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"We don't wear it on our sleeve": Sickle cell disease and the (in)visible body in parts

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ABSTRACT

This paper approaches the lived experiences of patients with a genetically inherited chronic disease, sickle cell disease (SCD), through the lens of (in)visibility. SCD has been referred to as an "invisible" disease for a variety of interrelated reasons, including the difficulty of objectively measuring its characteristic symptoms, the lack of popular or specialist attention, and its characterization as a "black" disease. By mobilizing "invisibility" as a way of probing the day-to-day reinforcements of marginality, this article delves into how structural forces are experienced, interpreted, and negotiated by individual actors. To this end, we present ethnographic data collected from November 2009 until November 2013 with SCD patients and healthcare workers in Chicago. These data emphasize that rendering (in)visible is not a totalizing act, but rather meaningfully breaks the body into differentially visible and ideology-laden parts. More broadly, this indicates the need to rigorously question sources and effects of authority in biomedicine.

In the fall of 2010, "Dianne"[1] described a recent experience in a Chicago emergency room. As she sat waiting, virtually unseen, crying in excruciating pain, people bustled in and out of rooms around her. She recounted: "*I was screaming, I was hurting, and I said 'Somebody needs to do something,' because I was throwing up. I was having a fever. I felt like I was going to faint and they were like 'Just give us two more hours because we're trying to get beds cleaned, we're trying to get people out of here, we're trying to get people up to the floors.*'" Two hours came and went, and nine hours later Dianne was finally escorted up to the appropriate floor for care. But even being up "on the floor" did not lead to being seen, she lamented: "*Nurses don't come. Nurses ignore you. I can't deal with that. So I called the supervisor—I don't care who gets mad at me! … I'm in pain, you're not, you're supposed to be helping me … I have to wait three hours just for the doctor to call up to the floor to get me my pain medicine going*!"

On its surface, this might just sound like a one-time horror story of a crowded emergency room. But when Dianne told this story at a sickle cell disease support group, others corroborated it. Angela responded to Dianne by saying: "*They make you wait, they don't care! I guess they think that sickle cell is not as serious as a person with a heart attack. Which it's not, but it's still up there, you know?*"

Dianne's pain was a symptom of her sickle cell disease (SCD), a genetically inherited blood disorder. Red blood cells become misshapen and sticky, which restricts their flow through blood vessels and deprives organs of oxygen (Parsh and Kumar, 2012). SCD is associated with a host of life-threatening complications, including stroke, organ damage, and high risk of bacterial infections (Meremikwu and Okomo, 2011). The most characteristic symptom is overwhelmingly intense—and often debilitating—pain. Individuals with SCD experience both chronic and acute episodes ("crises") of severe pain, either localized at extremely high intensity in one part of the body, or diffused throughout the entire body. These pain crises often result in long-term hospitalization (Minniti et al., 2013) and treatment with high doses of opioid medications (Dunlop and Bennett, 2006).

SCD is the most common genetic blood disorder worldwide. The majority of sufferers live in Sub-Saharan Africa (Serjeant, 2010; Williams et al., 2005). In the United States, 89,000 to 98,000 people are living with SCD (Brousseau et al., 2010; Hassell, 2010). Although not exclusively, most American sufferers are of African descent; approximately 1 in 350 African Americans are born with SCD each year (Bonds, 2005, p. 99). The disproportionate

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distribution along racial lines and a complex historical trajectory—including SCD's discovery during the time of American and European eugenics movement—has led to the overwhelming racialization of SCD (Carter and Dyson, 2011; Tapper, 1999; Wailoo, 2001).

The erroneous label of "black disease" has important and varied implications for the lived experience of SCD (Atkin and Ahmad, 2001; Bediako and Moffitt, 2011; Dyson et al., 2014; Dyson and Atkin, 2011; Rouse, 2009). As ethnographic and historical scholarship has shown, biomedical marginalization has characterized SCD research, treatment, and the experiences of patients (Baer, 1989; Bergman and Diamond, 2013; Byrd and Clayton, 2003; Rouse, 2009; Tapper, 1999; Wailoo, 2001). Further, Roberts (2011) notes that the false notion of exclusively black susceptibility to SCD is often used as "evidence" of a genetic basis of race. This use of pseudo-science obfuscates the reality—that SCD occurs globally and is associated with malarial regions rather than along racial lines—thereby supporting a distinctly social trend of othering (Roberts, 2011). Academic and public discourse on SCD is often limited to this reification of race, or to its role in malarial immunity. The experiences of diagnosed individuals, however, are rarely engaged.

Considering its historical context, as well as the often-literal invisibility of its symptoms, SCD has been called an "invisible illness" (Savitt, 1981; Wailoo, 2001). By using ethnographic methods, this article strives to capture patients' and practitioners' perceptions of routine experiences with SCD, interpreting them through a lens of (in)visibility.

1. Invisibility as a theoretical lens

In the pages of sci-fi novels and comic books, invisibility is defined by a state of lacking: the unseen, the unnoticed, and the formless. Within these popular cultural narratives, the protagonists are instilled with the power—and simultaneously the curse—of a loss of "thereness." In the social sciences, the "loss of thereness" takes on increased significance as subjects are rendered visible or invisible within the context of mundane relationships of power. Understanding the nature and interplay of visibility and invisibility in everyday life offers interpretive potential. According to Brighenti (2007), "visibility lies at the intersection of the two domains of aesthetics (relations of *perception*) and politics (relations of *power*)" (p. 324). In a published symposium, Pietrzak-Franger and Stoddard Holmes' (2014) provide examples of the salience of invisibility within the politics of embodiment. In its varied applications, the study of invisibility encompasses the asymmetries in surveillance, thereby emphasizing who is allowed (or forced) to be seen, who is hidden from sight, and who benefits from these politics of seeing.

In their edited volume, *Missing Bodies: The Politics of Visibility*, Casper and Moore (2009) emphasize (in)visibility as a product of the modern age of surveillance. Increasing technological developments and, especially in the West, a post-9/11 climate of security through legibility have increasingly placed bodies under scrutiny by the state and state apparatuses. Casper and Moore call for a new ocular ethic that considers both visibility *and* invisibility in analyses of subject formation. They propose the academic application of "techniques of magnification, including ethnography, to reveal, resituate, and recuperate" bodies (Casper and Moore, 2009, p. 14–15). This encapsulates both literal (in)visibility through absence or presence of bodies in social spaces, as well as the more figurative inclusion or exclusion of subjects in the designation of political worth.

By engaging the ocular ethic, the current work is situated alongside many feminist scholars, historians, and social scientists that have prioritized the study of the lack, absence, or loss of rights to "thereness" that accompanies life on the margins. Thus far, however, invisibility has been under-explored by social scientists of medicine. Scholars have denaturalized the myth of "objectivity" in biomedicine by deconstructing the deeply ideology-laden role of medical science within global networks of power (Baer, 2001; Baer et al., 2003; Greenhalgh, 2001). Further, many have explored how modern scientific medicine works through the "medical gaze" to produce, classify, and individualize bodies around a supposedly "scientific" norm (Davenport, 2000; Foucault, 1975; Greenhalgh, 2001; Malterud et al., 2004; Tremain, 2005). But despite this extensive theorization of the visual production of bodies under biomedicine, less has been said about the effect of being pushed *outside of* the medical gaze. If the medical gaze is productive of "normal" and "abnormal" bodies, then is the *lack* of medical gaze also productive, and if so, of what?

2. Invisibility and marginality

In this paper, we consider (in)visibility as the productive visual interactions (or lack thereof) that reflect and reinforce conditions of marginality. Unlike marginality itself, however, rendering (in) visible can be understood as a social practice of exclusion which is constituted through nuanced and normalized everyday interactions of power and social positioning (Carter, 2010). As enacted marginality, invisibility is the "dehumanization and devaluation of personhood" that often targets specific categories of people (Carter, 2010, p. 22). Broader trends of marginality are filtered through sources of authority that, in turn, are able to differentially render some lives more meaningful. By focusing on these sources of authority, the ideological inscription of bodies, and the literal invisibility or visibility of bodies in space, social scientists can target a more tangible manifestation of abstract power.

In the United States, the reinforcement of invisibility is integrated into the reproduction of racial politics in a multitude of ways. Systematic invisibility of racially defined groups, especially African Americans, is reinforced by a lack of representation in cultural media, the academy, and in politics (Mowatt et al., 2013). *Racism Without Racists* (Bonilla-Silva, 2010) deconstructs post-Jim Crow Era "color-blind racism" and myths suggesting that race is no longer a meaningful social fact in modernity. "Color blind" Americans claim not to see race, and instead attempt to naturalize and justify contemporary instances of inequities. The apparent invisibility of race shields us from addressing the geographical and social hypersegregation along skin color lines; if skin color is invisible, then the differential opportunities offered to white-skinned Americans appear purely coincidental, or worse, merited. Another way in which racial invisibility is enacted is through "passing"; Goffman (1974) writes of how *appearing* as a member of a different social category offers a means of managing the stigma of a "spoiled identity." Therefore, in the case of racial stigmatization, rendering one's race as invisible by passing as white—through daily interactions and by limiting visual interaction with non-whites—functions as a coping strategy to regain valued personhood (Dawkins, 2012).

Conversely, and equally important, marginality-as-race can also indicate a site of *hyper*visibility as well as invisibility; black bodies are socially constructed as "marked" bodies that, while marginalized, are easily identifiable as targets of stigmatization. Especially with regard to intersectional gendered body politics, blackness is reduced, misrepresented, and made into spectacle in order to facilitate objectification and exploitation (Mowatt et al., 2013). Biomedical technologies often have a particularly salient role to play in the "marking" of race, often lending a perceived objectivity to the production of black bodies as "other," "deficient", and as sites of consumption in the liberalized health care marketplace (Roberts,

2011; Wailoo et al., 2012).

In this work, we focus on the intersections of both literal and ideological (in)visibility as a repopulated exploration of embodied and enacted marginality. Especially in studies of chronicity and other under-prioritized biomedical conditions, this approach is invaluable for examining how biomedicalized bodies on the margins of vitality are delegitimized, excluded, and deprioritized through mundane encounters with authority. In this article, we use ethnographic methods and data in the exploration of the lived experience of invisibility for those with sickle cell disease (SCD).

3. Fragmentation and "bodies in parts"

By theorizing (in)visibility in this work, we are also fundamentally concerned with *bodies* and the subjects that they encompass. The nature of bodies cannot be taken for granted; conceptualizations and productions of the body are constantly changing as "a product of specific social, cultural, and historical contexts" (Lock, 1993, p. 134). Drawing on Foucault (1975), Sharp notes the pivotal role of medical dissection in producing fragmented bodies (Sharp, 2000). Further, genetic and immunological sciences—especially as they are represented, interpreted, and experienced by the public—emphasize DNA as tiny fragments of personhood at the most minute, biological level (Sharp, 2000). This is particularly relevant for bodies diagnosed with SCD; the so-called "sicklers" have *become* their genetics and their "malformed" cells. Diagnosis of SCD uses a biomedical lens to define certain bodies through certain isolated, representative, and microscopically visible parts.

In this article, we explore what happens at the intersection of biomedical fragmentation of bodies and the rendering (in)visible of the biomedical gaze. We argue that, as "marked" bodies with an invisible disease, African American patients with SCD are conflicting sites of legibility. The are not, therefore, wholly rendered visible or invisible bodies, but are reconstructed as (in)visible bodies-in-parts.

4. Methodology

In 2008, after reading the ethnography *The Spirit Catches you and You Fall Down* (Fadiman, 1997), a physician at a local urban "University Sickle Cell Center" (a pseudonym) became interested in what an anthropological perspective could offer the study of SCD. He approached the corresponding author of this paper, who knew very little about SCD at the time, and in response, she prepared an ethnographic and qualitative research project that allowed for the participation and training of undergraduate research assistants. The research was approved by the University of Illinois at Chicago Institutional Review Board (# 2008-0798) and ethical considerations included the ethical training of all researchers, the distribution of signed consent forms, and detailed discussion of the project purpose before engaging participants. The first objective was to elucidate experiences and identify tensions both within and outside of the clinic setting. As the project progressed iteratively over the five years of data collection (November 2008 to November 2013), the foci shifted to include: race and perceived injustice (see Enezwa et al., 2015 on this topic); barriers in the educational and workplace setting; biomedical and alternative medicinal strategies; and doctor-patient relationships. These objectives contributed to answering the general research question: what are the salient biosocial tensions in the everyday intersections of the biomedical system, caregivers, and patients with sickle cell disease?

4.1. Setting and data collection

The University Sickle Cell Center, located in Chicago, is the only SCD-focused care facility for adults in Illinois and was the primary site for this research. It employs a team of SCD specialists and nurses who partner with SCD-informed specialists, including cardiologists, endocrinologists, and transfusion medicine specialists. Generally, diagnosed patients attend regularly scheduled clinic appointments where they see a nurse, a physician, and a social worker, each of which have SCD expertise. The Center-affiliated monthly support group, led by a SCD nurse, is comprised of both SCD clinic patients and others that attend other Chicagoland clinics. A second monthly support group for adults with SCD meets on the south side of Chicago and is supported by a national organization. Both support groups welcomed the project researchers for focus groups and observations.

Data collected from participant observation (e.g., in waiting areas of the clinic and at focus groups) was recorded in field notes and through journaling. Semi-structured interviews and focus group discussions were used to elicit participant perspectives and experiences. Further, as rapport developed over the course of this five-year project, informal conversations gave additional insights into the experience and treatment of sickle cell disease. Semi-structured interview guides were used at each interview and focus group discussion, but as an iterative project, the focus of the guides shifted considerably to reflect the knowledge growth and emergence of new ideas.

Over the course of the five years, 70 adult patients (44 women, 26 men) were interviewed, and seven of these patients were interviewed more than once. Each participant went through the informed consent process, and the average length of these interviews was approximately 30 min. A total of seven focus group discussions were scheduled and conducted through the support groups; each went through an individual informed consent process before the focus group discussion began. Most participants attended more than one discussion, but a total of 25 unique individuals participated (13 females; 12 males).

We chose to include practitioners because we felt they would offer an important insight into the tensions within the health system. Potential practitioner-participants were emailed a project information sheet and invited to participate via telephone. If they agreed, practitioners went through the consent process and participated in a 30-min face-to-face interview. A total of 15 practitioners participated including doctors/specialists ($n = 4$, all male), nurses ($n = 8$; all female), social workers/coordinators ($n = 3$, all female).

4.2. Data management and analyses

All interviews and focus group discussions were voice recorded with permission. The authors and student researchers transcribed and de-identified the audio recordings. Transcriptions were read multiple times before any coding began, and the authors conducted one initial round of memoing by hand. Text data were then uploaded to *Atlas.ti* 7 for more rigorous analysis. The computer-based analysis process largely followed the methodology proposed by Friese (2012). Within *Atlas.ti*, we developed 100 close-to-text codes, including some *in vivo* codes. Then, we merged and organized codes into categories and sub-categories. After the codes were pared down, we used the query tool to find productive intersections of codes. These intersections formed super codes, and fueled visual network analyses. These network analyses helped to demonstrate clusters, which inspired our themes. This paper reflects one of the many ideas that emerged out of this multi-year, multi-method project. The centrality of (in)visibility reoccurred

throughout data analyses in reference to healthcare experiences, interpersonal interactions, and expressions of marginality. Throughout this process, we consulted with SCD specialists and individuals with SCD to discuss our interpretation.

4.3. A statement on positionality

The authors of this paper were with the project continuously from its inception. We are both medical anthropologists, female, and white. The team of student researchers was ethnically diverse, consisted of both women and men, and none were diagnosed with SCD. Over the years, we developed rapport with the patients, support group attendees, and practitioners, but we are nevertheless confined to an etic perspective. As academic researchers, we are privileged with a certain degree of visibility, and ethnography allows us to leverage our own visibility in order to shed light on underrepresented issues. But we aimed to maintain a degree of reflexivity about the limitations of this specific space of representation and the politics of our choices.

5. Results: themes

After analyzing the transcriptions, we identified three main themes related to (in)visibility; each of which approaches (in)visibility in SCD care from a distinct angle.

Theme 1: Delegitimization as Rendering Invisible in the Hierarchy of Care

> *One thing, I'm gonna tell you all this … one thing I love about our illness, it's also a curse, is that we don't wear it on our sleeve. People can't look at us and see what we got. That's our curse—when we ask to put in pain medication [into the I.V.], [they] can't see our pain. Can't see it.*
>
> *— Sam, Male patient, Focus Group*

SCD is literally invisible in the sense that its characteristic symptom—pain—is internal. Therefore, individuals can "pass" as healthy without anyone knowing that they have a disease (Atkin and Ahmad, 2001). However, as Sam indicates above, and as many other participants agreed, invisibility often leads to disbelief. Disbelief, in turn, has implications for the management of care.

Many patients spoke to their feelings of frustration at the inability of language to communicate SCD pain. They stressed that it is virtually impossible for a non-sufferer to imagine what the pain is like. The following quotation exemplifies the ways that patients resort to metaphors and imagery to convey pain severity and allow non-sufferers to understand:

> *In your joints, in your knees, in your elbows, in your chest, in your back, in your stomach—all at the same time. And you'll be in so much pain that you just want to say "Lord, I just want to die." I mean you really want to die just so it will stop. Sometimes you'll have a mild pain crisis where you can still do the things you want to do but sometimes the pain is so devastating that all you can do is cry and ball up in a knot. When your hemoglobin levels get real, real low—that is what triggers a pain crisis—and just imagine your blood not flowing through your veins the way it should be. It's not giving your heart and your lungs the right amount of oxygen. Your blood is being clogged up in certain parts of your body, and it just stays there. It's worse then having a migraine headache and going through labor at the same time. And people that have never been around somebody with a sickle cell pain crisis, they really don't understand. They can't imagine you being in this much pain and wondering what causes you being in this much pain and you can't explain why but you just know you hurting.*
>
> *—Anton, Male adult patient, semi-structured interview*

Here, Anton uses his deeply descriptive language to evoke a shared, emotional understanding of the SCD pain experience. In her book, *The Body in Pain: The making and unmaking of the world*, Scarry (1987) focuses on the inability of language to truly capture physical pain. She suggests that, because the internality of pain makes it the ultimate divider between "self" and "other," the sufferer must resort to metaphors in order to "objectify" —and therefore make visible—the pain for the listener (Scarry, 1987, p. 4–9). SCD patients, therefore, are charged with a kind of emotional work (Hochschild, 1983) to manipulate the affective state of caretakers; an evocative use of language and metaphor is crucial to objectifying pain, and therefore building a claim to legitimacy. But this only makes pain *metaphorically* visible, and biomedicine relies on a more observable, quantifiable reality. Even if individual biomedical *caretakers* are receptive to this emotional work, the biomedical *system* demands a skepticism that is often incompatible with the intangible, internal, and invisible nature of pain.

In the face of this doubt, blood tests—actual, visible cells—stand in for "real" disease. One middle-aged patient described being made to "prove" her SCD status mid-pain crisis through a blood test. Years of doctor visits, medications, and other management strategies were invisible to this new doctor, and the patient was not considered a reliable source of information about her own suffering. SCD, like most chronic illnesses, requires extensive self-care, and this leads to an increasing understanding of treatment needs. However, within the biomedical setting, the legitimacy of the knowledge produced through patient experience is overshadowed by tangible visibility and the privileged position of biomedical "expertise." Patients described their frustration when healthcare professionals doubt not only their pain, but also their treatment regimen. They felt that their own experiences were disregarded in favor of scientific knowledge. At a focus group, when another participant shared a story about being snubbed by a nurse after advocating for her child, Janet, an adult patient, responded:

> *They think because they went to school, they're better … that they know more than you. They know more than you because they went to school.*
>
> *—Janet, Female adult patient, semi-structured interview*

Here, Janet speaks to another incompatibility in biomedical SCD treatment. The type of knowledge that is valued by the biomedical system (and which doctors are trained to exclusively rely on) is not patient knowledge, but empirical, collective knowledge that comes from their schooling. Patient knowledge is therefore systematically undervalued as doctors are assumed to practice without bias. However, Rouse (2009) highlights how SCD physicians largely act on a foundation of medical uncertainty; patient experience is devalued, and biomedical knowledge is lacking. During a semi-structured interview, an interviewer asked Connie, an adult patient, if there are any treatments that she is afraid of. She responded:

> *They haven't found a treatment yet that I'm scared of—unless it's something new, [then] I get worried about it … Mostly, I hope SCD is more recognized and more paid attention to because right now where I live, I had to explain to my doctor—she's been my doctor for a while—what SCD was. They had never asked and I had never explained it to them, but they were treating me. That really upset*

me that I had never explained to them before or they never asked me before what it felt like.

—Connie, Female adult patient, semi-structured interview

Through the process of biomedical reductionism, patients' illness experience is reduced to a disease label, and treated by the practitioner as such; Connie's actual understanding of SCD was extraneous information and not the "diagnostic entity" targeted by her doctor (Kleinman, 1988, p. 5). Rather than serving as a resource in SCD care, patients' knowledge of their own (delegitimized) pain and treatment needs threatens the traditional roles of the doctor-patient hierarchical relationship in biomedicine. One of the social support coordinators on the SCD floor at the hospital described how this pervasive tension contributes to the stigmatization of SCD patients as drug addicts:

INT: Are there any difficulties with treating sickle cell patients?

SW: Difficulties in treating them? Yeah, because they are very demanding … they know that "Okay if I come to the hospital, they would give me 6 mg of morphine … [but] that don't do anything for me! I start at 8, or I start at 12 [milligrams]." And many healthcare providers, they don't see this as the patient advocating for themselves and knowing their history, they see it as "Oh they're drug seeking because they know too much about the numbers involved in medication dosages." And … many nurses and many doctors are like "How dare you—you know—tell me what you, what you need and what you want? I have to look at your medical history and make that determination."

—Rita, Social Worker, semi-structured interview

Doctors stressed the danger of opioids: there is no maximum dose, and they can cause patients to stop breathing. The fear of overprescribing is real, especially because the traditional objective markers of illness are not available to standardize the prescription of SCD medications. But tensions over opioids were not described in terms of immediate health risks as much as assumed long-term dangers; patients described how their demands for pain medication are often discredited and reinterpreted as indicators of addiction. This addiction focus is mirrored in other qualitative literature (e.g., Rouse, 2009, p. 72) and in a quantitative study by Shapiro et al. (1997) in which over half of physicians and approximately a quarter of hematologists thought that a substantial number (at least 20 percent) of sickle cell patients were addicted to opioids. In reality, evidence suggests that individuals with SCD are no more likely to become addicts than the general population, and that healthcare professionals often greatly overestimate rates of SCD patient drug addiction (Aisiku et al., 2009; Alao et al., 2003; Ballas, 2005; Elander et al., 2003; Marlowe and Chicella, 2002). But one doctor suggested a deeper reason for the perpetuation of this stereotype in spite of the evidence:

So there's a huge mistrust because they don't believe that patients are in pain, they think that they are addicts and particularly for you know … some patients will demand certain ways of getting medicines which is then we're not used to, we don't like the power issue, so … you start getting this conflict of what I want to do what you want to do, whose power, what's going on. But, so, but many staff do believe, it's not just here, it's all over the place, many places, we believe patients with sickle cell disease are drug addicts and that they are just waiting to get high.

—Dr. A., SCD specialist, Semi-structured interview

The incompatibilities of SCD care contribute to delegitimization and assumptions about patients' motives. These assumptions about SCD patients can have potentially dramatic consequences for the treatment of pain. A study by Lazio et al. (2010) reviewed the medical records of individuals with SCD and others with renal colic, a similarly painful chronic illness primarily affecting white populations, in order to compare the median time from admission until receiving pain medications. They found that the median was 80 min for SCD and 50 min for patients with renal colic. This difference alludes to the stark inequalities between SCD care and that of other chronic conditions, and parallels the experiences described in the qualitative data.

Patients describe the ways that disbelief is made explicit when they ask for high doses of medication to treat their pain. Many patients described what they term, "The Look"—an all-too-familiar facial expression that healthcare workers give when a SCD patient asks for their pain medication. "The Look" is a nonverbal way of questioning the legitimacy of pain, and implying ulterior motives, without confrontation (Fig. 1).

For other patients, the accusations are far more overt. When asked if she gets "funny looks" from her practitioner when she asks for pain medication, Tamara responded:

They think all sickle cell patients is crackheads. And I told them … if I was a crackhead I would rather go spend ten, twenty dollars on crack than come up here and give ya'll motherfuckers one hundred and some thousand dollars. So they just look at me like I'm crazy … It's been times when I sit home for two weeks in pain and my pain be at a ten [on a ten-point standardized pain scale]. Can't move, can't eat but I refuse to come in because I get tired of people sitting back and saying "Ohh you're a crackhead."

—Tamara, Female adult patient, semi-structured interview

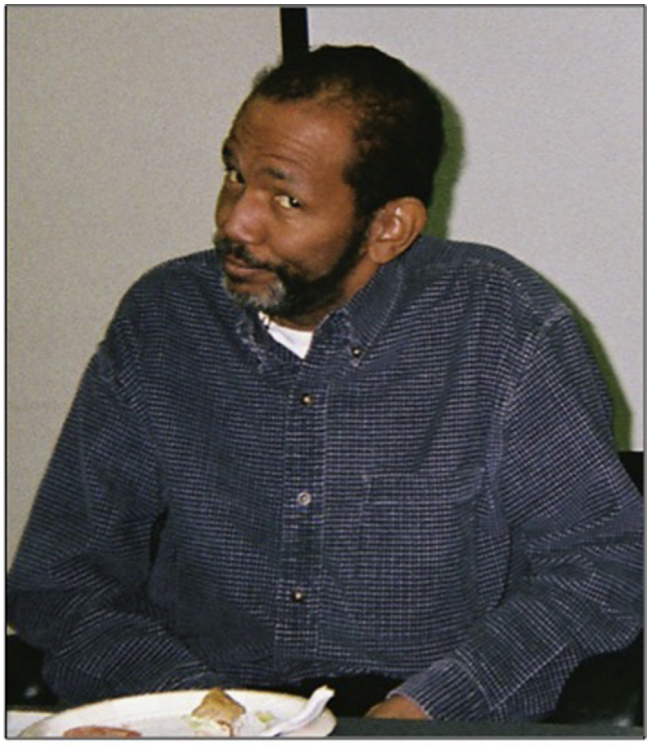

Fig. 1. A patient gives his impression of "The Look" at a 2010 FGD (photo credit: C. L. Patil, included with consent).

For this woman, and others like her, the invisibility caused by disbelief is not only a figurative one. Individuals who feel delegitimized within the biomedical system will sometimes "opt out" and refuse to seek treatment. Therefore, the dynamics of disbelief and rendering invisible are reified as patients are made entirely absent from the clinic; self-care becomes the norm in the face of perceived systematic disempowerment, with potentially dramatic consequences for vitality.

Just as disbelief preserves the inequities in the system, a shifting of blame from *systemic* fault onto the *patient* leads to minimal need for confrontation of these inequities. Routine interactions within the medical system, such as the one described in this anecdote by an adult patient at one of the focus groups, use displaced blame to further delegitimize (and thereby deemphasize) suffering:

> *My IV had came out, I forgot about what happened, but this nurse tried to stick me five times, kept missing … But look, she had the audacity to get mad at me and tell me, 'if you would have done such and such, this would have never happened'.*
>
> *—Cameron, Male adult patient, Focus Group*

Through shifting blame, the stigmatization that is experienced in the hospitals, the labels that obstruct care, and the general unavailability of the staff are not interpreted as the result of a broken system that devalues SCD suffering. Rather, they are interpreted as the failure of the patients themselves. The responsibility for managing the inadequacies of the system, therefore, appears to belong firmly on the shoulders of the patient rather than the broader social, political, and economic forces at work. The sickled cells themselves are, therefore, both physically and figuratively made invisible in SCD care. The moralistic responsibilization of care is a symptom of a broader ideology of individualism, and is used to deflect blame from the system itself onto the medically marginalized. This renders the patient invisible on multiple levels: minimizing suffering, obfuscating patient knowledge, and sometimes removing the patient from the space of the clinic entirely.

Theme 2: Visibility of a "marked" body

As exemplified in Wailoo (2014), the belief of pain, and the willingness to act on that belief, is wrapped up in political baggage; some pain is legitimized and some is considered undeserving, and this is not an arbitrary distinction. This question of whose pain is legitimized and whose is made invisible through disbelief is, especially in the case of SCD, inextricably tied to discriminatory racial politics. Patients expressed feelings that both medical professionals and laypeople interpreted SCD pain through a racial lens:

> *Most Caucasians have very limited interactions with black people … their interaction is what they see on TV. And 95% of that time is from a negative aspect. And that feeds a lot of the problems blacks have. You know, when a person of another race come in contact with a black person who is intelligent, that throws them out of the loop because that's not their idea of what a black person should be … We're poor, we're illiterate, and we're stupid. So when you told them that you have sickle cell, they didn't believe you cause you don't know what you're talking about cause you're black, and you're stupid.*
>
> *—Anne, Female adult patient, Focus Group*

> *Well of course you know it's a black disease. To me, that's what the general public have an idea of. When they hear sickle cell disease, if they haven't any clue about it, it's just a black disease. They think the majority of people that have it are black and so it's not important.*
>
> *—Sharon, Female adult patient, Semi-structured Interview*

These two women, Anne and Sharon, describe feeling that the skin color of SCD sufferers is more important than the suffering itself. While the inner symptoms and suffering of SCD are largely invisible, the hypervisibility of blackness and the racialization of the disease tend to overwhelm outsider impressions. Rather than being marked as *ill* bodies—as are many other chronic illness sufferers—and thereby garnering at least some potential for empathy, African American SCD sufferers are often primarily marked as "black" bodies.

Layered onto the marker of skin color itself, SCD is often accompanied by a number of visual signifiers that are misread as class and race stereotypes. For example, due to jaundice, many patients regularly have yellow eyes. Patients described being ostracized because people misunderstood their jaundice as a sign of drug use. Another potential SCD symptom is the swelling of the abdomen. To the uninformed onlooker, this can evoke assumptions of pregnancy, with particularly dramatic social implications for African American adolescent girls. Further, because many SCD patients receive regular injections for transfusions, fluids, and other medical needs, they often have very visible needle marks.

> *Carla: I go for blood draws and I have like five needle sticks. And they be like what is wrong with you?*
>
> *Daniel: How am I going to go to work like this? I have to wear long sleeves to cover that up.*
>
> *Janice: You got to. Tall long sleeves.*
>
> *Daniel: I wear short sleeves and they be like [points to forearm]"You haven't been here in a couple of days. Did you see his arm?" [laughter] … Those things get said. You might not know they get said, but they get said.*
>
> *—Adult patients, Focus group*

Unlike many other invisible chronic illnesses, the primarily African American demographic of SCD combined with ambiguous signifiers leads to an intersectionality of visibility. SCD sometimes manifests in a hypervisible way, but is reinterpreted to reinforce assumptions, while the suffering itself is simultaneously invisible.

Theme 3: Patient agency and making visible

The above data largely paint a picture of the subtle ways that the authority of biomedical professionals renders SCD patients' suffering and physical bodies invisible. These patients, however, are not purely passively ill subjects who are entirely sculpted by these forces of power. While understanding the interactions in which SCD patients are made *invisible*, we are able to also identify the ways in which SCD patients can agentively navigate the margins of visibility.

As discussed above, SCD sufferers are grouped and stigmatized as drug addicts who overuse medical resources for ostensibly dubious symptoms. Real suffering is made invisible as it is overshadowed by the politics of legitimacy. In response, many patients seem to internalize this logic and displace the stigma onto other "types" of patients.

> *There's a girl here, I've been knowing her for the past two years. She's about ninety pounds, and she is so sick. That's because certain things that she do in her lifestyle are not conducive to her life. And*

you can do these things and get away with it for only so long. You're sick because you don't take care of your own self.

—Anton, Male adult patient, Semi-Structured interview

I don't know. Sometimes it [doctors' drug addiction suspicions] could be the way you carry yourself and the way you act, the way you speak to the doctors and talk about the situations and what you ever did in your life, you know? Have you ever been on drugs? Have you ever did drugs or— I ain't never did none of that stuff.

—Mary, Adult patient, Semi-structured interview

For these patients, the delegitimization of SCD suffering is justified due to the behavior of *other* patients. In his study of stigmatized urban neighborhoods, Wacquant (2009) describes a similar tendency among residents. In order to mediate the "stain" of their stigmatized location, people distinguished themselves from their neighbors, emphasizing ways that others actually deserved the stigma. Similarly, by differentiating their own "good" patient behaviors from the "bad" behaviors of others, SCD patients legitimize stigma overall, while partially exempting themselves from its effects. These behaviors range from daily management strategies (e.g., diet, hydration, and lifestyle changes) to proper comportment when hospitalized. In the words of one SCD patient, Adam, at a focus group: "It's not appropriate to stigmatize all [SCD] patients for the issues of bad behaviors of a few." By displacing this stigma onto others—apparently because of others' wrong choices—and simultaneously emphasizing their own willingness to cooperate, individual patients aim to regain personal visibility and the re-legitimization of their own suffering.

In addition to engaging certain behaviors, patients are pressured to present their suffering in a certain way. By constructing and performing a more visible sick role, patients are able to negotiate validity and in turn, belief for their pain. Patients describe the tension of putting on a "show" in order to bring their suffering to the surface:

Chris: [Healthcare providers] give me that Look, because I said I was at a ten [on the pain scale] and because I wasn't kicking, screaming, crying, fighting. And I was like, yes I am at a ten, just because I'm not screaming, pulling my hair out, but I am at a ten.

Daniel: You know, it's like they don't want you to put that show on, but they really want you to put that show on.

—Two adult patients, Focus group

"The show" for this focus group involves "acting sick." Participants described how the sorts of calming, distracting behaviors that really help ease their SCD pain—e.g., listening to music, watching television, talking to visitors—are all behaviors that reinforce caretakers' doubt in the legitimacy of that pain. Instead, participants described behavior changes like using certain facial expressions to better project "believable" pain and receive care in response. An article titled "Are You Really Sick?" in the patient council newsletter (written by and for SCD patients) reflects this strategy, while also reinforcing a culture of displaced blame. The article reprimands patients for not fulfilling the appropriate sick role, and therefore making things difficult for other patients:

If you are sick and confined to the hospital room, why are you walking around the hospital premises going to the hospital store, visiting other patients and not being in accordance with what SICK patients should be doing? Perception spread way beyond your bedside. It affects every Sickle Cell Patient that comes after you! You may say 'I don't care what they say about me,' but it's not all about you, it reflects on me and my family of patients that have to endure the stigma of they're not really sick or they are drug seekers or they are combative or they are ignorant! I don't need that label placed on me when I come to the hospital seeking medical relief from a seriously chronic illness!

—Patient newsletter

Varul (2010) argues that medicalization and the increased normalization of chronic illness have not rendered the sick role obsolete, but rather changed its function. That role requires that the sick person *acts* "sick" for the sake of the observers: "the healthy public needs a constant reassurance that it is not nice to be ill, that ill people carry a burden" (Varul, 2010, p. 81). But SCD bodies do not conform to the normal "look" of illness, and there are implications for treatment. However, by performing a "chronic sick role" through certain expected behaviors, individual patients can actively labor to make their illness artificially visible.

6. Discussion

In this paper, we have framed invisibility as the ideological and somatic practices of exclusion that individuals face in everyday life. We have shown examples of the diverse ways that SCD patients in Chicago are rendered invisible, as well as the hypervisibility of select bodily parts under the medical gaze. Cells and internal complications that are only visible under biomedical technologies are foregrounded, reinforcing biomedical expertise. Meanwhile, surface-level markers of difference (e.g., skin color) are often highlighted and misinterpreted to reaffirm social biases. Building on Hacking (2007), our work shows the delegitimizated patient as an (in)visible "body-in-parts." We focus on this intersection of visibilities and invisibilities at which SCD skin and blood are given primacy at the expense of patient-as-whole-body, patient-as-expert, and patient-as-sufferer.

We argue that this stems from the politics of authority in biomedicine in which biomedical practitioners tacitly reinforce this (in)visibility-in-parts through their interactions with SCD patients. Practitioners themselves, however, are proximal actors, working within the milieu of neoliberal healthcare-as-marketplace in the United States. These politics of authority are central to the functioning of this broader system; authoritative medical knowledge is a commodity that is expected to be sold to the medical consumer (Peck and Conner, 2011). And, like on the broader economic marketplace, some consumers are more valued. As this paper is being written, we are seeing an even more pressing example of this in SCD care. This year, new state political leadership has announced substantial budget cuts to SCD funding. This has led to plans to close the University Sickle Cell Center, which could render SCD invisible in a much more totalizing way.

In the local community, this research has had some positive implications for clinical practice. As practioners learned about and became more aware of patients' lived experiences, they claimed to be more reflexive about the ways they communicate with patients. Additionally, they volunteered their time and offered continuing education about SCD to those in the emergency department and on floors where patients are hospitalized. But as we have noted, practitioners are acting within a much larger system. In order to better address imbalances in power, authority, and visibility in biomedicine, there must be more transformational shifts in the way the system operates. This paper contributes to social science and medicine by leveraging the ethnographic perspective, thereby highlighting the subtle everyday exchanges that reinforce and legitimize medical marginalization of people with SCD. But this

analysis also indicates the broader, systemic roots of (in)visiblity. There is, therefore, potential to expand analyses beyond the interpersonal dynamics discussed here. Future research should consider the complexities of biomedical bureaucratic structures, institutional cultures, and the biomedical market as a whole to engage the lense of (in)visibility across multiple scales.

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