations would require more information than we were given.

In my view, such contracts are frequently misused in this situation as a means to modify behavior (excessive use of services) that is viewed as inappropriate by the health care team. They can be coercive and have relatively draconian consequences, as detailed in this case (termination of care). It is not clear what the pediatric hematologists are providing the patient as an alternative to ED care as part of this contract. Transfer of care might be the most appropriate option if the local pediatric care milieu has become nontherapeutic. However, transfer to another care provider (adult hematologist) might cause problems because psychosocial support resources might be less available, the adult ED system might be much more aversive than the pediatric system, and a new care system might be difficult for the patient to manage without a proper transition, all of which might heighten the risk of poor medical outcomes.

Written opioid management plans for chronic noncancer pain can be helpful and should be drawn up when chronic opioid therapy is initiated and should inform the patient of risks and benefits. Therapy goals should be discussed and agreed on. For example, patients should be informed of the methods for prescribing and taking opioids; the expectations for clinic follow-up, monitoring, and use of concomitant therapies; and the potential indications for tapering or discontinuing opioid therapy. These indications might include failure to make progress toward therapeutic goals, intolerable adverse effects, or repeated or serious aberrant drug-related behaviors. "Behavioral" contracts are most appropriate as part of an overarching medical management plan and should be jointly developed by the patient and provider, with the assistance of a neutral third party if necessary, and include mutually agreed-on goals, responsibilities, and contingencies. This plan seems to have been followed in this case. Excessive use of acute care services is best addressed with a comprehensive plan of outpatient medical management (day hospital), psychological support services and therapy, and consultation with specialists in pain management and, if necessary, addiction specialists. Because this pattern of excessive use has likely been present for many years, early identification of at-risk patients and their families would allow for earlier intervention with appropriate medical and psychosocial services and, likely, better outcomes.

Carlton Haywood Jr

All else being equal, it can be beneficial for a patient with SCD to call a hematologist before using an ED. At times, the hematologist might suggest changes in the therapeutic regimen that can be made at home and prevent the need for an ED visit, or he or she might work with the ED staff to shorten the amount of time the patient will have to wait to be seen.

Despite these potential benefits, a contract that requires C.K. to call a hematologist before using an ED is not ethically acceptable given the information about the course of her pain management as reported in this case study. Furthermore, the "punishment" of having her care transferred to an adult hematology service if she does not

comply with the contract is fraught with unintended harms.

Part of what makes the provision of pain management for SCD so challenging is that behaviors that often cause clinicians to question a patient's trustworthiness (eg, behaviors that might suggest that a patient is drug-seeking) might, in reality, indicate inadequacies in the provision of pain management to the patient. Often, these inadequacies derive from the limits of clinician and scientific knowledge regarding SCD.

C.K.'s medical team seems to be concerned that she is drug-seeking because of her subjective evaluations of pain, her reports of nonimprovement in pain after varied interventions, and her admission to using narcotics to help relieve stress. However, experts in the care of patients with SCD know that there are no objective physiologic signs that reliably indicate the presence or degree of SCD pain. Clinicians cannot accurately gauge a patient's level of pain on the basis of an examination of the patient's demeanor, because patients vary widely in how they express and cope with pain. It is not clear that the interventions provided to C.K. were appropriately tailored to her level of pain, her previous exposure to opioids, or the types of pain sensations she was experiencing (neuropathic versus nociceptive). We are not told whether she had ever been provided with education on coping strategies or had access to the social support needed to help her deal with the many stresses she experiences in life. It is not clear that a multidisciplinary approach with input from not only hematology and psychiatric providers but also from social workers and a pain or palliative care service has been used in managing C.K.'s care. All of these providers might address important contextual features of the quality of her previous care that must be taken into account when attempting to make judgments about C.K.'s trustworthiness as a patient. Without first addressing these various aspects of her pain management, it would be unfair to label C.K. as a "bad" patient, which would occur implicitly if C.K. is deemed to need a contract because she is viewed as drug-seeking and, thus, untrustworthy.

Assuming that C.K. did have access to the resources and multidisciplinary expertise noted and that there were few reasons to be concerned with the quality of the pain management she had received in the past, it is still inappropriate to use transfer to an adult hematology service as punishment in an effort to modify her "bad" behaviors. Instead, transfer to an adult program should be seen as an important part of the care of any adolescent with SCD.

Most patients with SCD today live to adulthood. At 18 years of age, then, C.K. should already be well into the process of transitioning from pediatric-centered to adult-centered care. The successful transition of patients with SCD to adult-centered care is now an essential component of a life-span approach to the care of this population.

When not facilitated properly by the pediatric health care team, the transition process for patients with SCD can be traumatic. It might stimulate intense feelings of loss or abandonment. The patient might not be adequately prepared to become an active participant in his or her own health care. C.K. needs to learn skills for disease self-management. She must be made aware of the importance of the transition process. If she does not, then she is at risk of becoming "lost" to the health care system. By casting her transition into adult care in a punitive light, C.K.'s medical team risks making the naturally challenging transition process even more challenging and might seriously hinder its success. This failure in making a successful transition could have a serious negative impact on C.K.'s long-term health. Rather than judging C.K. before all the evidence is in and condemning her to potentially inadequate care for the rest of her life, C.K.'s medical team needs to investigate the motivations for her behavior and develop a plan for transition to adult care that focuses on her needs rather than her transgressions.

CLINICAL ETHICS CASE REPORT: PART II

Shortly after the contract was agreed on, without having called the hematologists, C.K. returned to the ED complaining of pain. During the ED visit she asked for, and was given, narcotics. C.K. then made a phone call to the attending pediatric hematologist impersonating her mother and asked for additional narcotics. The story was corroborated by the ED staff and by a follow-up call to C.K.'s mother, who told the physician that she had never called him and that she was not involved in any of this conversation. When confronted, C.K. apologized. She understood that her inappropriate behavior violated the terms of the contract. She asked for one more chance.

Question: Should the Hematology/Oncology Team Refuse to Continue Treating C.K. and Refer Her to Another Center?

Carlton Haywood Jr

Sadly, by impersonating her mother to receive narcotics, C.K. has displayed objective behavior that might lead doctors to legitimately question her trustworthiness. Such behavior can destroy the mutual trust necessary for a doctor-patient relationship and might justify dismissing a patient from one's practice.

SCD, however, is unlike most other clinical circumstances. SCD is a serious and complex disorder that requires a comprehensive level of care

to ensure the best health outcomes for patients. It is also the most common genetic disorder identified by newborn screening in the United States. Despite its prevalence, however, there are few centers that can provide comprehensive SCD care. Good care for patients with SCD is far harder to find than is care for patients with less common genetic disorders such as hemophilia and cystic fibrosis. This discrepancy is particularly true for adult patients with SCD and raises questions about social justice that are often not addressed when physicians make clinical decisions.

Given these concerns, the standards necessary to ethically justify the dismissal of a patient with SCD from a practice should vary according to the level of care provided by the center and the availability of comparable levels of care at other institutions in the area. C.K. is currently receiving comprehensive pediatric SCD care. If no other center in the area provides a comparable level of care for adults with SCD, a higher threshold of inappropriate patient behaviors might have to be reached before it is ethically permissible to dismiss her from the practice and refuse to provide her care.

In addition, the hematology/oncology team must also attempt to discern and consider the reason that C.K. manipulated the team to receive additional narcotics. Has C.K. developed an addiction to the narcotic medications? Did this addiction develop over the course of her relationship with the pediatric team? If C.K.'s behavior is found to be a result of an addiction to narcotics, the ethically appropriate response of the hematology/oncology team would be to help C.K. gain access to the treatment she needs for her addiction. If the pediatric hematology/oncology team can provide her with the best level of SCD care, and the same center has the resources to incorporate treatment for addiction into her overall care plan, then the team should continue to provide her with this now-modified plan of care.

If the pediatric hematology/oncology team lacks access to the resources and services necessary to provide the additional level of treatment necessary for C.K.'s addiction, they should transfer her care to a center at which she could receive the addiction treatment she needs.

Alternatively, C.K. might not be addicted to narcotics. Instead, she might want to divert the narcotics to other persons for nonmedical reasons. Unlike addiction, which in itself is a medical condition that requires a special type and level of medical care, the desire to divert narcotics is not a medical condition that is amenable to therapy. A patient who diverts narcotics has displayed a serious breach of the trust necessary between the patient and the clinician. Such behavior crosses a line. In such circumstances, doctors might appropriately refuse to provide further care to that patient.

Through the act of impersonating her mother to receive additional narcotics, C.K. behaved in a way that can be used to justifiably question her trustworthiness as a patient. However, the complex and serious nature of SCD, inequities in the availability and distribution of comprehensive SCD care in the US health care system, and the medical implications of true substance addiction must all be taken into account when the serious act of dismissing a patient with SCD from a medical practice is under consideration.

Carlton Dampier

Should the hematology/oncology team refuse to continue treating C.K. and refer her to another center? No. I believe attempting to maintain a therapeutic relationship for as long as possible is usually in the patient's and providers' best interest.

By failing to comply with the contract, the patient might be showing that following the contract was of no real benefit to her, or it might be that well-established maladaptive behavior patterns can be difficult to change. Ongoing supportive counseling and behavioral therapy by mental health professionals as part of the overall pain-management plan might contribute to the success of the contact. Frequently reassessing the patient's behaviors and the contract goals with the patient and family is important. Although various agreed-on contingencies for noncompliance could be included in the contract, limiting ED care is difficult without the availability of medically appropriate alternatives.

The patient's inappropriate behavior in the ED is complex. Some patients develop maladaptive behaviors in an attempt to obtain adequate analgesics, a condition often referred to as "pseudo-addiction." Previous ED encounters with poor analgesic outcomes can lead to patient-provider disagreements over analgesic therapy, particularly in the setting of chronic pain, which can be difficult to assess and treat. A consistent, detailed, mutually agreed-on plan for prescribing ED analgesics, one that takes into account previous analgesic use and best practices, might be helpful but requires considerable coordination between ED care providers and on-call hematologists. The message that increasing opioid usage can be harmful and can cause more severe pain is often a difficult concept to convey to patients who view opioids as their only analgesic option. To be successful, the message would need consistent reinforcement from the entire health care team.

The hematologist's response to aberrant drug-seeking behavior should reflect a clinical judgment about its seriousness, its causes, the likelihood that behaviors of this type will recur, and the clinical context. Pain specialists suggest that patients who engage in limited relatively nonserious aberrant

behaviors should be managed with patient education and enhanced monitoring. More troubling behaviors, such as using multiple providers to obtain opioid prescriptions, forging prescriptions, frequently "losing" prescriptions, and frequently needing early refills, might be consistent with opioid diversion or addiction. Issues of opioid diversion might require interaction with local pharmacy regulatory or law enforcement officials depending on clinical practice guidelines and local legal statutes.

Treatment for opioid addiction is generally beyond the scope of practice of pediatric hematologists; it usually requires referral to addiction specialists or programs. Opioid tapering to reduce hyperalgesia should be accomplished by pain specialists with experience in opioid pharmacology. For medical situations in which pediatric hematologists decide that continued care in their program is not medically appropriate because they lack the necessary specialized expertise, referring the patient to a more appropriate adult care setting might be the best plan of action.

EDITOR'S COMMENTS

Nothing is as morally compelling as another human being who is in pain. As physicians, we want to do whatever we can to make the pain go away. However, nothing is as maddening as a patient who lies to us and seems to take advantage of our empathy and compassion. Sometimes, as in this case, these 2 challenges come together. It is a natural emotional impulse in such a case to want to dismiss the patient. As physicians, and particularly as pediatricians, it is important to recognize that emotional response, and acknowledge its temptations and its power, but not necessarily to act on it. Medical ethics sometimes demands that we not turn away from patients in need or turn them away from us, even when there are seemingly good reasons for doing so. Such patients need us more than most others.

—John Lantos, Section Editor

STAY AT HOME DADS: *On countless animal shows, juvenile male mammals, whether elephants or lions eventually have to leave the comfort of home and fend for themselves. The females usually stick together sharing hunting and infant raising activities, while the dominant male hangs out and defends his territory from attack or poaching. Of course, there are actually many variations on this theme. As reported in* The New York Times *(Science: June 1, 2011), among early human ancestors, it was not the males who left the home community but the females. Scientists reached this conclusion after examining the fossil teeth of 19 australopithecines living approximately two million years ago. By examining isotopes of trace amounts of chemicals such as strontium in the enamel of the teeth, the researchers could determine the geography of the diet consumed. To their surprise, males in the group were from the same locale but half the females had come from distant areas. The females apparently left the home community for neighboring communities after puberty. Such behavior is common among chimpanzees and some human hunter-gatherer groups. Why the females dispersed is not entirely clear, but one possibility is that males who grew up together were better able to defend their territory. Still a mystery is how human ancestors about 1.8 million years ago moved away from promiscuous behavior to a pair bond. As social structures cannot easily be discerned from the fossil record, we may never know the answer to that question.*

Noted by WVR, MD

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