We Are No Longer Invisible

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Abstract: Sickle cell discourses are not merely descriptions of medical matters but contentious sites that invoke rhetorical arguments to support racialized medical borders, human difference, and ontological essentialism. In this essay, I examine the way that those stricken by Sickle Cell Anemia appropriate the disease to advocate for their voice and visibility. I disclose how the construction of SCA as a black disease becomes a contested terrain which is often a "cultural centering on identity and dignity." At odds is how the body is inscribed with a set of meanings in its association with blackness, the woeful ignorance that's pervasive in the medical community of those who treat sickle cell patients and the indomitable will of the warrior to survive regardless. I consider the "warring ideals in one dark body," urgings to be seen and heard. These manifest as performances of resistance, acts of resilience, and ways of asserting agency to maintain a semblance of humanity in the midst of situations that are anything but.

Introduction

I begin this essay with their voices—those who have been told that sickle cell anemia (SCA) is their death sentence, those who suffer with perpetual pain, those who have been marginalized, those who are rendered invisible and maltreated because they are considered and called a problem. Andre bemoans the maltreatment regularly received by sickle cell sufferers:

> I wish people in the medical field would take the disease more seriously. I've had experiences where they've called me 'drug seeker.' It's as if we're going to the emergency room once a month or once a week for our drug fix. They treat us atrociously, and I'm just tired of the whole situation. (Barrow, D5, 2011)

Noah informs that sickle cell screams through its sufferers:

I did not choose this disease, but it has chosen me. I'm a survivor like many other survivors. We will keep battling this disease for our own lives and for the lives of people in the future. Sickle cell is screaming loud but no one is listening. This disease is terrifying and it grabs the souls of the young, helpless and defenseless. Sickle cell anemia disease is overlooked, a forgotten hell that a lot of people need to be rescued from. (Williams, 2015, p. 1)

For Amy Mason, sickle cell is an isolating disease:

Every time, it's a battle. Nobody cares about people with sickle cell. (Amy Mason, regarding the emergency room where the staff suspected her of faking her condition in order to score opiates and viewed her as a non-emergency because she "only" had pain.) (Begley, 2017, p. 1)

The chorus of sufferers, also known as sickle cell warriors, harmonizes with Ralph Ellison's protagonist in *The Invisible Man*:

I am invisible, understand, simply because people refuse to see me. Like the bodiless heads you see sometimes in circus sideshows, it is as though I have been surrounded by mirrors of hard, distorting glass. When they approach me they see only my surroundings, themselves or figments of their imagination, indeed, everything and anything except me. (1980, p. 3)

Often time sicklers' public personas presume that they are a problem. Sicklers find themselves addressing and answering W. E. B. Du Bois' poignant query "How does it feel to be a problem? And yet, being a problem is a strange experience—peculiar even for one who has never been anything else" (1986, p. 363). Their identity has been subsumed into the material existence of SCA. The sickled cells and pain crises, the blood transfusions and organ damage are the physiological consequences; loneliness and isolation, marginalization and stigmatization are the social consequences. Doctors who appear indifferent, researchers who funnel resources on other more attractive diseases, pharmacists who prescribe at their discretion; these are an assemblage of practices that articulate and categorize a particular identity unique to SCA. It is what we know, what has been historically told, and a narrative that continues to be perpetuated. How do we come to know ourselves? How is our story told? These queries are central to understanding the identity of a sickle cell patient and how their sense of belonging

takes shape. Sickle cell discourses are not merely descriptions of medical matters but contentious sites that manifest as corporeal circumstances to invoke rhetorical arguments to support racialized medical borders, human difference, and ontological essentialism.

I examine in this essay the way that those stricken by SCA appropriate the disease to advocate for their voice and visibility. I disclose how the construction of SCA as a black disease becomes a contested terrain which is often a "cultural centering on identity and dignity" (Kelley, 1996, p. 3). Although medical science has disproven SCA as a black disease, culturally the currency of perpetuating this falsehood serves to engage the incongruity of thought in determining the duality or cultural contrast of blackness, or, as Du Bois (1986) opines, the "double-consciousness" of blackness (p. 364). Du Bois' (1986) description of the dual existence of being an American and a Negro is ideal for understanding the constructed identity of someone with SCA:

> It is a peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. One ever feels his two-ness, an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder. The history of the American Negro is the history of this strife- this longing to attain self-conscious manhood, to merge his double self into a better and truer self. (p. 364)

At odds is how the body is inscribed with a set of meanings in its association with blackness, the woeful ignorance that's pervasive in the medical community of those who treat sickle cell patients and the indomitable will of the "warrior" to survive regardless. In this essay I consider the "warring ideals in one dark body" and the "longing to attain self-conscious manhood." More specifically I examine these as performances of resistance, acts of resilience, ways of asserting agency to maintain a semblance of humanity in the midst of situations that seek to define anything but. My primary focus will be on websites that function as a "network of relationships" (Asen, 2018, p. 298) to re-appropriate how we talk about SCA, to confront stereotypes, negotiate agency and provide tools for surviving and thriving with this disease. I examine the following websites: sickcells.org, sc101.org and onescdvoice.com. Of the numerous sickle cell community advocacy sites, these are significant because of the national attention they garner, the

creative and concise ways that knowledge is dispensed, and the thoroughness of each, not only to provide means for advocacy in the public square but also a place for warriors to be informed, empowered and have candid discussions on how to live with SCA. In these we find what Kent Ono and John Sloop (1995) call vernacular discourse, rhetorical enactments that represent "discourse that resonates within and from historically oppressed communities; that does not exist only as counter-hegemonic, but also as affirmative, articulating a sense of community that does not function solely as oppositional to dominant ideologies" (p. 140). The rhetorical enactments I speak of are seemingly as pedestrian as sicklers informing each other how to travel with SCA, and as significant as which emergency room offers the most expeditious and efficient service during a pain crisis. These communicative acts not only display agency but also speak to a common bond of affiliation, inextricably woven ties connected with shared pain, stigmatization and isolation. I draw attention to relationships, "the connection, the in-between," what Asen (2018) considers essential to the construction and maintenance of a public (p. 298). The commonality that these websites demonstrate in establishing relationships among fellow warriors is significant. Whether through blogs, events, correspondence etc. there are opportunities that invite and welcome others to voice their sentiments about SCA.

   These websites function as a gathering place where the marginalized assert their voice, assume agency, create a common language, develop strategies for survival, and establish a community of affiliation. Relationships then become symbolic gestures that serve rhetorical purposes, to re-constitute identities and formulate publics to contribute to quality care for sickle cell patients. Michael Warner (2002) observes that publics are created through shared relationships and discourses; they are assembled in the moment and traverse throughout exigencies. Because of this, rhetorical situations are verdant pastures for publics to graze, grow, and make arguments that are disruptive to normative thought. Thus, "A public is a relation among strangers" and therefore these strangers are "...on a path to commonality" (Warner, 2002, pp. 56-57). By means of discourse and transgressive acts, publics produce the world they inhabit. Again, Warner identifies the use of discourse as essential in the formulation of the publics' world. He also considers the formulation of the identity of publics. "People do not commonly recognize themselves as virtual projects. They recognize themselves only as already being the persons they are addressed as being, and as already belonging to the world that is condensed in their discourse" (Warner, 2002, p. 82). Relationships

are valued in the SCA community, as each member understands the necessity of being present for one another and the harm of isolation and detachment. This attention to relationships strengthens their potential for public effectiveness. To this point Asen (2018) argues, "At one level, relationship serves as an organizing principle...Yet, more fundamentally...relationships give publics their energy, dynamism, productive force. Public makes and transforms through its relationships" (p. 298). These become transformative gatherings that symbolize people coming together as vital publics and ways to understand how the larger populace misinterprets SCA. Historically SCA has been a marginalizing disease. Its alignment with race sets it apart as an affliction of the diseased other.

This "network of relationships" requires resilience from each other, placing greater emphasis on agency, change and hope in the daily lives of individuals and groups (Asen, 2018, p. 298). As witnessed through these online communities we find that resilience entails "self-reinvention, reflexive meaning making, and an ability to respond proactively, even when the future looks bleak" (Flynn, Sotirin, & Brady, 2012, p. 8). In the online communities we find acts of rhetorical resilience that begin as individual expressions of courage and coalesce into community engagement responsive to various exigencies. Flynn *et al.* write rhetorical resilience is about "recognizing and seizing opportunities even in the most oppressive situations" (2012, p. 8). Their model of resilience fits into the paradigm that they construct as they broaden our understanding of this useful trope:

> We see resilience not as a quality of the heroic individual but as always relational, not only because individuals learn moral qualities and derive social and material support through "a web of relationships" but because resilience is in itself a form of relationality...Finally, resilience is transformative not necessarily through affecting a change in circumstances— which may remain bleak or oppressive—but in changing the way a life is lived. Resilient living can involve determination, perseverance, hope, and imagination. (Flynn *et al.*, 2012, p. 7)

With attention to the testimony of sicklers I focus on the materiality of blackness in the everyday lives of SCA patients. Their humanity is contested in the emergency room, which becomes a place of judgment and criticism. Their bodies are read as racialized subjects. Their blackness precedes them historically and thus, "The lived experience of blackness is among other things a constant demand for an ontology of disorder," writes Fred Moten (2008, p.

187). Whereas the social understanding of the disease and the violence of the emergency room constitute them as "difficult patients," this essay analyzes SCA warriors' methods of resisting this moniker. I consider how they create their own meaning of life with SCA by exploring the nature of patients' resistance and how they find "new ways to rebel" in the formulation of becoming a public and counterpublic (Kelley, 1996, p.3). Resistance is fluid for the SCA patient. Their ways of fighting back are chameleon-like, as they learn how and when to exercise agency. Robin D. G. Kelley's work guides our inquiry into the "new ways to rebel": the creative measures that SCA patients employ to recover their identity and reclaim their humanity in the cauldron of a racialized disease lived out in the emergency room (1996, p.3).

The Difficult Patient in the Emergency Room

The SCA patient maintains a keen awareness of their body and how it should be cared for and managed. They have to adopt the posture of an expert, because of the dearth and paucity of information on how to care for a SCA patient. This rhetorical performance of expertise often brings about a negative connotation in places of hospital care, as they are labeled as "difficult patients." What often occurs is that the SCA patient appropriates the "difficult patient" *ethos* and disrupts its conventional meaning for their good. The nature of their knowing more or knowing best disrupts the rhetorical expertise of their caregivers. Their insistence on including their voice, their expertise in caring for their own body is important in defying the social scripts of SCA patients as indolent sycophants. Sicklers choose to take on what Lisa Keranen calls "the knowledge partner persona as they appeal for greater participation in their treatment and care" (2010, p. 142).

   Although sickle cell patients are frequently labeled by health care workers as "problem" or "difficult," according to Samir Ballas (1998, p. 11), they seek to redefine their ethos into a sickle cell "warrior." The moniker "difficult patient" derives from the often unfortunate exchanges that are held between caregiver and patient. Although this characterization is intended to harken back to a history when African Americans were resistant and recalcitrant to the ways of the slave masters, the phrase "difficult patient" misrepresents intentionally the shrewd genius that is evident in the ways sicklers adapt and resist. To this point Bergman and Diamond (2013) report that "sickle cell patients tend to be knowledgeable about their pain medication, including previously effective dosage levels" (p. 5).

At the source of the "difficult patient" trope is SCA pain crises or episodes of pain felt in various parts of the body. Pain crises result when red blood cells become sickled, clump together in blood vessels, and thus prevent oxygenated blood from reaching body tissues. Patients have described the pain crises as: "gnawing agony that goes to the bone; similar to acute arthritis, but instead of just my joints hurting, the whole bone itself hurts; pulsating pain, hard in intensity, that usually occurs in that same spots" (Leary, 1994, p. 5). In order to assuage the pain, often strong and addictive analgesics are needed. Requesting drugs as a sickle cell patient in the emergency room is problematic as now the individual must convince the medical staff that there is a need for the medication. Administering analgesics is a subjective decision, for there is no test or diagnostic test that a sickle cell patient has to undertake to assess the level of pain and its frequency. In other words, emergency room staff must take the word of the individual in pain. Not only does the patient have to communicate a seemingly amorphous subjective biological feeling, but also the sickler is aware of the historical representation that the black body in pain has and the neglect it has suffered. The response of medical attendants, the interactions between patient and physician in having to prove or legitimize pain is part of a larger narrative in which African Americans have been considered inured to pain. Regarding the historical lineage of black bodies in pain, Debra Walker King writes,

> Black bodies have a history of being the most "visible" objects for pain's public consumption. In fact, the popular and recurring image of black bodies in pain as a normalized representation of suffering in photos, film, and other cultural products has come to position those bodies as material representations of pain. (2008, p. 15)

SCA is used to shape and produce a body that is designed to withstand pain because of the rhetorical claims that black skin is thicker and thus resilient to pain (Hoffman, Trawalter, Axt, Oliver, 2016). Keith Wailoo (2017) references the University of Virginia study by Hoffman *et al.* in pointing out disparities in pain treatment:

> And it illuminates what I've called the divided state of analgesia in America: overtreatment of millions of people that feeds painkiller abuse at the same time that, with far less public attention, millions of others are systematically undertreated. Think of it as a pain gap between the haves and the have-nots, along lines of class and race. (2017, p. 1)

What Wailoo and others point out is that the rhetorical currency of pain is central to constituting medical practices and health policies that affect the care of SCA patients.

Those suffering with pain often have to engage in a performance experience that entails having the correct attire, knowing the appropriate jargon and knowing the correct amount of medicine and so forth, in order to receive respectable treatment. "Knowing the attitudes they'll encounter, patients therefore prepare for the ER as for a job interview. 'I always dress professionally,' said Wanda Williams, 67, a retired school administrator in the Bay Area: nice shoes, 'interesting earrings,' every hair in place, and Vogue-worthy makeup. 'It's crazy that you, as an African-American, have to do this so you aren't treated like a drug addict'" (Begley, 2017.

Although a public place, an emergency room, for a SCA patient, functions as a site of counterpublicity, a place to engage tangible exigencies, material rhetorics that spawn from cultural discourses supporting black bodies as diseased. The emergency room for a sickle cell patient is a place where blackness functions as a historical albatross and a liberating freedom. It is a site of contention, where racism is ensconced in practices that are designed to make and discipline subjects, where language is predicated upon the notion of difference and essentialism. The emergency room is a place of assumptions, judgments, and conclusion. Rhetorically then, the black body becomes a reflection of racial gaze, an inscription of institutional human difference. This material consequence of the body is essential as it reminds us of "the ways in which rhetoric marks, represents, or constitutes bodies in socially consequential ways" (McCann, 2010, p. 11). Living through these consequences of being in a black body, stigmatized with a racialized disease often proves deleterious for sufferers, as they come to the emergency room for help and instead experience less than competent care. Patients are faced with the harsh reality "that the body is socially understood and treated as a discursive text that is read by interactants" (Jackson, 2006, p. 2). Consequently then, "there are various racial meanings attached to bodily texts that can inspire individuals to behave differently toward foreign or unfamiliar bodies when encountering them in public and private spaces" (Jackson, 2006, p. 2). Reconstituting the black body is the nature of the fight that takes place in the emergency room.

When considering the medical community of sicklers it is also noteworthy to observe how the emergency room is a place of public memory, where certain acts are required for survival and

subsequently passed on to others as rhetorical rituals of hope. Integrating Sara Ahmed's cultural economy of affect as that which sticks with public memory scholarship, Dickinson, Blair and Ott note, "Ahmed's point of course, is to understand how objects, signs, and bodies 'become saturated with affect'" (2010, p. 11). "Ours is to understand how particular memories capture the imagination and produce attachment, and how memories achieve durability over time or compelling force in a particular context. In Ahmed's terms, how do memories 'stick?' How do they come to matter?" (Dickinson *et al.*, 2010, p. 15-16). The emergency room garners attention as command post in SCA discourse in that it bellows out orders, it organizes hierarchy, it structures behaviors, all of which remain relevant in how sicklers orient their lives. As a result, it is a "memory place" operating as a signifier of immense importance (Dickinson *et al.*, 2010, p. 25). Dickinson *et al.* explain, "The signifier—the place—is itself an object of attention...It is an object of attention because of its status as a place, recognizable and set apart from undifferentiated space. This signifier commands attention, because it announces itself as a marker of collective identity" (2010, p. 25). George Yancy interprets the generative aspect of social spaces that determine who belongs and who doesn't. "Within such social spaces as these, the sheer cumulative impact of such racist actions can result in a form of self-alienation, where the integrity of one's Black body is shaken, though not shattered" (Yancy, 2008, p. 2). As sicklers relive their testimonies of ER encounters, their bodies are read as diseased as the historical violent traces of blackness precedes them. "The corporeal integrity of my Black body undergoes an onslaught as the white imaginary, which centuries of white hegemony have structured and shaped, ruminates over my dark flesh and vomits me out in a form not in accordance with how I see myself" (Yancy, 2008, p. 2). Their experiences reveal that the ER is often a rhetorical space where sickle cell patients must negotiate cultural and historical claims of a racialized disease in "white space." Or, what Elijah Anderson posits as a place where a "black person enters and others there immediately try to make sense of him or her—to figure out 'who that is,' or to gain a sense of the nature of the person's business and whether they need to be concerned" (Anderson, 2015, p. 13). Consequently then, we have competing narratives of how this space is navigated and how memories of this contentious public place constitute identity and coordinate actions.

The apparent, visible material restrictions seemingly silence the voice of warriors and mute their being. These visible limitations become liminal spaces of transformation, where we witness the

creativity of sicklers to make room for their needs, to carve out conversations that center sickle cell sufferers as people and not props. This then foreshadows their resistance to structural norms that racialize bodies and highlight their iterations of resilience.

The Voice and Visibility of a Community of Warriors

Sickle warriors learn through various websites how to perform for pain relief, where to find the most comprehensive care, and who will believe their narrative. These online spaces are constructed with their survival in mind. The circulation of their words, to help their own kind, locates strategies that were dismissive of disciplinary powers of whiteness. Their creative articulations refigure ways of establishing community and resisting the sense of isolation that SCA is oftentimes associated with. All this and more highlights the need and value for online communities and reiterates the attention given to how warriors identify themselves and why they have chosen that posture. Their acts of naming facilitate a community of SCA soldiers, providing also the context for understanding how resilience informs the creation of their identity. What is evident in the lives of SCA patients are transgressive acts cloaked as seemingly mundane, pedestrian acts like dressing a particular way before going to the E.R., like going to the E.R. on a particular day, making sure you don't visit the E.R. alone and drinking plenty of water prior to the visit, just to name a few.

   Evidence of their rhetorical resilience can be located on the home screen of sickcells.org: "Sick Cells seek to elevate the voices of the sickle cell disease (SCD) community and our stories of resilience." Under the column stating FACES of SCD there are 35 black sicklers, and 2 brown sicklers, with their own defiant story, asserting the identity as a warrior, intentionally welcoming other warriors into the community.

   This public space, created by sicklers, recalls Catherine Squires' assertion that, "not every group or individual enjoys the same access to public spaces, media resources, or other tools to participate in discursive activities" (2002, p. 449). And consequently, we observe online members of sickcells.org seizing space, telling their story, and announcing their agency. Chantelle writes, "Hello I'm Chantelle Rodgers and today I AM TAKING OVER!!!" Sharon explains the value of voice in the refuting the politics of identity that SCA often invites: "I am 55. If you do have

sickle cell, don't shy away from why you have. Don't seclude yourself; talk about it. Talk about it with people, talk about it with your doctors." Kamia articulates that silence contributes to isolation and the perpetuation of a marginalized public and thus reiterates the value of voice, embodied with power and agency; thus demonstrating how "the 'voice' announces the body's presence; it utters the body's sensory experience of its environment and of others" (Watts, 2001, p. 180). Kamia writes on sickcells.org,

> It's already a silent disease and a lot of people don't talk about it. My husband was in the military, and we were in Georgia and the doctor asked him, What is this, what is sickle cell?" And it blew my mind. I was like; You're a physician, and you're asking me what sickle cell is.' So don't give up, even if this is not the cure for you—continue to talk about it, continue to tell people, speak about it all the time, just keep the conversation going. Because if you don't talk about it people tend to forget, push it off to the back.

The resistance of the online community contributes to the formulation of an emerging black public, fighting against the "erasure of black resistance" demonstrating the existence of what Squires sees as the Black public, "an emergent collective composed of people who engage in common discourses and negotiations of what it means to be Black" with SCA (2002, p. 454). To this point Tristan writes about her advocacy activism from youth,

> Since I was 11, I've tried to spread awareness and advocate for sickle cell. I was the poster child for the local chapter of our Red Cross blood drives. I have hosted numerous spoken word events for the cause, spoke about in the newspaper, radios, and have been featured in different publications talking about sickle cell disease. I think what the sickle cell community needs is for us to have way more of a public presence. We need to come out of the shadows of the past and step into the spotlight. (sickcells.org)

Resilience distinguishes this community, as Monique reminds us in her rallying call to fellow sicklers on sickcells.org, "Keep fighting. We're a rare breed. Keep fighting."

On the home page of oneSCDvoice.com there is an obvious call towards community with an immediate invitation to "join the conversation." The opportunity to participate in the featured poll as well as go back to previous polls gives warriors a place to identify

with each other and find a community of affiliation. The heading "community gallery" provides a listing of members' names, their roles as patients, advocates, health care providers, health communicators, or caregivers, their join date, profile and the opportunity to send messages to members. If a warrior wants to maintain a more private community, "SCD Teams allow you to create a small group with whom you can share and communicate exclusively, rather than with the entire community." A host of opportunities are provided on this site to encourage community involvement. These acts of engagement function rhetorically as they coordinate ways of being human, ways of being present for each other, ways of giving voice and representation. It seeks to strip away the racialization of SCA and reveal the humanity of these while also seizing upon opportunities to reclaim how a sickle cell patient identifies and what modes of agency he or she employs.

   Whether identified as patients, sufferers, or warriors, cultural meanings often stifle the ability to resist public judgments brought on by rhetorical characterizations and assumptions that black bodies are inclined to sickness, because of inherent defective qualities. For this reason the creation of counterpublics and the implementation of vernacular discourse within the SCA communities is noteworthy and instructive as a method of protest. Nancy Fraser considers counterpublics as "parallel discursive arenas where members of subordinated social groups invent and circulate counter discourses to formulate oppositional interpretations of their identities, interests, and needs" (1990, p. 67). These groups of warriors often find resilience in creating ways to enable each other in managing SCA. Their language is familiar and necessary as it affords them opportunities to chart ways of survival when their cries and pleas for help are often ignored. The community of affiliation in online communities infuses them with modes of resistance and resilience. As these sites reveal, community is essential in how warriors resist societal and cultural discourses regarding the inferiority of black bodies. These online platforms coordinate actions of survival as members become dispensers of knowledge and take control of their future. Their assumption of agency to gather together is furthered as they converse amongst various platforms, in different forms to help the other survive. Communities of sickle cell warriors replace feelings of isolation and marginalization in society and more particularly in the emergency room. They compensate for the paucity of knowledge received from health care facilities on SCA and assert creative methods to live. As previously mentioned, physicians are often culpable in not understanding how to treat sickle cell patients, not realizing that

SCA is genetic, not fully understanding the biological process of pain crises and unfortunately still embracing the supposition of biological difference. Thus the ways in which warriors communicate and inform each other is essential to understanding their ability to re-appropriate a health system designed to marginalize them and ultimately erase their suffering. Resilience, says Flynn *et al.*, is "creative, animating the potential of whatever comes to hand as a suitable rhetorical resource…Thus resilience realizes possibilities and resources by shaping and enacting relationships among selves and others, speakers and audiences, things and dreams, bodies and needs, and so on" (2012, p. 7). Each site offers ways of communicating the management of SCA through language that is common to warriors. Sc101.org is very helpful in the creative, but concise ways to dispense knowledge to community members. In their twitter feed SC101 provide posters with messages that correspond with images to offer "education + awareness" tips that clearly communicate salient facts about SCA.

The need to survive, the strategies to inform sicklers how to live and how to fight are part of the tips that warriors pass on to each other. Not only are the tips directed toward the physiology of the patient but also their mental and social well-being as is evident by the following admonition and encouragement. On any given day, a sickler would be reminded of the following on sc101.org:

> You are not a burden.
> You have a burden,
> Which by definition is too heavy.
> I fight for my health
> Every day in ways
> Most people don't understand.
> I'm not lazy, I'm a warrior.

On the site oneSCDvoice.com there is the "SMART Social Wall" where each warrior is invited to "voice your thoughts, feelings, add photo and add video." The rhetorical practices demonstrate agency by informing other warriors and intervening as activist. Amanda echoes these sentiments:

> oneSCDvoice is a positively-charged space where you can find support from others who get and trusted resources (like this one on tips for advocating in the ER.) Check out this guide on how to live well with sickle cell…Find good medical care, get regular check ups, prevent infections, learn healthy habits, look for clinical studies, get support.

Embodied acts of helping by testifying and assuming a measure of expertise disrupt the notion of sickle cell patients as indolent and ignorant of their body and its disease process. Their subject position conceived and created by the racialization of SCA and health care agencies is resisted through the implementation of knowledge. The SMART Social Wall takes on these rhetorical processes by offering advice and giving guidance for fellow sicklers. It operates as a trusted space, a safe refuge to receive fact and help. It is evident of how sicklers demonstrate rhetorical resilience by recognizing and seizing opportunities even in the most oppressive situations. Deanna of sickcells.org demonstrates her frustrations with systemic health care injustices: "I feel like we're judged when we say we need something for pain. Stop judging us. You can't tell me how much pain I'm in. Just because I'm not crying, you can't tell me I'm not in pain." Kelley gives credence to the various ways that sicklers resist, "while the meaning and effectiveness of various acts differ according to the particular circumstances, they do make a difference, whether intended or not" (1996, p. 8).

The voice and visibility that is evident in the emergency room, on the social wall and everywhere in between communicates the longing of sicklers to be visible, for their pain to be acknowledged. They are resilient because they have to be, they need to be. It is their life story, a clarion call to communities indifferent and undecided in how they choose to deal with the people that carry the stigma of what is believed to be a black disease.

Conclusion

The resilience of warriors is in their willingness to re-appropriate SCA and take ownership of their narratives, to tell their story in their vernacular to other fighters as they engage not only a health care system often aligned against them but a culture that persistently labels them as sufferers of a black disease. Through various online communities and in public spaces such as emergency rooms, SCA patients wrestle with a prescribed historical narrative of this disease as a byproduct of blackness. They contend with ideologies that have become normalized and consequently alter their way of being in society and their sense of identity. It is a perpetual fight for visibility and fight against erasure. The labels that are ascribed to SCA patients have historical adhesiveness; they are fixtures, not easily removed. Strategically this draws attention away from racial inequalities in health care as well as deflects from the pernicious practices of racism in inscribing bodies deformed and debilitated because of race.

In the previous examples we find not only an exertion of being, but also an extension of community. They demonstrate that "resilience is not only an individual matter. It is the outward and visible sign of a web of relationships and experiences that teach people mastery, doggedness, love, moral courage and hope" (qtd. in Flynn *et al.*, 2012, p. 26). The significance of relationships cannot be overlooked in how sicklers invoke stamina and invite hope. Online communities of SCA warriors demonstrate "how people who experience marginalization and oppression and their allies may work to overcome exclusions and to fight for justice and equality" (Asen, 2018, p. 300). These warriors engage in material practices that function to resist social narratives of sickle cell patients that are less than complementary. Their negotiations of the SCA world are done so in a common vernacular that facilitates an even stronger bond amongst each other, while also excluding a larger community of critics. What these rhetorical choices exhibit are creative ways of survival. Resilience and agency, writing and talking, reading and walking are means of resistance to a racialized subject position. These tips assume the need to validate one's existence and authenticate transgressions against the body. They are a methodical plan of resistance that "create a space in the ritual site that excludes them, simultaneously forging relational bonds with others...and resisting the discursive images of disease constructed on their bodies" (Bennett, 2009, p. 122).

Resistance through resilience demonstrates everyday practices that build community and establish relationships in response to exigencies evolving from living with SCA. Sickle cell warriors appropriate what Foucault calls "technologies of the self," as these websites facilitate practices "to 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, conducts and ways of being" (Rabinow & Rose, 2003, p. 146). Through this means of rhetorical negotiation, a community is created, an identity is sustained and marginalized voices are heard.

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