

# Pain Diaries: Technologies of the Self

Often, when pain comes to mind, one is apt to think of the time they broke their leg after falling off a tree, scraped both of their knees after falling on the concrete, or maybe even the day their beloved pet died. We all experience pain, yet it is so hard for us to explain at times. We are given different devices to help communicate our pain (On a scale of 1-10, how bad does it hurt? Is it sharp or dull?). But even that seems unfit to properly communicate what is going on with our bodies. If the pain is not physical but emotional pain, communicating that pain may get a little trickier. But why? Pain is universal. We all experience both physical and emotional pain, so why is it so hard to explain? Maybe more important than the “why” is the “how.” How do we bridge the gap between the person in pain and the person/ people helping them? How do we effectively help ourselves when we are in pain?

As a part of the Pain Diaries, young patients with sickle cell anemia were asked to fill out a questionnaire to describe their pain. The act of conjuring up answers to the questions the patients were given is a type of technology of the self; however, the questionnaire itself is a form of confessional technology. Vihn-Kim Nguyen, in “Confessional Technologies,” defines confessional technology as a technology used to get people to speak and “instantiated a relationship to an inner self that could be examined, prodded and told” (39). These patients were asked to provide information about their pain for other people to analyze, thus creating this power dynamic – the doctors, or the helpers, had power over the patients. Everyone dealing with the information the patients provided will not be reciprocating equal information about themselves back to these patients, including the students from Oberlin College in Ohio and Texas A&M University-Corpus Christi. Doctors, parents, professors, and students alike have the ability to make judgments about and manipulate the information provided without ever having

their own confessions analyzed by the patients in return. However, these questionnaires also function as a technology of the self. Nguyen borrowed the term technology of the self from Foucault, who defined the term as “practices that ‘permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being,’ the purpose being to transform the self in order to attain ‘happiness, purity, wisdom, perfection, or immortality’” (39). In other words, technologies of the self are used for self-betterment. As the patients are being asked to think about their pain, some are inclined to think about what helps them cope with their pain or areas of their lives that are affected by their chronic pain. At the very least, the patients are guided to think about what makes their pain worse, which may make the patient disposed to avoid certain situations if they are not already. Further, the questions function as a technology of the self, as they offer the children a vehicle to describe their pain and how it affects them in hopes of getting some kind of relief from their chronic pain. In general, it is important to think of pain through technologies of the self for the same reasons that these young patients are being asked to do because otherwise, our pain may never be alleviated or we could be constantly putting ourselves in situations that are harmful.

Before diving into the study and explaining further how pain could be better understood through technologies of the self, it is important to understand the disease behind the study: sickle cell anemia. The Oberlin students explain that sickle cell is where red blood cells are stiff and crescent-shaped due to irregular hemoglobin, which causes clots in small blood vessels and decreased oxygen flow. The lack of oxygen causes ischemic pain in affected areas and fatigue due to organs not receiving enough oxygen. Patients with sickle cell are also more sensitive to temperature change (1).

The study on sickle cell pain includes the answers of nine different patients who were asked the following questions:

1. Describe your sickle cell pain using words like “slow, sudden, sharp, heavy, all over, pinpoint, hot, cold.”
2. What parts of your body are usually or always affected with sickle cell pain? You can use words like “head, arm, leg, back, hip, knee, all over, everywhere.”
3. Where or when do you usually have sickle cell pain? You can use words like “school, home, mom, dad, friends, outside, inside, winter, summer.”
4. How does sickle cell pain affect your school work or work at a job?
5. Does sickle cell pain affect your home life? If it does, how?
6. Does sickle cell pain affect your life with your friends? If it does, how?
7. Does sickle cell pain keep you from doing things you like? If it does, how?
8. Are you in pain right now? If so, how would you rate your pain on your usual scale?

All quotes from the pain diaries will reference the above questions. These questions push the patients to think about the specific situations that cause their pain to get worse, possibly enabling the patients to think about their pain in ways they may not have thought of before. For example, rather than merely asking the patients to describe their pain as either sharp or dull, the questionnaire leaves the question more open and offers other adjectives to help the patients to think about their pain in terms of descriptions that would help pinpoint the source or severity of the pain for doctors, or, as in the case of Oberlin College and TAMUCC, science, and English professors and students. Essentially, they are being asked to get more creative about how they think of their pain. What may help even more is if descriptions, such as the basic sharp and dull, were further explained, as the Oberlin students did in their analysis of the Pain Diaries. They

describe sharp pain as sudden because the signals reach the brain more quickly, whereas dull pain reaches the brain more slowly (8). Helping the patients understand what is meant by sharp or dull pain would help them to begin to understand how to begin to communicate their pain. For example, with my foot injury, when I was asked to explain my pain, dull or sharp, I had a hard time declaring it as one or the other because I did not know if how I viewed my pain would communicate to my doctors what they needed to know. I initially viewed sharp and dull as a range, much like a rating between 1-10, but narrower. If the patients do not have an accurate perception of what sharp and dull pain means, then they may not be able to properly communicate their pain.

Specifics of the techniques of the confessional technology aside, the Oberlin students explain that the descriptions enable caregivers the ability to synthesize the patients' pain and figure out what they are experiencing medically, such as by describing their pain as either sharp or dull and/ or using metaphors (such as in Pain Diary #9 in response to question #1: "it feels as if someone is taking a hammer and nail and hammering a nail into my bones"). The students at Oberlin explain how the differences in the way the patients describe their pain could indicate whether the physiological cause of the patient's pain may be from either being "more susceptible to changes in physiology," causing large clots that then break up into smaller clots, resulting in highly localized pain; or from small clots throughout the body, causing "constant overall pain, as opposed to large localized clots which cause larger variation in pain perception" (3). The Oberlin students analyze the TAMUCC students' descriptions of round and flat characters as they apply to the sickle cell patients, declaring that round characters are "more complex in both motivation and temperament, and [describe] their experiences in various ways, making their experiences more relatable to outside individuals," whereas flat characters are "relatively

uncomplicated and describe their experiences as being centered around one unchanging idea”

(3). In Pain Diary #1, question #4, the patient states, “I can’t concentrate. It’s hard not to cry in pain and not disrupt the entire class. I stop what I’m doing and try to put pressure on the part that hurts.” This “round character” would be more likely to be experiencing pain from larger clots, as described above. In Pain Diary #7, question #1, when the patient states, “My typical sickle cell pain would be sharp and feel like somebody is poking my stomach with needles,” would describe a flat character who likely, in these instances, is experiencing small clots. These answers are considered technologies of the self because they are enabling not only the doctors to understand their pain but the patients as well, hopefully enabling all involved to try to address the pain. Though there is only so much these patients and their doctors can do about their pain, understanding their pain is a step in the direction of self-improvement.

Beyond helping everyone involved to better understand their pain, the Pain Diaries also reveal different techniques of technologies of the self already used by the patients:

1. “I stop what I’m doing and try to put pressure on the part that hurts” (Pain Diary #1, question #4)
2. “-Walking normally, crawling is usually what I do. / -Walking freely without a wheel chair(sic)” (Pain Diary #1, question #7)
3. “I might tell my friends I can’t go somewhere so that I don’t over do(sic) it and end up hurting and not enjoying myself” (Pain Diary #3, question #6)
4. “Sometimes, because I can’t go outside all the time, sometimes I wake up my family in middle of the night because I’m in a lot of pain and can’t sleep” (Pain Diary #6, question #5)

5. “I try to hold off going to the nurse until I can’t anymore, but I have noticed I can’t do that cause(sic) the pain could get worse. It affects my grades also because I may miss a lot of days, but I try not to let it at all” (Pain Diary #7, question #4)
6. “I explain to them [friends] I have sickle cell, and they understand” (Pain Diary #7, question #6)
7. “I have to take it easy” (Pain Diary #9, question #7).

In examples 1, 2, and 7, the patients are using techniques to manage their pain. For example 1, the Oberlin students explain, “The pressure that this patient applies to the painful part of their body offers a competing stimulus to the nerves that communicate the pain, thereby decreasing the pain stimulus and increasing the pressure stimulus” (11). Then in examples 2 and 7, the patients avoid the pain altogether by using a wheelchair or taking it easy so that they limit their physical activity. In Pain Diary #9, the patient discusses how temperature affects their pain. This patient does not overtly say that they regulate the temperature in their home, though one can assume that they, or their parents, do their best to do so. The Oberlin students explain that the patient “uses the HVAC as a technology of the self because it helps control their symptoms, and understanding that temperature is a trigger helps a person with an illness manage their symptoms” (9). Examples 3 and 6 are examples of technologies of the self, as the patients are doing their best to make sure those around them understand what they are going through. By doing this, they are helping themselves by making those around them aware of the situation to avoid further complications, such as their friends being upset with them for never joining in physical activities, such as sports, or sending their friends into a panic because they do not know what is going on. Both of these kinds of misunderstandings could have negative effects on the patient's mental state and possibly even their physical pain due to increased stress, as the Oberlin

students explain that stress can lead to increased pain, as stress would “cause an increase in heart-rate and a greater demand for ATP, which would increase the demand for oxygen. With the oxygen in the blood being rapidly used up, there would be more of the sickle cell hemoglobin existing in the deoxy form (existing without bound oxygen), and they bind to each other more easily in this form” (10). Examples 4 and 5 show the patients asking for help when they need it, which is a technology of the self because they are realizing they cannot handle their pain on their own and are doing what they need to do to improve their situation. The second part of example 5 shows how the patient is also helping themselves academically by not allowing their pain to take too much control when possible.

The Oberlin students discuss further technologies of the self that sickle cell patients could be using. They explain, “The sensory information of moving muscles and joints may help override the signals of ischemic pain. Moving may also allow the patient to change their experience of pain by interacting socially or engaging in an activity they enjoy, which decreases stress and serves as a distraction” (5). However, they also acknowledge that staying still could also help with the patients’ pain. It all depends on what is going to help a particular patient in any given situation. It is up to the patient to use technologies of the self to understand their own pain, which is why the Oberlin students also suggest that patients understand what is medically happening with their bodies, not only for their own understanding but for those close to them as well. The Oberlin students state, “knowing which regions of the body are grouped together in this way [which pain receptors are grouped together] can help a doctor or friend better understand the pain of someone experiencing a sickle cell pain crisis” (2). This would help all involved to understand where the pain may be originating from, as it may not be the part that actually hurts.

Furthermore, more of the patients' technologies of the self could be revealed through extra questions placed on the questionnaire. These extra questions could also generate ideas of other technologies of the self that the patients may not have thought of. The Oberlin students suggest adding questions regarding stress and how different levels of activity affect the patients (10). These kinds of questions will give a fuller understanding of how the patients experience pain. Asking about stress levels, what tends to cause them stress, how they tackle stress, and how their stress affects not only their physical pain but emotional pain as well could also reveal other areas of the patients' lives that may need to be addressed. Evaluating the patients' pain levels as they relate to activity levels would also help to gauge what the patients can handle, enabling them to know how much and what they can participate in, as feeling left out is a common theme in the answers to question 6 in the Pain Diaries: "I can't go running or run like they can" (Pain Diary #1), "all my friends like to run track and things like that and I can't because of my sickle cell" (Pain Diary #6), and "my friends like to play rough sports and work out alot(sic) and I can't do alot(sic) like them so on some stuff they do I seat(sic) out on" (Pain Diary #8). The theme of feeling left out, as shown in these answers, would be another good reason to explore the idea of also evaluating stress levels, especially since stress can affect sickle cell pain.

It is important that we use technologies of the self when we are experiencing pain, especially chronic pain, as the sickle cell patients are. Not using technologies of the self to better understand what causes or increases pain and what can help our pain will, at best, stagnate our improvement and, at worst, increase our overall misery. When there is no realistic way to eliminate chronic pain, using various technologies of the self will enable us to find ways around the pain in order to increase our quality of life.



## Works Cited

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“Pain Diary #5.” Collected by Prasad Brodas.

“Pain Diary #6.” Collected by Prasad Brodas.

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