Use of the Word “Crisis” in Sickle Cell Disease: The Language of Sickle Cell

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Abstract: Language matters. The words used to name and describe disease phenomena are a reflection of society. The authors address the use of the word “crisis” to describe pain in SCD, starting with a historical etymology of how the word came into use in SCD, the use of the word “crisis” to describe pain in SCD, and the result can be undertreatment of patients suffering severe pain, because people endure differing amounts of pain before stating they are “in crisis.”

What’s in a Name?
The diagnosis of illness never occurs in a vacuum. Historical and social factors are often embedded in the naming process. This social construction of illness includes the voices of patients, physicians, advocacy groups, government, media, insurance companies, scientists, and the pharmaceutical industry to name a few. It also includes an invisible context: transmissibility, moral judgment, and stigma. All of these ingredients make for a complex frame in which to hang what may seem like a simple diagnosis. Disease in this way goes far beyond pathology and genetics, and into the realm of medical sociology where people make Janus-like assignments: normal/abnormal, victim/villain, guilty/innocent, heroic/pitiable, good/bad. These assignments dictate how individuals, family members, and society perceive and respond to medical conditions.

If the meaning of an illness derives from what are its prominent features—such as hallmark symptoms, how it is contracted or transmitted, and/or the vulnerability of specific individuals or groups to it—this understanding is also bound to its name, which can convey subtle and not so subtle ideas about stated notions of good and bad. Collectively, these notions produce our biased assumptions about who has the disease, how they should be treated, how much attention they should get and respond to medical conditions.

In the case of SCD, the social factors that impact the perception of the disease (race, ancestral disease origin, education levels, poverty levels) begin with the diagnosis. In 1923, Sydenstricker and colleagues wrote that the sickle cell disease diagnosis is made “without difficulty—the race, the symptoms of anemia, with a history of rheumatic pains and abdominal crises, the scleral discoloration, the absence of splenomegaly, the presence or history of leg ulcer, all suggest the condition.” There is a specific social context in which this diagnosis was made. By 1923, medical researchers had begun to associate sickle cell with the black race. For decades after, though scientific racism was debunked, notions of inferiority regarding African Americans remained, along with...
assumptions that certain clinical experiences were inherent to the black race.

In the present day, many assumptions about SCD are still made in the medical community. Sickle cell disease and its related painful crises are often associated with urgency, unpredictability, bad behavior, narcotic use and abuse. These crises are also entrenched in power dynamics and certain racial identities that translate into implications for access to care, awareness of the disease, and legitimacy of the patient population and patients’ experiences. The historical, pathological, and personal narratives that follow will illuminate the importance of the word “crisis” and its relationships with the sickle cell population and outside worlds.

HISTORICAL PERSPECTIVE

Crisis. What does it mean to say that someone is “in crisis” or is “having a crisis”? Our usual understanding is that that person is experiencing “an emotionally stressful event or a traumatic change” in his or her life.6 “Crisis” is not now a medical word, though for centuries it was used as one. The Oxford English Dictionary’s (OED) first definition of the word is medical:

The point in the progress of the disease when an important development or change takes place which is decisive of recovery or death; the turning point of a disease for better or worse; also applied to any marked or sudden variation occurring in the progress of a disease and to the phenomena accompanying it.7

Despite the wording of this definition, diseases do not experience crises. Only human beings can have or be in a crisis. The classical medical “crisis” described above, where a patient has a fever that either breaks and resolves or progresses and ends in death, refers to a human event, not an event of the disease. This crisis is the result of the way the disease affects a person. Human observers label an event in the life of the patient with the disease a “crisis”—a critical point in the patient’s experience with a particular illness.8

Early use of “crisis” in English (1400s) referred to that turning point in a fever.9 The word originated from the Greek krisis, meaning “discrimination, decision.” The first use of “crisis” in English to mean a “decisive moment” is identified in the OED as occurring in 1627. This new use was a logical change in his or her life. According to the OED, “crisis” is now used to describe:

A vitally important or decisive stage in the progress of anything; a turning-point; also a state of affairs in which a decisive change for better or worse is imminent; now applied especially to times of difficulty, insecurity, and suspense in politics or commerce.7

The word thus came to be associated with events outside of existential human ones, for example the Cuban Missile Crisis or “the world is in crisis.”

How does this discussion of etymology relate to SCD? We refer to the acute pain episodes associated with SCD as “crises.” Why do we use that term? Certainly the image “sickle cell crisis” evokes is of a person suffering sudden-onset, unrelenting, excruciating pain that feels like it must be relieved immediately. Such a situation would appear to others as a crisis in the sufferer’s life.

The first description of SCD was published in 1910,10 the second, third, and fourth in 1911,12, 13 1915,14 and 1922,15 respectively. Based on the medical literature (which is the only source available because none of those early physicians or patients is alive today), physicians began using the word “crisis” in reference to SCD pain episodes after the fourth case appeared in print in 1922. By that time, Drs. Virgil P. Sydenstricker at the University of Georgia Medical Department (now called the Medical College of Georgia) and John G. Huck at Johns Hopkins University and Hospital were studying numbers of SCD patients. They and others recognized what came to be known as sickle cell anemia (SCA) as a disease entity with its own unique characteristics and applied certain words to describe those characteristics. “Crisis” became one such descriptor.

The first written record applying that word to SCA appeared in a paper Sydenstricker delivered in November 1923 at the Section on Pediatrics of the Southern Medical Association’s 17th annual meeting in Washington, DC, and subsequently published in the March 1924 issue of the Southern Medical Journal.16 (pp178,180,183) Referring to the diagnosis of SCA, Sydenstricker stated: “This [diagnosis] is made without difficulty. The race, the symptoms of anemia, with a history of rheumatic pains and abdominal crises [italics added], the scleral discoloration, the absence of splenomegaly, the presence or history of leg ulcer, all suggest the condition” (p180). In response to others’ comments during the discussion of this paper at the meeting, he used the word again: “We feel … that the gastric crises [italics added] with severe pain are due to infarcts of the spleen” (p183).

In another paper Sydenstricker delivered, this one to the Section on Practice of Medicine at the 75th annual session of the American Medical Association in Chicago in June 1924, he compared SCA to familial hemolytic icterus: “The jaundice in both is due to increased red cell destruction; the type of anemia is similar, and the evidences of erythropoietic activity seen in the blood are much alike. Both diseases exhibit hemolytic crises [italics added] with increase in jaundice and in pigment excretion, with diminution in the red count and hemoglobin, and with abdominal pain referable to the spleen.”17 (p12) He repeated this observation in a comment made after a paper on SCA delivered by his colleagues WA Mulherin and RW Houseal at a meeting of the AMA Section on Diseases of Children in 1924 (perhaps the same AMA meeting as above—in June in 1924, but the discussion appears in the 1925 Annual Report of the AMA).
Chicago: “We have seen [sickle cell] cases pass from the latent into the active state, and vice versa. In the first instance [latent to active], the development of ‘activity’ is associated with ‘crises’ similar to those seen in congenital hemolytic icterus.” In 1927, only one author of an article on SCD used the term “crisis” with regard to a severe pain episode:

The clinical picture of meniscocytic anemia presents varying degrees of anemia, palpitation, weakness, dyspnea, muscular and arthritic pains without evidence of inflammation, a greenish-yellow discoloration of the sclerae, abdominal crises [italics added], ulcers of the legs, and a tendency to remissions and exacerbations. The clinical picture of meniscocytic anemia presents varying degrees of anemia, palpitation, weakness, dyspnea, muscular and arthritic pains without evidence of inflammation, a greenish-yellow discoloration of the sclerae, abdominal crises [italics added], ulcers of the legs, and a tendency to remissions and exacerbations.

The term appeared in a French medical-journal article the following year and then occasionally in sickle cell articles over the next few years, usually in reference to abdominal pain. By the early 1930s, the term seems to have become part of the lexicon of those treating SCD patients. Indicative of physicians’ acceptance and common use of “crisis” in sickle cell disease are two articles that include the term in their titles. The authors of the 1931 Journal of the American Medical Association article “The Pathology of Sickle-Cell Anemia: Report of a Case with Death During an ‘Abdominal Crisis,’” remarked that “crises of abdominal pain are not uncommon in this disease” and that a patient of theirs “was suffering from the usual ‘abdominal crisis.’” The following year, an entire article in another prominent medical journal discussed the topic: “Abdominal Crises in Sickle-Cell Anemia.” The word “crisis” was becoming an integral part of the language of SCA.

One of the hallmarks of the disease from the very first case onward was pain—epigastric pain, gastric pain, muscle pain, joint pain. For example, in that first recorded case Herrick described one of Walter Clement Noel’s episodes as “one of his ‘bilious’ attacks, in which he had had quite severe epigastric pain.” Often authors added the modifier “severe” to the description. Just as often they used the word “attack” or other terms such as: critical attack, episode of severe pain, severe pain(s), paroxysms of prostration, paroxysmal crises, periods of distress, paroxysmal abdominal pain, critical episode. Both “severe” and “attack” moved the description of SCA symptoms from strictly clinical, medical-journal-like language to the language of feeling—language that gave readers some insight—even if they did not realize it—into what people with SCA were experiencing. The word “crisis” added an even more human dimension to the description. It gave the reader a sense of the immediacy of the patient’s situation.

Or it should have. Physicians, however, had been applying “crisis” to other medical conditions since the latter part of the nineteenth century, which may help explain how easily they adapted the term to SCA. In addition to the traditional use of “crisis” to describe a point in the natural history of fevers, late 19th and early 20th century physicians applied the word to pain and hematological events associated with, among other conditions, “lardaceous disease,” gastric sarcoma, skin diseases, angio-neurotic edema, pernicious anemia, familial hemolytic icterus (as Sydenstricker mentioned in his 1924 paper at the AMA Section on Diseases of Children), and, most prominently and regularly, tertiary syphilis. Syphilitic crises identified in a 1903 medical dictionary included bronchial, chilioral, genital, nephralgic, pain, urethral, and vesical. A syphilis textbook of 1920 added nephritic, laryngeal, cardiac, intestinal, rectal, and gastric crises to the list. The word was thus familiar to readers of medical journals and, presumably to physicians in their everyday practice.

Sickle-cell authors in this early period occasionally used the term “crisis” to describe not just the severe abdominal pain attacks, but also other aspects of the phenomena associated with the disease. Sydenstricker, in his 1923 paper at the Southern Medical Association meeting, used “crisis” to describe both a blood phenomenon (“normoblastic crisis”) and a pain episode (“abdominal” or “gastric” crisis), and at the 1924 AMA meeting to describe another blood occurrence (“hemolytic crisis”). Two articles on sickle cell appeared in 1927 that mentioned febrile crisis and erythroblastic crisis. And in a discussion of a paper presented at the 1932 annual meeting of the Section on Pediatrics of the AMA, Thomas B. Cooley of Detroit, well-known for his clinical research on sickle cell anemia and thalassemia, mentioned several kinds of “crises” he had encountered in SCA patients, including hemolytic, abdominal, joint, and splenic.

Most, if not all, physicians writing about sickle cell anemia between 1910 and 1932 appear to have been white. Some of these physician-authors, practicing in both northern and southern cities, seemed, by their choice of words when describing patients in crisis, to recognize and appreciate that these African Americans were truly suffering:

Eight days before admission to the hospital, while doing housework, severe pain in both legs developed which forced her to bed. The pain continued unremittingly. On the last admission she was fairly well nourished, anemic, and apparently in great pain. During her stay in the hospital the child was drowsy and moderately prostrated, with an anxious expression, marked dyspnea and periods of restlessness. It may then develop that the pains [experienced during abdominal crises in sickle cell anemia] . . . are nothing more than the so-called toxic pains which occur in the course of many infectious diseases. They are however peculiarly severe in sickle-cell anemia.
The patient was an anemic, undernourished black girl, aged 4 years, very restless, tossing about, with her legs drawn up.26 (p385)

On many occasions during the patient's long stay at the hospital he was seized with severe abdominal pain, at times localized in the upper quadrants and at other times in the lower quadrants.... The agony was so excruciating that the patient assumed all kinds of bizarre positions, at times extreme opisthotonos.26 (p384)

This acknowledgement of patients-of-color as human beings capable of feeling pain and experiencing suffering merits mention because of the generally negative attitudes of whites who, during this era, often saw African Americans as lesser members of the human family.

Additionally, these white physicians caring for almost exclusively black sickle-cell patients provided their African American charges with strong pain medicines and, at least in published articles up through 1932, made no disparaging racial remarks, overt or covert, about drug-seeking. For example:

From the time he was admitted to [United States Veterans'] Hospital No. 88 he was not entirely free of pain either in muscles or back, limbs, joints, or gall bladder region. On July 15 all the above symptoms became markedly exaggerated, morphia gr. 1/6 gave no relief.29 (p498)

The patient was in the hospital six and one-half weeks until her death. During this time the pains in the legs were practically continuous and excruciating, requiring frequent injections of pantopium hydrochloricum daily with only partial relief.25 (p1672)

In the population generally, many individuals present hypochlorhydric states of a like degree but certainly do not have pains which are only relieved by morphin as was true of our first 2 [sickle cell] patients.26 (p389)

The patient died 5 months after admission to the hospital. During this time she had frequent episodes of severe lower and upper abdominal pain which were relieved with difficulty only after repeated administrations of morphin.26 (p385)

In fact, the authors of one article even commented matter-of-factly about a patient who might have been addicted to opiates:

During the remission phases this patient asked for no medication. This seemed to controvert a thought entertained by some that he was experiencing some morphin withdrawal effects.26 (p389)

Why, then, did physicians apply the word “crisis” to certain pain episodes of patients with SCA? Did they see these people as undergoing a crisis—an existential experience? Based on the few descriptions available from the time period, patients were suffering excruciating pain that they urgently wanted relieved. Patients seemed to see these episodes as crises in their lives—crises where their very existence seemed to be at stake.

**CLINICIAN AND RESEARCHER PERSPECTIVE**

The clinician’s central question around use of the term “crisis” is whether continued use, or change in pain nomenclature in SCD, would improve SCD diagnosis and treatment. In contrast, the researcher’s central questions around use of terms to describe pain in SCD relate to validity and meaning. Further, there are some questions around use of pain nomenclature in SCD that concern both clinicians and researchers. The answers to these questions are only partially known. Below are the central questions, and some evidence that relates to each set of questions.

**Will use of the word crisis, or change in pain nomenclature of SCD, improve SCD diagnosis and treatment?**

Many studies have documented mistrust or misunderstanding between patients and physicians about SCD pain,45, 46, 47 or claims of undertreatment of SCD patients’ reports of pain48, 49. Consequences of undertreated pain may be as far-reaching as loss of employment and productivity by patients and caregivers, and even strained relationships between patients and their family members and friends. Perhaps continued use of the word crisis will bring attention to the need for acute and prompt treatment of pain in SCD that presents for medical attention.

**Are the term “crisis” or other terms to describe pain in SCD valid, reliable, and meaningful? What are the measurable subjective correlates of crisis in SCD?**

How much of SCD pain managed at home qualifies as a crisis? Might crises at home be undertreated because they are unmeasured? Is the number of crises predictive of short-term or long-term prognosis? If not “crisis,” what terms could be substituted to describe pain in SCD, other than “pain”? (How) should we score the severity of a crisis, apart from scoring pain severity?

Like all pain, pain in SCD is a subjective symptom, with biological, affective, and social components, each deserving of measurement.
The term “crisis,” as used by clinicians and researchers, is meaningful, but is highly prone to misclassification.

The word “crisis” traditionally has been associated with urgent health care utilization. In clinicians’ parlance, we say, “The patient came to the hospital for a crisis,” or, “The patient was admitted, but this time not for a crisis.” We almost never say, “The patient came to the clinic for a crisis,” or, “The patient went to work in a crisis.” We use the word “crisis” to connote disabling pain, interferring with function, and requiring acute emergent health care attention.

This use of the word “crisis” influenced the way SCD pain was characterized in research studies. Pain was thought to be mainly acute, and mainly due to vaso-occlusion and its inflammatory and ischemic consequences. “Crisis” was almost synonymous with SCD pain, which was almost synonymous with formal Emergency Department and hospital utilization (Figure 1). Pain was therefore thought to be easily observed. A landmark study used the term “pain” to describe health care utilization due to pain in SCD, and found pain rates to be infrequent. It also found pain between and within subjects to be quite variable and unpredictable, suggesting that the intensity of the underlying pain stimulus was also variable and unpredictable. This research showed that the number of crises per year was predictive of mortality, and that it was lower in patients with higher fetal hemoglobin levels, or lower total Hb levels.

But this use of the term “crisis” also implies that any disabling pain will by necessity result in a visit for a physician’s acute attention. This use therefore creates a measurement problem, in that crisis may be conflated with pain, vaso-occlusion, and utilization. This may result in an under-measurement of pain, especially if it doesn’t result in emergent health care utilization, yet it is deemed by patients sufficiently severe or disabling to be called a crisis. Health care workers’ and some researchers’ definition of a crisis ignores crisis pain treated at home.

In fact, new results show that severe SCD pain, pain severe enough to be called a crisis, may occur far more frequently than was once thought, and that the substantial majority of SCD pain, even crisis pain, is managed at home. It reveals that pain in SCD, and crisis as defined by patients if not physicians, has been vastly under-measured and often misclassified in previous research studies. Figure 2, based on data from the Pain in Sickle Cell Epidemiology Study (PiSCES), shows that, opposite to what was predicted by previous studies, the frequency of pain for most adult patients is high, and only a small minority of adults has very infrequent pain.

Further, based on PiSCES, patients experience SCD pain on 55% (95% CI, 51% to 61%) of days, but experience crises on 15% (CI, 13% to 19%) of days, and only utilize care for pain on 4% (CI, 3% to 5%) of days. PiSCES also suggested patients must experience a certain intensity of SCD pain before they call it a crisis, and that crises can be graded in severity. Patients experienced an average pain severity of 4.2 ± 2 (0-9 scale) during SCD pain that wasn’t described as a crisis, vs. 5.5 ± 2.1 during crises that didn’t result in utilization, vs. 6.5 ± 2.3 during crises that resulted in utilization.

Are crises objectively verifiable with biomedical correlates? For example, are there objectively measureable correlates of vaso-occlusion that are present during a crisis and not outside of a crisis?

Crises are only partly objectively verifiable with biomedical correlates. The pathophysiology of SCD results from erythrocytotic vaso-occlusion, due in part to autosomal recessive hemoglobin alteration, hemoglobin S. Hemoglobin S demonstrates impaired oxygen binding, and deoxy-hemoglobin S polymerizes inside the erythrocyte. Polymerization of deoxy-hemoglobin S results in, classically, sickle-shaped erythrocytes. But also, SCD vaso-occlusion is associated with adhesions expressed on the erythrocyte membrane. The altered erythrocytes occlude the microcirculation.

Although crises seem dramatic and acute, vaso-occlusion seems chronic: it results in chronic, ubiquitous hemolysis, ischemia, infarction, hemolytic anemia, and ultimately organ damage. Endothelial function in SCD is impaired both during and after crises. The increased expression of vascular adhesions on sickle erythrocytes seems to be stable over time within a given patient, but differences in expression between children are correlated with differences in crisis frequency. In contrast to the constancy of expressed vascular adhesions, evidence shows that microvascular hemodynamic forces within patients constantly change, mediating widely variant adherence of sickle cells to the vascular endothelium. This could account for sudden painful episodes within patients. Home-managed and hospital-managed sickle cell disease pain may thus be at opposite extremes of a varying continuum.

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**Figure 1.** Conflation of vaso-occlusion, pain, and health care utilization in sickle cell disease.

<table>
<thead>
<tr>
<th>Sickling</th>
<th>Vaso-occlusion</th>
<th>Pain</th>
<th>Utilization</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terms Conflated</td>
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of pain frequency and severity caused by correspondingly varying but chronic underlying vaso-occlusion.

Researchers have organized evidence supporting a theory of distinct phases (e.g., evolving, inflammatory, resolving) of a crisis that results in hospitalization, complete with objective serum or clinical correlates. But this theory is not yet completely validated, nor have researchers produced therapies successful at aborting a crisis by aborting underlying vaso-occlusion.

PATIENT PERSPECTIVE

Like any sub-group in society, the community of persons with SCD is not a monolithic one. Rather, we are a heterogeneous bunch. While the vast majority of us might share the experience of SCD pain in at least some of its many varied forms, there will be great variation among us in the ways that we experience that pain, the ways that we cope with that pain, and the ways in which we talk about our pain.

As an adult living with SCD, the word “crisis” has been a part of the lexicon I use to describe some of my experiences with the disease for as long as I can remember. Like most, if not all, persons with the disease, I was initially taught to use the word by the medical profession. However, the varied experiences that I have had throughout my life with the disease have caused me to develop my own particular ways of using the term. What I refer to as my “typical sickle cell crisis” may be a little bit different from the next person’s with SCD, whose use of the term may differ still from the next person with SCD, and so on. For example, I frequently make distinctions in my life between the impact of “minor crises” or “little crises” as opposed to the effects of “severe crises” or “really bad crises”. For me, those distinctions hinge on such factors as the severity of the pain...whether or not I had to seek help from a medical professional...and the extent to which I was forced to miss school or work. The fact that I use the term “crisis” in this way, though, doesn’t necessarily say anything about what is meant when another person with SCD uses the term.

Although the specifics of how persons with SCD use the term “crisis” may differ, there is some evidence to suggest that there is widespread agreement among us that the term has a role in describing some of our experiences with pain. An online forum for persons with SCD recently conducted a poll to determine the extent to which persons with the disease thought that use of the term crisis was appropriate to describe sickle cell pain. Twenty-one of 24 respondents agreed that use of the term “crisis” was appropriate. However, a close examination of the responses for and against use of the term reveals an interesting trend. Examples of statements in favor of the use of the term “crisis” include:

I think it’s totally appropriate. Literally when I’m in pain it’s a “crisis”. I need help, support and attention immediately.

I think [it is] appropriate but at the same time why is it hard for nurses to take it seriously? They think “what’s so critical and why do they need help so bad?”

Crisis implies that immediate help is required therefore I do feel it is the right word. The problem is that the medical community does not take the word literally.

It is clear from each of the statements quoted above that the respondents believed the term “crisis” adequately expressed a desired sense of urgency and immediacy in efforts to get help for their sickle cell pain. This is in contrast to the few statements provided from persons who disagreed with the appropriateness of the term “crisis”:

I don’t like the terminology crisis because it honestly doesn’t express how severe or serious the event is. I don’t know what would be a better word to describe it.

Crisis is not appropriate. We use terms such as incapacity, inability to mobilize, and severe disability. They probably get more attention.

It appears, then, that disagreement among persons with SCD regarding the appropriateness of the term “crisis” to describe our pain hinges in large part on the extent to which we believe that the term adequately expresses the severity of our pain and the urgency of response that we feel should be provided to us accordingly when we do decide to seek medical professional help for our pain.

What role should the term “crisis” have as a descriptor for part of the experience of living with SCD? From the patient’s perspective, I believe that the term only holds instrumental value. Yes, many of us living with SCD, especially those of us who are adults, have an affinity for the term. It has been an integral part of our language since childhood, and it holds real
meaning for us. However, if tomorrow the medical and public health professions came out with a joint statement saying that they were going to eliminate the term “crisis” from the SCD lexicon in favor of some new terminology, I suspect that most, if not all, persons with SCD would gladly go along with the change...assuming, of course, that the reason for this shift in language is because the medical and public health communities assure us that this shift in language will lead to fewer disputes between patients and healthcare providers about the legitimacy of our pain experience, an increase in the urgency with which medical professionals respond to us when we present for acute care, and an overall improvement in the quality of the SCD pain management experience.

Unfortunately, it is the continued lack of those desired quality-of-care outcomes that constitutes the most significant “crisis” faced by the sickle cell community.

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