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### Organized ambivalence: when sickle cell disease and stem cell research converge

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## Organized ambivalence: when sickle cell disease and stem cell research converge

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**Objective.** This article analyzes sickle cell patient families' responses to stem cell transplant recruitment efforts. It identifies key dynamics that explain why sickle cell patient families are not undergoing stem cell transplants at the rate of other patient populations. It challenges the conventional focus on 'African-American distrust' as a set of attitudes grounded in collective memories of past abuses and projected on to current initiatives, by examining the *sociality of distrust* produced daily in the clinic and reinforced in broader politics of health investment.

**Design.** It draws upon a two-year multi-sited ethnography of a US-based stem cell research and cures initiative. Fieldwork included participant observation in a state stem cell agency, a publicly-funded stem cell transplant program, a sickle cell clinic, and semi-structured, open-ended interviews with caregivers and stem cell research stakeholders, all of which were subject to qualitative analysis.

**Findings and implications.** This paper finds *ambivalence-in-action* structured by three contextual strands: therapeutic uncertainties of the clinic, institutionalized conflation of healthcare and medical research, and political contests over scientific and medical investments. The paper posits that *organized ambivalence* is an analytic alternative to individualized notions of distrust and as a framework for implementing more participatory research initiatives that better account for the multiple uncertainties characteristic of regenerative medicine.

**Keywords:** distrust; race-ethnicity; sickle cell disease; stem cell research; uncertainty

### Introduction

Why am I in such demand as a research subject  
when no one wants me as a patient?

Unlike stem cells derived from embryos, 'adult' stem cells (e.g., haematopoietic stem cells) are tissue-specific and are responsible for cell maintenance and repair. Adult stem cells are highly concentrated in umbilical cord blood, making this a prime renewable tissue source to remedy blood-based ailments such that sickle cell disease is one of the few illnesses for which there are currently stem cell treatments. To that end, researchers at the Garvey Medical Institute (a pseudonym, hereafter 'Garvey') utilized a federal grant to collect and store cord blood units. They sought to enroll

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families from around the country whose child was diagnosed with a haemoglobinopathy and who were expecting the birth of an unaffected child from whose umbilical cord stem cells could be collected. Despite serving a large sickle cell patient population, however, researchers were frustrated by the low enrollment and transplantation rates from families at Garvey as well as from other institutions. At the time of this study, the program had managed to collect approximately 2000 units of cord blood, 500 of which were from sickle cell patients, but of which only 6% of well-matched siblings from sickle cell families underwent the transplant. Compare this to 60% of eligible beta thalassaemia (hereafter ‘thalassaemia’) families who consented to the transplant. From the perspective of proponents of the procedure, sickle cell patients were ‘under-utilizing’ the novel treatment.

For stem cell transplant enthusiasts, this underutilization is especially difficult to grasp partly because the 85% event-free survival rate (i.e., minimal complications) is considered extremely good odds for a relatively new treatment. By contrast, for some haematologists and their patients, the curative potential is not easily outweighed by the 5% mortality rate and potential for serious complications. These include life-threatening infections, sterility, and chronic Host-versus-Graft disease in which the patient’s immune system attacks the foreign tissue (a risk minimized but not completely eliminated with close sibling matches). Unlike the vast majority of thalassaemia patient families who are considering whether to undergo the procedure and who are faced with the prospect of a lifetime of monthly blood transfusions and attendant complications without the transplant, the wide spectrum in sickle cell severity (Collins and Guttmacher 2007) make the decision to accept the risks of the procedure a much greater medical gamble. Not only is the transplant outcome unknown, but also a patient’s disease progression if he/she does not undergo a transplant is equally unknown. Some experience relatively mild symptoms with periodic pain crises that families learn to manage while others experience strokes as young as five years old and hip replacements by the age of 15 years. A diagnosis of sickle cell disease (SCD) does little to inform parents about where their child might fall on this spectrum and so hope in a high-risk cure is often outweighed by hope that one’s child will be one of the lucky ones with mild symptoms. This personal risk calculus, however, is not sufficient for understanding why sickle cell patients are not undergoing stem cell transplants.

In part, I suggest that disaggregating the biological experience of the illness from clinical contexts that give that experience meaning is difficult, if not disadvantageous, for social analysis. The way in which stem cell program staff theorize the transplant ‘disparity’ is, for example, often an extension of racialized dynamics in more routine clinical encounters. To illustrate this point, consider how the lead caseworker who oversaw all aspects of enrollment, cord blood collection, processing, and storage explained the different transplant rates.

Although it is rather crude, sickle cell patients act like they do not have any control over what happens – fatalistic, and it may be that they do not trust medicine and science. But then thalassaemia patients are so controlling. They have a completely different perspective of medicine and science. They absolutely trust it. (Fieldnote 01/11/06)

Here the caseworker invokes popular, racialized notions about science-philia among Asian Americans and science-phobia among African-Americans, suggesting possible

cultural differences among these patient populations that explain the transplant disparity. This and similar deployments of 'culture' have a long history within social scientific literature. Arising most influentially within the 'culture of poverty' framework, the focus on the 'learned helplessness' of subordinated groups (Rabow *et al.* 1983) leads well-intentioned scholars to exhort health providers to 'promptly identify fatalistic persons' (Powe and Johnson 1995) as the primary intervention to increase medical compliance. Not only does this focus obscure the relative trustworthiness of medical institutions but also, as I show, this focus on fatalism leads analysts to misrecognize rejection of biomedical treatments with lack of agency writ large.

Challenging such cultural generalizations, a number of important scholarly contributions examine why and under what conditions African-American patients trust medical professionals (Dula 1994, Gamble 1997), exploring links between distrust to patients' unwillingness to participate in biomedical research (Corbie-Smith *et al.* 2002), with greater attention to the experiences of sickle cell patients specifically (Hill 1994, Randall 1995). Illustrative of this trend, Braunstein *et al.* (2008) report that among 717 study participants, African-American participants were more likely to report that 'doctors would use them as guinea pigs without their consent, prescribe medication as a way of experimenting on people, and ask them to participate in research even if it could harm them' (p. 1). This study finds that even after controlling for race, sex, socio-economic status (SES), and disease risk profiles (as individual characteristics and not dynamic processes of objectification and agency), African-Americans continue to express less willingness to participate than White participants. As in the majority of this work, medical distrust is operationalized as a set of individually-held views about physicians, medications, specific procedures, and protocols that are, in turn, typically measured using survey methods. While this work does well to move us away from the cultural generalizations of an earlier era and provides important insights into how differential levels of trust among individuals may impact service provision and health outcomes (potentially de-essentializing distrust as a 'Black problem'), the focus on individual attitudes does not adequately account for what I refer to as the sociality of distrust as both a 'disposition and a social position' (Bourdieu 1998, p. 18) that are produced within the US racial system. Partly because the thrust of this growing literature aims to reduce patient 'noncompliance' by improving doctor-patient relationships, hone informed consent protocols to increase human subject participation among 'hard to reach' populations, and create standing trust relationships (Harris *et al.* 1996) far in advance of recruitment efforts (c.f. 'recruitmentology'; Epstein 2007), it obscures some of the very social processes that reproduce estrangement among many patients.

As one African-American respondent expresses it, 'why am I in such demand as a research subject when no one wants me as a patient?' (Levine 1996). In these words we glean that when routine quality of care is lacking, when healthcare and research are conflated, and when patients feel alienated from medical priority setting, resistance towards the experimental enterprise is a reasonable response. This query, I suggest, leads us in to the broader context of decision-making that sickle cell patients inhabit, drawing us closer to the contested processes of biomedical recruitment and resistance, and compelling us to contextualize this bare expression of ambivalence. By reorienting the conventional approach to studying African-Americans' 'unwillingness to participate' in biomedical research, then, this paper

seeks to draw our attention to the processes that organize people's experiences as both objects and agents of medical treatment. In so doing, not only are we confronted with the multiple uncertainties within which scientific and medical decision-making take place (Timmermans and Angell 2001), but also to the ways in which the query of a neglected patient-cum-research subject resists biomedical purgatory – a limbo void of reason or action. Rather, as the cases below illustrate, ambivalence can actually give rise to forms of agency and resistance that defy the narrow decision-making frames (to undergo a transplant or not) posited by transplant proponents – hence the qualifier ambivalence-in-action. In many cases, caregivers enact nonmedical modes of treatment and care to counter the growing biomedicalization and uncertainty of everyday life with more durable care regimes that seek to prevent and treat the onset of sickle cell-related pain.

To be clear, the narratives that follow are not presented to prove one or another hypothesis about why African-American patient families may be reluctant to use stem cell treatments, but to take an opportunity to examine ambivalence-in-action. The intent is to leave the terrain unsettled, to show that the organization of ambivalence towards experimental medicine emerges as socially 'situated knowledge' (Haraway 1991, p. 581) that can be both incomplete and true. It accounts for the ways in which peoples' decisions to undergo or decline participation in novel treatments are characterized by incisive determinations about, for example, how much one is cared for or how much one is being used to advance institutional agendas. In this way, it does not seek to predict outcomes, but provides a way to conceptualize the connections between sentiments and everyday practices *in situ*. Following an important shift in scholarship on SCD initiated by Dyson *et al.* (2007) and Abuateya *et al.* (2008), this paper finds that the relatively low sickle cell transplant rate, conceived more accurately as ambivalence-in-action, is fueled by three contextual strands: the therapeutic uncertainties of both novel and more mundane treatment regimes, institutionalized conflation of healthcare and research, and political contests in which sickle cell patients are symbolically, but not structurally, included in medical investment decisions. It argues that together, these three features of sickle cell patient care 'organize' an ambivalent response to stem cell recruitment in which caregivers are justifiably resistant to this latest biomedical cure even as they hold out hope for more robust forms of institutionalized care and even cure.

### Background and methods

To investigate the factors that shape sickle cell patient families' decision-making about stem cell transplants, I draw upon multi-sited ethnographic fieldwork in the California Stem Cell Research and Cures Initiative (August 2005 to August 2007; Benjamin 2008). In this larger study I triangulate participant observation from three main sites (biomedical, regulatory, and civic) and interview a purposive sample of stem cell initiative stakeholders ( $N = 63$ ), employing a grounded theory analysis of how existing social structures impact the development of the California Stem Cell Research and Cures Initiative. In what follows I draw upon a subset of interview responses and ethnographic field notes to examine the stakes for the sickle cell patient community in the age of regenerative medicine.

Garvey Medical Institute is the study's primary biomedical site – an urban teaching hospital and research complex that houses a cord blood banking and stem cell transplant program, a regional sickle cell clinic, and a number of other clinical and research departments. In addition to the stem cell transplant program described above, my fieldwork at Garvey included shadowing the head physician in the sickle cell clinic during which time I also attended medical rounds, observed 15 patients who came for clinic visits, and noted discussions between physicians, nurses, and social workers that included medical and social histories of an additional 10 patients. I was given access to the files of several hundred enrollees of the cord blood program, and observed the process by which families collect and store blood for possible use in a stem cell transplant. Institutional review boards at Garvey and my home university approved this phase of the study (IRB# 2007-007).

Outside of Garvey, I observed patients and health professionals in a number of settings: home visits with patient families, two sickle cell community gatherings, one hosted by the sickle cell clinic attended by approximately 150 patient families, and another hosted by Garvey's research wing, which approximately 100 research and administrative staff attended; a medical school presentation by the sickle cell clinic's head physician; and two community-based talks by scientists working on stem cell transplantation. In addition to the on-site interviews and home visits with clinic patients, I conducted 13 remote interviews with families over the phone, all of whom had banked umbilical cord blood from an unaffected sibling at Garvey's tissue bank.

Building upon work that analyzes issues pertaining to sickle cell patients in broader contexts of power and inequality (Hill 1994, Wasserman *et al.* 2007, Abuateya *et al.* 2008), the larger study from which this discussion draws examines ethnoracial, gender, class, and disability politics as a constitutive feature of stem cell research. Proponents of this new field seek to neutralize resistance to this massive state investment by strategically depicting patient families as impatiently awaiting stem cell cures, thereby ignoring the social fault lines that cause some patient populations to resist easy 'bioethnic conscription' (Montoya 2007, p. 94) as stem cell supporters, much less as human subjects. In what follows, I illustrate three contextual strands that fuel ambivalence-in-action and close with a discussion of the implications of these findings for the 'stem cell debate' and other public science initiatives.

### **Therapeutic uncertainties**

In my interviews with parents of sickle cell and thalassaemia patients who were enrolled in the Garvey cord blood bank and were eligible for a transplant, the large majority of sickle cell families declined the procedure while over half of thalassaemia families underwent it. Among the reasons that caregivers repeatedly gave for declining the transplant were that they did not want to use a less refined (i.e., experimental) procedure for their children and they did not perceive the potential benefits to outweigh the known risks. To illustrate this therapeutic uncertainty, I examine the case of the Hart family: Ms. Sethe Hart is a 55-year-old grandmother and primary caregiver of 15-year-old Destiny Hart. Shadowing the head physician, Dr. Wright, in to the hospital room, I found Destiny being checked by a pulmonary specialist, who went on to tell Ms. Hart that Destiny's breathing was a bit abnormal and that she wanted to test whether Destiny would benefit from an inhaler. Hearing

this, Ms. Hart proceeded to ask the specialist a battery of questions closing with ‘why would you give steroids [in the inhaler] to a child?’ Lest Ms. Hart’s query be seen as misguided skepticism, we should note that this exchange came on the heels of FDA safety warnings about the possible side effects stemming from the very inhaler brand under discussion (US FDA 2005). Even so, after further explanation by the specialist, the compromise seemed to be that Destiny would use the inhaler every day for a month then come back in to see whether it had helped or not. What I learned a week later when visiting the Harts in their home, was that they had other plans altogether. Turning to the inhaler issue during our interview, Ms. Hart explains

Speaking of asthma, we’re challenging the test that we’re supposed to be in right now. We’re not taking that stuff. We’re walking [i.e. exercising]. So when we go back in a month, they’re gonna say ‘OH! It’s the results.’ Check this out. We fixing to make a fool out of them. We’re gonna walk everyday, build up that breathing, whatever it is they’re looking for with them lines on that machine, and we just gonna make a fool out of them. Don’t believe everything you hear from man, cause if you do you’ll be in bad shape, cause they’re side effects to everything, they’re side effects to all medications. (Fieldnote 12/07/05)

We should note how Ms. Hart expresses concerns about a generalized risk that she attributes to all medications, not just those deemed ‘experimental’ by health providers. This proves especially critical for those caregivers whose child has experienced relatively mild symptoms up to that point. Ms. Hart also predicts that Destiny’s improved breathing will be falsely attributed to the inhaler by the pulmonologist. Since they do not intend to use the medicine she intends to advance the claim that a nonmedical method (i.e., taking walks to improve lung capacity) is a superior treatment to the inhaler medication. As with Whitmarsh’s (2008) ‘potential asthmatics’ who are prescribed medicines as part of the diagnostic process, Ms. Hart is skeptical towards what she perceives to be a tendency to overprescribe medications. While Whitmarsh’s respondents observed pharmacists taking out the insert describing serious side effects before giving it to caregivers ‘suggestive of a dangerous secrecy’ (2008, p. 58) to induce compliance, several of Hill’s (1994) sickle cell mothers expressed concerns about the administration of penicillin. One of these respondents who knew that a particular study sought younger children ‘refused to participate in the penicillin program by waiting until her daughter was technically too old to be part of the study’:

I didn’t want them testing her to see if penicillin would help new sickle cell children under the age of five. They had no long-range test of that. And penicillin could block the immune system. What would she do later on when she got older . . . what happens to your child later on when she can’t function because she needs penicillin?... I’m sorry, I know you need these experiments and stuff, but this is not the part that we choose to participate in for sickle cell. (p. 107)

As with many caregivers negotiating the risks and benefits of agreeing to experimental treatments within the context of their long-term carework, Hill’s respondent is not willing to take on the burden of unknown future complications. Similarly, I observed Ms. Hart’s ambivalence-in-action when confronted with the experimental protocols routinely offered to her at Garvey:

Ever since Destiny was born they have always tried to get me to okay tests, you know, with different medicines. Every time we come to an appointment they want to introduce me and Destiny into a study, and I tell them 'no!' every time. Don't even waste your time! Cause I don't want them. . .

When Destiny was young . . . they wanted to do a study to see if she was going to have a heart attack! They were going to inject stuff, give her medicines, and once we leave the hospital, I'm the one who has to give her all the medicines and stuff. And I said 'no way! I'm not gonna do that', because she was still young, and her body was pure, and clean. But the only thing that she had inside her body that was a little defect was the sickle cell, so why go throw something else in the body to be tested, and the bodies still pure, clean . . . This is a little brand new body. Don't try to test a brand new something.

What I've seen with the other patients, the other children, is that because they've done their tests, blood looks funny, their hair loss, they're traumatized. Those kids are a mess. And I believe putting all of those fluids and testing those kids, and the parents have allowed those doctors to do it, and I believe that is a large contribution to why our kids, our sickle cell kids, are still sick . . . (Fieldnote 12/07/05)

When I questioned Ms. Hart about the tension between her frustration with both routine and experimental treatments and her seeming enthusiasm for stem cell research, she offered no resolution, leaving the tension in place. Her answer to my question was to say that while she thinks it's fine for taxpayer money to be used for research that may cure sickle cell, she does not believe they will ever find a cure because the scientists do not acknowledge the spiritual source of cures. By seeing themselves as the source of the cure, researchers sabotage their own success. Here, Ms. Hart appears to turn the question of who the biomedical saboteur is back on to the scientists, pointing to their lack of confidence in spiritual intervention and not her own lack of confidence in experimental protocols, as the reason why stem cell treatments may not advance. What may be labeled as her 'distrust' towards medical studies may be better understood otherwise: as her confidence in something other than an experimental method, namely the practical and emotional support she receives from her Church community including prayer meetings held specifically for Destiny. Lest her religiosity appear misguided or even dangerous, consider the growing body of epidemiological findings that show a 'protective religious effect on both morbidity and mortality' especially for African-Americans (Levin *et al.* 2005, p. 237), and most notably among sickle cell patients (Harrison *et al.* 2005). Her seeming sabotage of the breathing test and avoidance of medical studies, in turn, grows out of her experience as a caretaker and observer of other children's run-down conditions, which she attributes to their participation in clinical procedures with uncertain therapeutic efficacy.

Ms. Hart's assessment relates to what Hill (1994) finds in her research on African-American mothers' management of SCD wherein they draw upon situated knowledge to guide their care-giving practices. Most of their attention is directed towards reducing the frequency and severity of pain crises by carefully monitoring medications, diet, physical activity, and the emotional well-being of their children: 'Mothers do not simply follow medical advice; they also learn from experience. Their care strategies are often tailor-made, based on experiences with their own children' (p. 98). These findings suggest a surplus of experiential knowledge that directs care-giving practices and shapes health outcomes. For example, many mothers point to a correlation between stress and pain crises, such that they make an effort to reduce

stress-inducing encounters (e.g., intervening in sibling arguments or withdrawing their child from a hostile school environment; cf. Dyson *et al.* (2007) for a fuller discussion of the role of school climate in sickle cell health outcomes). One mother insisted:

A headache can trigger a crisis because it's stress. Stress kicks off sickle cell. Arguments kick off sickle cell. The pain doesn't just start *naturally*. Something triggers it off. (Hill 1994, p. 97; emphasis added)

This mother's understanding about the interaction between environment and biology, an epigenetic argument at its core, echoes Ms. Hart's concerns about asthma medications in that both resist a dominant framing of SCD and biomedicine as 'unnatural'. They deploy the trope of 'nature' in different ways, thereby achieving different ends. For Ms. Hart, that physical activity is more natural than the inhaler means it is a superior method of addressing Destiny's breathing irregularities. The inhaler may not only lead to side effects, but it also involves greater biomedical dependency which may be understood in terms of time and money to the extent that she and Destiny must travel to and from the clinic, wait to be seen, and possibly pay a portion of the medication costs. Thus what is 'natural' about exercise can be understood as avoiding a medication that may or may not work, but also avoiding the expenditure of money and time required to come back to the clinic. Exercise, by contrast, is described as an activity they would integrate in to their day, a time set aside that grandmother and granddaughter would enjoy spending together, enhancing one another's well-being.

By contrast Hill's respondent describes how stress induces pain crises and considers a purely biological explanation inferior to one that takes in to consideration 'triggers' of pain *outside* of the red blood cells. For her, a 'naturalized' framing undercuts her own ability to manage her daughter's condition, whereas for Ms. Hart a 'naturalized' framing enhances her agency vis-à-vis biomedicine (cf. 'strategic naturalization'; Thompson 2005).

Most important for this discussion is that caretakers are shown to enact specific responses with and against the idiom of nature-as-biological in decidedly non-deterministic ways, illustrating the dynamic processes of healthcare fueled by therapeutic uncertainty. But even noting this relative agency, we observe a similar ambivalence-in-action across their narratives that are directed towards biomedical authority and, as I argue, cannot be explained only with reference to their children's precarious disease progression or the unknown outcome of experimental treatments. Rather, as the next section illustrates, their ambivalence is also produced by the institutionalized tension between healthcare and health research, competing agendas that are likely to be more conflated in the kinds of medical institutions in which the majority of African-Americans seek healthcare (Blustein 2008).

### **Conflating healthcare and research**

In what follows, I first present examples of malign racialization that too often characterizes the everyday clinical experiences of sickle cell patients and their families. I follow this with examples of the purposeful conflation of research with healthcare in the context of stem cell transplants, positing that this problematic

confluence is central to the larger process of organized ambivalence. The depiction of sickle cell patients as either excessively stoic or chronically drug seeking are both racialized depictions that form the collective experience of this patient community (Rouse 2004). Together the relative invisibility of pain and the difficulty in establishing a standard of care has led to neglect and mistreatment for many patients (Anionwu and Atkin 2001), as in the following description by Roxanne:

Most recently, not here, at another hospital, I went through the emergency room and there were people coming in with scrapes on their knee and nosebleeds and things like that. And they would go right in. I waited there for 8 hours in an emergency room waiting to get treated when everyone else just walked in and out. The doctors didn't know much about sickle cell, they were really insensitive and rude and kind of just brushing me off. [The doctor] said some mean things too. I didn't get treated for another eight hours. It's really difficult sometimes. I don't even like to talk about it (crying). (Fieldnote 02/13/06)

Roxanne's and other patients' experience of basic healthcare is a crucial element in the organization of ambivalence towards stem cell transplants. In at least one hospital with which I triangulate my observations at Garvey, nursing staff have developed a 'behavior contract' to curb what they experience as disruptive behavior on the part of some patients: 'a zero tolerance policy with regard to abusive/threatening/ intimidating behavior. Failure to comply with the following rules will result in your immediate discharge from the hospital and/or the intervention of law enforcement personnel' (Fieldnote 02/10/10). A nurse in this teaching hospital intimated that while the contract itself does not specifically name 'sickle cell patients' as the target population, her experience is that the contract was developed and is selectively applied to them. The exceptional penalization of Black patients described here is a pronounced feature of African-Americans' experiences, not only in sickle cell care, but also in many different medical encounters (Roberts 1998).

Sickle cell families' decision-making is not only shaped by an assessment of the relative efficacy of a novel procedure or by a patient's relative severity, but also by broader politics of access to quality health services. When families experience a disproportionate emphasis on their value to research and much less attention on their everyday healthcare needs, skepticism towards research solicitations appear justified. But for this precise reason, experimental procedures are all too often presented as altruistic cutting-edge healthcare, where 'cutting-edge' can be understood as a euphemism for risk and uncertainty even as it may result in a remarkable cure.

Consider, for example, that while Garvey's transplant program is 'public' in the sense of being subsidized by federal and state grants, the cord blood units collected through the program are not publicly available. While only families who bank a unit have access to their own unit, the units are available for scientific research once a family no longer needs it (i.e., the ill child either dies or gets a successful bone marrow transplant, or the five-year free storage life of the unit draws to a close). Nancy Somers, the lead caseworker at the transplant program explains:

NS: Well that's a huge challenge for the program. There's all this blood that we can't throw away.

RB: So what's done with all the blood that the families aren't going to use?

- NS: For the affected blood, we used to get lots of requests from scientists who wanted to use it for research.
- RB: And you all can do that?
- NS: Families have the option of donating it for research once they don't need it. There's a checkbox on the informed consent form when they enroll.
- RB: And how many enrollees actually do that?
- NS: About 20–25% check 'no', that their collections can't be used.
- RB: Oh, so the majority don't mind?
- NS: Yeah, they figure that if their family isn't going to use it, the blood may as well be put to use to help *someone*. (Fieldnote 12/05/05)

Somers' explanation corresponds in part to the high levels of public support for innovative research programs that promise to improve the health of the citizenry (e.g., passing of the California Initiative), with strong precedents in the US culture of blood and organ donation (Waldby and Mitchell 2006). However, from the perspective of racialized groups who have routinely been excluded from or stereotypically derided by mainstream American institutions, the Garvey arrangement may very well be understood as a case of altruism masking research interests. The same medical institution offering stem cell banking for free through government funding, makes its unused cord blood available to researchers – a dynamic that is aided by the extremely low rates of blood usage by the families themselves. Consider an excerpt from an outgoing letter addressed to each enrolled family's health provider that essentially seeks to recruit the most well-matched patient-sibling duos to take part in the transplant:

Recently, we confirmed that a cryo-preserved HLA-identical sibling donor cord blood unit collected for your patient, (name inserted here), who has sickle cell disease, has characteristics that we believe makes it suitable for transplantation. Thus, we are writing to inform you about our prospective, government-supported umbilical cord blood transplantation study entitled (name inserted here), for which your patient may be eligible . . . We hope that you will consider enrolling this patient in this clinical trial.

This correspondence is one of the few in which the experimental nature of the transplant 'study' is plainly expressed, albeit still within the framework of biomedical 'outreach' to a 'hard to reach' population. This window in to stem cell recruitment raises a question about the superiority of 'public' stem cell banking as touted by proponents who suggest that publicly maintained repositories will reduce disparities in access to therapies (Bok *et al.* 2004). But this ignores the cost to *particular* publics of being so available to research solicitations such as the one above. This cost is incurred because of the purposeful conflation of research and treatment, especially when the rate of successful transplant is perceived as 'low' and therefore 'risky'. Under such conditions, the already fragile relationship between many African-Americans and medical institutions may corrode further. By contrast, when the transplant success rates are perceived as relatively high, researchers may justifiably gloss the experimental nature of the process, leaving them open to backlash if and when serious post-transplant complications arise. In the following section, we turn to the final process in contextualizing the ambivalence of many sickle cell families, examining the importance of political contests over medical investment. Here we find SCD invoked as a political tool for officials to appear responsive to 'underserved

populations' without at once ensuring that sickle cell communities are substantively included in agenda-setting.

### Political contests over medical investment

As early as the 1950s sickle cell had become 'a new source of income, a commodity in a growing [medical] service sector' (Wailoo 2001, p. 11). Research on sickle cell was characterized by an influx of philanthropic and government funds, such that experts in molecular biology, clinical specialists in haematology, patients' rights advocates who sought recognition for this 'orphan' disease, and politicians who were determined to lobby for grants on behalf of their African-American constituencies, all clamored to increase the visibility of sickle cell. Indicative of changing economic and social relations on the national scene, SCD's newfound celebrity also met with backlash by those who 'simply resented the fact that political pressure from African-Americans and liberal politics had influenced the direction of National Institutes of Health research dollars' (p. 8).

In the clinical context, a succession of therapeutic 'breakthroughs' were celebrated then disparaged as serious side effects came to light. Bone marrow transplantation (BMT) was the immediate precursor to the cord blood transplantation procedure examined here, and in many cases is still used in conjunction with cord blood to minimize immune rejection, or to supplant low stem cell counts in the cord blood. Beginning in 1984, BMT was lauded in the *New York Times* as a 'life-saving therapy' though 'fatal about 30% of the time' (Wailoo and Pemberton 2006, p. 148). One of the main factors preventing people from undergoing BMT is the requirement that they obtain a donor with matching bone marrow. It is precisely this barrier that sibling cord blood collection and transplants aim to get around, since the likelihood of HLA-matching siblings are significantly higher than if one is seeking an unrelated donor. As with many of the contentions around BMT wherein 'the question of what physicians owed to their patients, what risks and choices ought to be offered to them, and whether BMT should be understood as an "experiment" or as an "innovative therapy"' (Wailoo and Pemberton 2006, p. 149), there is a very wide spectrum in how people view stem cell transplantation that is shaped by similar racial and class politics found in previous iterations of treatment 'hope and hype'. Against this historical backdrop, it is useful to consider that sickle cell disease is facilitating the emergence of stem cell research as the latest iteration of profitable and promise-filled science. The California Stem Cell Initiative is the largest single government investment in the new field to date, and includes the building of an entirely new research infrastructure (facilities, training, grant competitions, etc.) to support the research investment. But the 'public benefits' of this taxpayer funded initiative continue to be called in to question (Hall 2005), hence the imperative to appear responsive to the state's diverse constituency.

Participant observation, interviews, and content analysis of documents reveal the Initiative was infused with inclusionary symbolism through the use of sickle cell disease as the paradigmatic neglected disease of a potentially neglected public. In 2004, when voters in the state of California voted whether to invest \$3 billion in the Stem Cell Research and Cures Initiative (Prop. 71), both the 'Yes' and 'No' on 71 campaigns made their case with reference to whether or not the Initiative would benefit the African-American sickle cell community for whom adult stem cell

transplants were already underway – a proof of principle about the public benefits of the new field. In this way, sickle cell demonstrates political dexterity, where advocates on multiple sides of the debate draw upon its racial symbolism to make competing claims about the Initiative's benefits or harms. Consider the official ballot summary produced by the California Attorney General's office, in which the main contention is that corporate economic (i.e., biotech) interests are pitted against the will of the people. In the 'No on 71' summary, under the heading *Bad Medicine*, the sole example provided to support the claim that Prop. 71 is corporate fraud refers to adult stem cell transplantation that uses cord blood to treat SCD. Among the signatories oncologist/bioethicist H. Rex Green (Cancer Center Director) expresses his disdain for Prop. 71 in these terms:

The big question is we live in a community, and the community has to make difficult judgments about how to spend its resources, and if *we're actually gonna take resources away from sick people who happen to be poor, who happen to be African American or Hispanic in the hopes of curing something twenty years after they're dead*, that kind of discussion belongs in the legislature where interests are fairly heard and competing interests have a chance to make their case. What instead has happened, and this by clear intent of the proponents of this initiative, they went the initiative route because this is the best way to bedazzle and befuddle the public. . . . And they have fooled a lot of really reputable organizations [emphasis added]. (Fieldnote 01/17/08)

Green, unlike other signatories whose main concern is to advocate for fiscal conservatism, identifies himself as 'a progressive' who opposes Prop. 71 in the name of 'voiceless' racial-ethnic minorities and poor people who, he contends, will not be served by this state investment. Though he does not name them explicitly, surely Green would count the Sickle Cell Disease Foundation among those organizations 'fooled' by the promise of therapeutic gold, made all the more troubling by the omission of SCD representatives from the stem cell agency's governing board.

In the 'Yes on 71' official rebuttal statement, supporters are quick to clarify that the Initiative does in fact fund adult and cord blood stem cell research (including that which is used to treat SCD). This effort to align the 'Yes on 71' campaign with the state's diverse racial-ethnic public was vital, because at the time the state's liberal base was beginning to publicly express nervousness about whether the Initiative was an elitist endeavor fueled by biotech companies at the expense of people of color and women (Beeson and Lippman 2006). While the 'science for the people' framing proved successful in the end, the point here is that proponents and opponents invoked sickle cell as a political proxy that implicitly drew marginalized publics into the debate, if only rhetorically.

As indicated previously, among those patient advocacy organizations that signed on to the 'Yes on 71' campaign, the Sickle Cell Disease Foundation was one of only two supporting organizations that were not subsequently represented among the disease advocacy seats on the stem cell agency's governing board. The rhetorical inclusion and administrative exclusion of SCD fuels ambivalence among those affected by an illness that was relatively prominent in the stem cell campaign. This disjunction, in turn, has material consequences in the allocation of research grants that may, in fact, prove a liability for the Initiative and reason to re-imagine the parameters of public participation in future endeavors.

In the first round of grant allocation, the new stem cell agency awarded over \$50 million to research programs across the state, failing to fund a proposal by the only institution primarily serving sickle cell patients. In response, the director of this institution rallied health disparities advocates in a letter writing campaign to the agency. One of the most important of these was from the Greenlining Institute, a 'multi-ethnic public policy think tank', that at one point asserted that the state stem cell agency must be held accountable for providing benefits to its diverse ethnoracial public in the form of work contracts and cures for ailments that disproportionately affect people of color. One Greenlining spokesperson poignantly expressed the idea that people of color 'need to be *at* the table, not just *on* the table' of cutting-edge science.

In a letter writing campaign to appeal the decision, minority health advocates linked investment in SCD with a commitment to the principles of diversity and just inclusion. But, as I elaborate elsewhere (Benjamin 2008), to the extent that advocates politicized health as a 'right' that should 'collectively benefit' subordinated ethnoracial communities, the neoliberal-bent of the stem cell agency inhibited any substantive acknowledgement of advocates' demands. Rather, Prop. 71 explicitly codifies individual stem cell scientists' 'right to research' (Brown and Guston 2009) without at once institutionalizing a corresponding right for social collectives (e.g., the sickle cell community) to shape the direction or access the fruits of this state investment through participatory governance or benefit-sharing structures.

After the letter writing campaign was shown to have little effect, the sickle cell institute director attended a stem cell agency board meeting to make his appeal in person. In a heated debate over the relative accountability of the agency to California's ethnic majority and whether such scientific lobbying undermines the integrity of peer review, the agency's governing board voted 10 to five not to revisit the grant decision. Even so, this series of events won several key supporters among the agency's board in favor of the sickle cell appeal, most significantly the HIV/AIDS disease advocate Jeff Sheehy. Following an admonition by a Greenlining health program director that 'funding the facilities grant would have been an important step in building a trust relationship with ethnic communities', Sheehy called the failure to fund the grant a 'missed opportunity', adding that 'these communities would be needed when research moved into clinical trials and without a prior trust relationship with those implementing the Initiative, it would be difficult to recruit a diverse donor pool'. Sheehy compared this dynamic to his experience working with HIV/AIDS researchers, who were forced by those affected by the illness to recognize the importance of making good faith efforts to address the needs and interests of the patient community from which human subject research participants would be needed.

In short, several prominent Stem Cell Initiative stakeholders argued that funding a grant proposal from an institution with a known commitment to SCD research could have been an effective preemptive strategy to build political support among the agency's diverse constituency, thereby priming patients' willingness to participate in research. Their warnings reveal that scientists and board members alike are cognizant of the way in which the political exclusion of the sickle cell patient community, both on the governing board and among grantees, potentially alienates this population in the clinical sphere.

## Discussion

In its broadest terms, this paper focuses on stem cell transplant procedures using cord blood – a more established subfield of stem cell research – to examine the complex relationship between medical inclusion and social marginality just as both grow increasingly relevant to the ‘biotechnical embrace’ (Good 2001) of contemporary medicine. While the stem cell debate in the United States has largely focused on the ‘moral status of the embryo’, a growing number of analysts point to issues that extend beyond the ethics of embryo use, to the racial politics of egg banking (Bok *et al.* 2004), the racialized gender politics of recruiting particular kinds of women to supply oocytes (Thompson 2007), the racialized disability politics of seeking cures on behalf of groups who themselves seek integration not elimination (Disabled Peoples’ International Europe 2000), and to the challenges of implementing inclusive governance structures for publicly mandated science (Winickoff 2006). This discussion contributes to this effort to expand the bioethical terrain as one structured by existing social faultlines and does so in a way that foregrounds racialization at the nexus of sickle cell treatment and stem cell research. By drawing three explanatory strands together, therapeutic uncertainty, conflation of healthcare and research, and political contests over medical investments, I offer organized ambivalence as an analytic alternative to notions of ‘fatalism’, ‘personal distrust’, ‘noncompliance’, or ‘scientific illiteracy’ as competing ways to explain why sickle cell patient families resist participating in stem cell research.

Finally, in the context of novel biomedical initiatives, I suggest that the multiple uncertainties that characterize the field are better not concealed through hyperbolic rhetoric that seeks to bolster public support. Rather, by acknowledging the ‘foundational instability’ (Whitmarsh 2008) that characterizes the institutionalization of biomedicine, we may tap in to the ‘potentiality’ (Ganchoff 2006) for deliberating across social, ethical, and political differences. Providing a vital perspective for reimagining healthcare, the convergence of sickle cell and stem cell research impels us to situate the relative burden of caring for an ill child within broader contexts of suffering and resilience which temper the meaning of illness as strictly biological. One father of four articulates this best:

There’s an old proverb that [says] when your house is on fire you don’t worry about broken windows. In a lot of communities where sickle cell is present, they’re struggling. People are very poor and they have a lot of problems so they don’t look at this particular problem as being one that’s overwhelming in relation to other problems they have. (cf. Duster and Beeson 1997)

The words of this caregiver brings us back to the social dissonance produced by an overinvestment in experimental research when quality healthcare is scarce for many people living in a country without comprehensive national health services. For many of my respondents, focusing on the 6% sickle cell versus 60% thalassaemia transplant ‘disparity’ at Garvey is comparable to sweeping up broken glass, all the while the more pressing flames in their lives are left to wreak havoc. Research administrators and proponents of novel scientific initiatives alike would do well to heed this father’s structural metaphor to the extent that it forces us to pay attention to the social processes that organize ambivalence towards novel treatments. In this way, the convergence of SCD and stem cell research provides a model for conceptualizing the

politics of inclusion in the medical context in so far as the multiple uncertainties associated with SCD progression (mild or severe), transplant outcomes (event-free or severe complications), and socioeconomic contexts of this patient community (access to affordable quality healthcare or not) form an unstable nexus for decision-making. Examining this convergence *in situ*, rather than surveying peoples' discrete attitudes about treatment, reveals how caregivers continue to reason, negotiate, and act without great certainty, but in ways that strategically reinforce regimes of long term care. How, then, can we 'scale up' and coordinate novel biomedical initiatives that, like these caregivers, organize ambivalence explicitly for the collective good? This, I suggest, is a worthy focus for ongoing study and implementation.

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