

AN ETHNOGRAPHIC STUDY OF THE EXPERIENCE OF BLACK
TRAUMATICALLY INJURED PATIENTS AT A TRAUMA CENTER IN
PHILADELPHIA

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DEDICATION

In loving memory of my father, John S. Jacoby,
who taught me to always question the difference between who I am and what I represent

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ABSTRACT

AN ETHNOGRAPHIC STUDY OF THE EXPERIENCE OF BLACK TRAUMATICALLY INJURED PATIENTS AT A TRAUMA CENTER IN PHILADELPHIA

Sara F. Jacoby

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The intent of this ethnographic study of trauma care was to contextualize the etiologic factors that perpetuate disparities in survival and recovery among Black traumatically injured patients in the United States. Race-based disparities in trauma injury outcomes in the U.S. are perplexing given the legislative protections that require that all people, regardless of insurance status, are admitted to trauma centers and that accreditation of these centers requires adherence to strict standards of care. This dissertation offers an interpretive analysis of ethnographic data collected among twelve Black traumatically injured patients and the clinicians who provided their medical and nursing care between December 2012 and December 2013 in a Trauma I Medical Center in Philadelphia. Participants discussed their perceptions of injury care and the consequence of being injured in the context of their lived experiences, shaped by violence, poverty, underemployment, lack of health insurance, and disenfranchisement from local healthcare institutions. The socio-structural context of the trauma center and its clinical culture were similarly constituted by these racialized economic and political dynamics of the city-at-large. These findings prompt re-thinking of practice and processes in clinical trauma care to recognize and accommodate the lived experiences of socially marginalized patients in medical and public health responses to injury in the urban environment.

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CHAPTER 1

Introduction

There are numerous lenses through which researchers investigate the complex structural and individual characteristics that contribute to health outcome inequities. The need for such scholarly exploration has been emphasized by policy and advocacy organizations like the Institute of Medicine, in recognition that interactional phenomenon (clinician bias, stereotyping, and clinical uncertainty in race-discordant patient-clinician interaction) and the influence of clinical environments are poorly understood and under-researched as etiological drivers of the health outcomes experienced by minority racial groups in the United States (Balsa & McGuire, 2003; Cooper et al., 2003; Meghani et al., 2009; Smedley B, Stith A, & Nelson A, 2002; Van Ryn, 2002). Our contemporary understanding of racial inequities in injury outcomes illustrates this knowledge gap. Epidemiologic studies of National Trauma Databank records over the past decade have documented the presence and magnitude of racial and ethnic inequities in injury outcomes (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Haider et al., 2008; Shafi et al., 2007). Very few subsequent inquiries have focused on the processes that underlie outcome differences by race in the context of injury care.

Urban Trauma Centers provide a useful setting in which to begin study of the processes that underlie injury outcome inequities. These institutions are often located in areas of racial and ethnic diversity, are designated as centers equipped to treat a wide spectrum of injuries, and typically have a higher census of injured patients when compared to smaller non-urban institutions. The care of the traumatically injured individuals in the Trauma Center is expected to be 'blind' to patient factors often

associated with race and ethnicity-based health inequities like health literacy (Marquez de la Plata et al., 2007) and ability to pay for services (Blanchard, Haywood, & Scott, 2003). In the acute management of injuries, trauma clinicians rely on algorithmic care guidelines developed by professional societies such as the American College of Surgeons, Committee on Trauma (Committee on Trauma, 2014). This algorithmic approach to care is suggested to be resistant to social phenomena that might interfere with health care practices (Willard, 2009). Essentially, the application of practice guidelines is believed to prevent racial discrimination. A wealth of research, however, makes this assumption problematic. Black patients in the U.S. receive inferior care in comparison to their White peers for other conditions that use standardized approaches to treatment, for example cardiac care (Ayanian, Weissman, Chasan-Taber, & Epstein, 1999) and pain management (Blanchard et al., 2003; Burgess, van Ryn, Crowley-Matoka, & Malat, 2006; Cone, Richardson, Todd, Betancourt, & Lowe, 2003; Pletcher, Kertesz, Kohn, & Gonzales, 2008; Willard, 2009).

To more deeply explore the foundations of racial differences in injury outcomes the goal of the research described in this dissertation was to use ethnographic methodology to understand Black patients' hospitalization experiences, the impact of social interactions, and processes of racialization and race consciousness in an urban Trauma Center. Though centered on patient experience, observation and interviews also explored the perspective of clinicians who provide treatment for injured patients. This methodological framework permitted flexibility to explore patient-clinician interaction with a focus on race and race consciousness, while providing space to allow a naturalistic inquiry through which other dynamics in the social world (judgments of blame for

injuries, trust, and communication) emerged as important to understanding Black patients' experience.

The specific aims of this dissertation research include:

- 1) To broadly describe the experiences of Black individuals with traumatic injury hospitalized in an urban Trauma Center;
- 2) To illustrate patient and clinician behaviors that comprise and surround patient-clinician interactions with a particular focus on how characterization of race, culpability for injury, and trust is constructed and communicated; and
- 3) To explore the perceptions of interpersonal interactions from the point of view of both Black trauma patients and the clinicians who provide their care.

Organization

This dissertation is organized to include an introductory chapter, two papers that explore the major findings of the study, a paper that describes the interpretive and methodological insights of reflexive practice during the research process, and a final discussion chapter. Chapter 1 explores the background and significance of the study of racial disparities in injury outcomes in the United States, the gaps and limitations in extant biomedical literature, and an overview of the theoretical framing, methods, and human subjects' considerations that guided this inquiry.

Chapter 2 is a paper that explores the experience of injury and hospitalization from the patients' point of view. This paper centers on how Black trauma patients who participated in this ethnographic inquiry perceived their early injury experiences and interactions with first responders and Emergency Department (ED) staff, embody their physical and psychosocial responses to injury during hospitalization and in relationship to

the clinical environment and clinical care providers, and understand the enduring consequences of their injuries in the context of their lived experience.

Chapter 3 is a paper that describes the influence of the social and structural context of urban Philadelphia on the experience of Black injured people in one of the city's major Trauma Centers. Specifically, it explores how race and other social constructions play out in the cultural milieu of hospital-based injury care. This paper includes perspective from both patients and their clinicians and critical interpretation of the culture in which their interactions occur.

Chapter 4 is a methodology discussion paper in which I discuss the processes through which I learned the insights and challenges of reflexive practice in conceiving, engaging, and analyzing ethnographic research. I describe the ways in which reflexivity guided my practice as a novice researcher who was both an insider and outsider to the clinical environment and among the participants whose experiences I sought to understand.

Chapter 5 synthesizes the findings of the study overall and situates these findings in the context of clinical and theoretical literature. Here, I offer suggestions for research that extends the findings of this study and its implications for health and social policy.

Background and Significance

Black patients are disproportionately affected by both injury mortality and post-injury disability (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Haider et al., 2008; Shafi et al., 2007), and the severity of disparity appears to be most significant among younger patients (Hicks et al., 2014). In a stratified nationwide Healthcare Cost and Utilization Project (HCUP) inpatient sample, Black patients had 14% higher odds of

dying after injury when compared to White patients (Odds Ratio [OR] 1.14; 95%CI 1.03-1.27) (Arthur et al., 2008). This disparity persisted even when adjusting for potentially confounding variables including: age, gender, comorbid conditions, injury severity, primary payer, median income of zip code of residence and hospital type (trauma center designation). A similar analysis of over 200,000 patient encounters recorded in the National Trauma Databank demonstrated increased odds of mortality among both insured (OR 1.2; 95%CI 1.02 -1.33) and uninsured Blacks (OR 1.78; 95% CI 1.65 -1.90) in comparison to insured and uninsured Whites (Haider et al., 2008). In the single study that examined outcomes among injury survivors, Black patients with traumatic brain injury were 15% less likely than White patients to be placed in comprehensive rehabilitation facilities, despite comparable injury characteristics, severity, age, gender and insurance status (Shafi et al., 2007).

It is unknown how hospitalization influences the perpetuation of racial inequities in traumatic injury outcomes. Naturalistic study of the healthcare experiences of Black injured people are limited to the experiences Black males with violent injuries like gunshot wounds (Corbin et al., 2013; Lee, 2012; Liebschutz et al., 2010; Rich, 2009; Rich & Grey, 2005). These studies begin to illustrate how perceptions of trauma care providers can hinder open communication and trust during the hospitalization experience. In their study of Black men with violent injuries in a Boston Hospital, Liebshutz et al. (2010) illustrate the extent to which patient participants expressed suspicion of trauma clinician motives and felt that there was poor distinction between medical providers and the criminal justice system in the clinical environment (Liebschutz et al., 2010). These findings are consistent with research that suggests Black Americans are more likely to

report low levels of trust in healthcare clinicians and this low trust is associated with fewer quality interactions (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Halbert, Armstrong, Gandy, & Shaker, 2006). Injured Black patients also described a sense of disconnection from the predominantly White medical staff. This sense of disconnection worsened their feelings of vulnerability and dehumanization in trauma care processes (Liebschutz et al., 2010; Rich, 2009). Barriers to therapeutic patient-clinician communication and trust can impact factors like adherence to medications, physical therapy, and self-care skills, which in turn, have potential to deter long-term functional and emotional recovery (Street, Makoul, Arora, & Epstein, 2009).

Inequities in pain treatment for injured patients provide a concrete example of care processes based in patient-clinician interaction that can contribute to poorer outcomes. Black patients who seek care in hospital emergency departments are less likely to receive pain-relieving opioid drugs when compared to White patients for conditions like long-bone fracture (Pletcher et al., 2008). Black patients relate negative experiences with pain management as an important predictor of negative hospital experiences (Hicks, Tovar, Orav, & Johnson, 2008). Understanding inequities in pain management in the injured patient population provides insight into both the experiential quality of the hospitalization and also uncover unmet physiologic needs in the post-injury rehabilitation and recovery process.

The influence of the relationship between race and assumptions about a patient's culpability in the events leading to their injuries has only been explored in experimental research (Balsa & McGuire, 2003). Social psychology research suggests that the role of blame can influence the rapport and trust that shapes the patient-clinician relationship. In

an experimental study, patients viewed as being at fault for the circumstances surrounding an injury were more likely to experience prejudice, less social interaction, and were less likely to receive help from experienced nurses (Linden & Redpath, 2011). In another scenario-based psychology experiment, healthcare professionals expressed significantly more negative attitudes and less intention to help patients whom they blamed for the injury (i.e., had positive toxicology screen in the context of a motor vehicle accident) (Redpath et al., 2010). This latter finding is particularly salient given that Black trauma patients are tested for alcohol and drugs at emergency department intake at a significantly higher rate than White trauma patients (Kon, Pretzlaff, & Marcin, 2004).

The way that patient race is constructed in cognitive, behavioral or affective processes of trauma clinicians is not well described. If we apply conclusions from broader study of racial dynamics in US healthcare, it is reasonable to consider that patient-clinician interaction in trauma care is racialized. A cadre of 26 predominately White health professionals (nurses and physicians) were interviewed to examine how they understand the etiology of race-based health disparities. The following themes describing overt racial biases emerged: 1) disparities are attributable to Black patient's perceived shortcomings in treatment adherence and compliance and/or as a result of the incapacitations of addictions or poverty; 2) White patients demand or advocate for more specialized and attentive treatment and thus receive it; 3) providers manifest racial bias emerging from unconscious racism and/or lack of empathy for non-White patients; and 4) when compared to White Americans, members of minority groups have poorer access to

health services due to lower socio-economic status and poorer insurance coverage (Clark-Hitt, Malat, Burgess, & Friedemann-Sanchez, 2010).

A controversial social psychology methodology known as Implicit Association Tests (IATs) has been used to study clinicians' implicit feelings about race and their patients (Green et al., 2007; Sabin, Rivara, & Greenwald, 2008). Comparative psychometric testing demonstrated that clinicians had no overt racial preferences (Sabin et al., 2008). In assessing implicit judgment, however, IAT results illustrated an overall preference for White patients and a stronger association between the concept of 'cooperativeness' and White patients when compared to 'cooperativeness' and Black patients. Among a cohort of 95 predominately White female pediatricians, IAT scores similarly revealed an implicit preference for White patients (Green et al., 2007). This sample of physicians also held a stronger implicit association between patient compliance and White patients when compared to Black patients (Green et al., 2007). In the single study to examine unconscious biases of trauma and acute care surgeons, IATs administered to a convenience sample of members of an academic medical trauma society demonstrated that surgeons held unconscious preferences for White people and people of higher socioeconomic status but that these biases were not associated with clinical decision making in their response to clinical vignettes (Haider et al., 2014).

Though it is difficult to link implicit associations with racially discriminatory practices, especially when biases are not demonstrated in response to clinical vignettes, these studies begin to support the proposition that race consciousness is an inextricable part of the healthcare experience. Black patient perspectives provide further evidence of racial bias and race consciousness in healthcare interactions. Using in-depth interviews

and focus groups, Peek et al. (2010) report that Black patients recruited from a Chicago Medical Center perceived that White health care providers hold biased and discriminatory views that impede open communication. This perception, according to interviewees, contributed to less adherence to prescribed regimens and diminished the likelihood that Black patients would ask clinically-relevant questions of their White healthcare providers (Peek et al., 2010).

Nicoliadis et al. (2010) reinforced some of Peek et al.'s findings. Among 30 Black patients in treatment for depression, respondents perceived the healthcare system in general as 'White' and thus deserving of mistrust. This mistrust was an important impediment to openness in clinical encounters related to mental health care. The effect was most pronounced in race-discordant interactions- when Black patients were cared for by White mental health clinicians (Nicolaidis et al., 2010).

Specific to trauma care, a sample of 25-38 year old Black male gunshot or stabbing victims participated in semi-structured interviews designed to illustrate the range of their experiences during recovery from life-threatening injuries (Liebschutz et al., 2010). The prominent theme that emerged was that the Black men felt disconnected from the predominantly White healthcare staff and that, in general, there was a lack of meaningful interaction (Liebschutz et al., 2010). Moreover, many described suspicion of clinician motives whose actions were perceived as reflective of a culture with which the patients did not identify (Liebschutz et al., 2010). One participant reflected: "But they were happy to have people of color to patch up and profit off of. So, I guess they were grateful for that way. But, other than that, I was treated indifferently, especially by the nurses and the um, after-care portion, the few days I spent in the hospital, I might as well

have been a piece of meat.” Many participants also spoke about how hospital staff would allow police interrogation during treatment which made them feel as if they were viewed as criminals and increased their sense of vulnerability- already heightened by physical injuries (Liebschutz et al., 2010).

The research described in this dissertation offers a naturalistic perspective of the lived experiences of Black injured patients cared for in a Philadelphia academic medical center with specific attention to processes of racialization and stereotyping in patient-clinician interactions. It builds upon other naturalistic studies of the experience of Black trauma patients with violent injuries to develop a nuanced perspective of the ways in which clinical interactions in the hospital environment contribute to the development of inequitable outcomes for Black trauma patients regardless of mechanism of injury. Its intent is also to identify modifiable factors that can be used to meet the national priority to reduce health disparities related to injuries (CDC, 2009).

This study is unique in its inclusion of the nurse-patient interaction as a part of the exploration of racial inequities in injury outcomes. The study of racial and ethnic based clinician biases that interfere with the equity of healthcare provision is predominantly focused on the physician-patient dyad (Dovidio et al., 2008; C. Lee, Ayers, & Kronenfeld, 2009; Sabin et al., 2008). Nurses comprise the majority of the healthcare workforce, and are beholden to “deliver nursing care with respect of human needs and values, and without prejudice,” as outlined in the American Nursing Association Code of Ethics (American Nurses Association, 2001). Yet study of nurse-patient interaction is conspicuously absent from this line of research. This study sought to elucidate interactive process between injured patients and all hospital-based clinicians, including nurses.

Theoretical Approach

The inquiry is informed by Critical Race Theory (CRT), to purposefully situate the social construction of 'race' as a focal point through which to explore power in the delivery of trauma care in a hospital. This research attempts to open up the ways that race and racial identity are socially constituted throughout institutional space and the purpose that this construction fulfills through Foucault's theory of power and 'dividing practices,' and Bourdieu's theory of Practice. The intention was not to produce discourse in which racism is understood as a manifestation of the perspective or practice of specific individuals, but rather to explore race as it appears as a symbol of learned subjectivity, to challenge the dominant discourse in which the care of trauma patients is viewed as entirely physiologic and 'blinded' to a larger social world.

Critical Race Theory

Critical Race Theory (CRT) frames the research question, choice of methodology and informs my understanding, as the investigator, of the social world of contemporary urban life in the United States. CRT is a transdisciplinary race-equity theory that emphasizes the critical study of contemporary societal dynamics and socially and institutionally marginalized groups to meet the need for scholarship that theorizes race within practice disciplines (Delgado & Stefancic, 2001). CRT first appeared in public discourse in the 1980s through legal scholars who sought critique of the mechanisms through which purportedly neutral standards like legislation were enacted and enforced in ways that perpetuated inferior treatment and inequitable social and economic conditions for people of color in the United States (Delgado & Stefancic, 2001). Application of this

theory has since spread to the fields of education, public policy, social work and most recently to public health, medicine, and nursing.

The core tenets of CRT (Delago & Stefancic, 2001; Ford & Airhihenbuwa, 2010a; Ford & Airhihenbuwa, 2010b), based on the foundational work of Bell, Chrenshaw, and Matsuda, are as follows:

- 1) Racism is an ordinary, everyday experience for people of color in the United States. It is not an exceptional feature of particular interactions or institutions but rather, the underlying norm that is integral to dominant notions of American political and social life.
- 2) Race is not a biological or genetic reality but rather a social construction that shifts and transforms with social evolution.
- 3) Because racism is constitutional to social inequity, contextual analyses of race and racism are required to challenge positivist claims of neutral knowledge.
- 4) There is a unique voice of that emerges from the lived experiences of people of color which must be privileged to counter the dominant perspective.

With these tenets in mind, this research focuses on the lived experience of the Black trauma patient during hospitalization to provide critique of dominant claims about neutrality, objectivity, and colorblindness (Matsuda, Lawrence, Delgado, & Chrenshaw, 1993) in injury care and to theorize how race consciousness is constructed in hospital space. The singular focus on Black patients is purposeful- not to make Black patients emblematic of all patients of color or to reinforce a Black-White binary in discourse on

social power- but rather as a starting point from which to challenge the structural and material conditions and relationships that are particularly dominant in the context of the city of Philadelphia. Moreover, this focus in the context of the single hospital, permits in-depth analysis so that the findings that emerge are not overly deconstructed by characterizations of patients through a wide array of intersecting identity constructions (by race, gender, educational level, income, insurance status, etc.).

The choice of ethnographic methods as a platform for this research offered the development of counter-narratives or counter-stories which are foundational to the CRT approach to knowledge development (Delago & Stefancic, 2001; Ford & Airhihenbuwa, 2010a; Ford & Airhihenbuwa, 2010b). In CRT, the process of racialization must be forefront in any investigation of racial inequities (Ford, 2010b). Thus, in this study, the voice of Black patients was privileged so that they were given opportunity to ‘name their own reality,’ in trauma care. This challenges the totalizing medical discourse which privileges positivist knowledge production, and typically frames the notion of ‘race’ as a discrete, biological, category. Use of ethnography informed by CRT also requires the investigator to carefully examine the extent of their own race consciousness and disciplinary perspective as a fundamental component of establishing a reflexive practice of research.

Race and race consciousness in contemporary clinical interactions

Though CRT contends that racism is a permanent feature of racialized societies, to study racism’s effect on health requires conceptualization of racism current to the period of interest to a health study (Ford & Airhihenbuwa, 2010b). Contemporary discourse on racism in healthcare highlights the mismatch between: “robustly

demonstrable population inequities and the difficulties around interpersonal communication with healthcare staff where discrimination is difficult to measure” (Bradby, 2010, pp. 11). In the current historical context of the United States in which racial discrimination is illegal and socially unacceptable, research seeking to identify overt behaviors and communication in healthcare that could be construed as racist is a problematic pursuit. In continuing to define racism, using outdated formations from the peri-civil rights era (overt racial discrimination), the examination of racism in patient-provider interaction may spuriously provide evidence that contributes to an illusion of non-racism in healthcare (Johnstone & Kanitsaki, 2009). Moreover, the absence of overt discriminatory action on the part of healthcare professionals does not sufficiently capture the potential impact of disavowed or more subtly racialized behavior and communication linked to structural and institutional norms that contribute to the persistence of racial inequities in the healthcare arena. With this contemporary context in mind, the focus of this research was to understand how racialization and race consciousness shapes trauma care practices and the lived experience of Black trauma patients through theories of practice.

Dividing Practices

In *Birth of the Clinic* philosopher Michel Foucault describes the historical events in eighteenth century Europe that transformed the way in which the role of the clinician became the powerful mediator in the relationship between life and death. The clinician’s ‘gaze,’ became the preeminent and academically justified source of authority based on a theoretically accepted understanding of anatomy and the relationship between symptoms and pathology (Foucault, 1994). Foucault maintains that there is a political

relationship that develops between the body and the social institutions related to the care of the body. In the most emblematic of these social institutions, the hospital, this political relationship is maintained through objectification of the patient and ‘dividing practices’ that subjugate the patient’s body (Rabinow, 1994).

Dividing practices in the context of the traumatically injured can be understood by the processes, including racial stereotyping and blaming, that make patients the source of objectification and restraint. In initial management, a severely injured patient might be rendered unconscious through sedative and pain medications, cut off from verbal capacity with a breathing tube, and then assessed based on the functioning of individual body systems (cardiovascular, respiratory etc...). The acutely injured person is taken into a medicalized space and apart from their social world to the emergency department, operating suite, or the Intensive Care Unit (ICU) room. They are further separated from family members and friends by visiting restrictions and other practices that create physical barriers to the patient- enforced with the intent of maintaining patient safety or continuity of medical interventions.

Foucault further theorizes that beyond bodily and spatial separation, the patient comes to understand himself or is understood by his friends and family as the subject of medical objectification - assuming the passive position in the interplay between his body and the actions imposed upon it (Rabinow, 1994). There is an overlying complexity when an injured person is stripped of agency with sedation, intubation, and physical restraint but is nonetheless present as these technologies are removed. Reflecting on the perspective of the trauma patients’ quotes (as in Leibshultz et al.) - as distressing as it was in retrospect- the patient allowed himself to be handled ‘as a piece of meat. (2010)’

While all trauma patients may feel at some point similarly objectified, one central intent of this project was to uncover the ways in which Black patients internalize, communicate and interact with others based on the ways that race is understood as factor contributing to their subjectification.

Habitus

Foucault's analysis of dividing practices is useful when examining how agency and authority of clinicians and patients function in the trauma center but perhaps incomplete when thinking about the complexity of how and why clinicians might differentially view and interact with specific patients and how individual patients in the objectified state express themselves and interact with clinicians. Philosopher and anthropologist, Pierre Bourdieu, theorizes in his Theory of Practice, that the reproduction of social hierarchies in any field (including the hospital) reinforces deeply rooted unconscious beliefs and values that underlie an individual's actions and thoughts (Bourdieu, 1977). Rather than to view the structure of social hierarchy and power within social institutions as discrete and objectifiable, Bourdieu contends that the subject of study needs to be the way that social structures are constituted and how this process of constitution reproduces or reinforces itself. Members of a social sphere become a part of the process of actualization and reproduction of structural power through their habitus, or way of being. Members of a culture create practices that may be adapted or molded to the contexts of a situation but their habitus is enduring- embodied in physical presence, postures, attitudes, and interactional style whose interpretation create and concretize practice.

A clinician, whether nurse or physician, will embody a specific habitus or professional disposition which is enduring and learned and though while not necessarily a product of consciousness, is reinforced by the structures of hospital space and interaction. Clinician habitus is essentially the way that social phenomena become entrenched within individual practitioners guiding them to think, feel, and behave in determinate ways in the structure of the healthcare setting. The hospital as a structure both reifies and is simultaneously the consequence of the habitus of those who constitute it as clinicians. Examining whether or the extent to which race consciousness becomes part of the clinician's habitus was a major goal of this research.

A trauma patient rarely enters the hospital embodying a habitus consistent with being a 'patient'. When patients are set into the objectified state, deemed necessary by clinicians in order to provide medical intervention, they are expected to yield many aspects of their pre-patient personhood. If patients are awake and interactive during the course of trauma care, interaction with clinicians may highlight the tension between their non-patient habitus and the new role that is expected of them. Overlying this tension and potentially more exaggerated in cases where patients are unconscious or otherwise voiceless, is the potential for differential objectification based on classifications like injury type or race. Assumptions about pre-hospital habitus may, for example, affect care in the way that clinicians view Black patients with injuries with a superimposition of socially deviant behavior which contributes to their own pathology and is reinforced by larger discourse that posits ill health as the result of failing to live in a correct way. This distorted albeit experientially reinforced pattern of objectification among clinicians has a potential impact on practice and patient-clinician communication.

Notes on the use of social categories

When centering the social construction of ‘race’ as a focal point through which to explore power hierarchies that pervade trauma care in a hospital, it is important to acknowledge the complexity of what ‘race’ is and what it is not. During fieldwork, I collected information on the way that participants self-identify in terms of racial categories (on participant information forms and during the course of observation and interview) and the ways that this identification informed their personal experience of race in the context of the healthcare institution. This research, however, focused on the way that social actors in the trauma system (whether patient or clinician) are raced and race one another and how these processes were congruent with or opposed self-identification categories. This conceptualization of race is concordant with a novel definition of race as described by Ford and Airhihenbuwa (2010) when discussing the integration of CRT into health research. These public health researchers discourage study of ‘race’ as a population categorization based in particular phenotypic or cultural characteristics, but advocate that race is studied as a ‘risk for racism-related exposures.’ Centering ‘race’ on the way that racism can impact the lives of healthcare users in this way creates space for different and more dynamic ways of understanding racialization in healthcare encounters. It permits the presupposition that racism impacts healthcare and that non-White individuals are at a particular risk for biased or discriminatory interactions.

Practically, this inquiry focused on the way that Black patients experience care for traumatic injury. I analytically approached participants as they were raced from the point of view of the healthcare system, whether this is through interpretation of skin color and other phenotypic characteristics or other social and cultural constructions that come into

play during the course of observation and interview. My choice to use the term ‘Black’ as opposed to African American is purposeful in order to include as potential participants all persons who are raced as ‘Black’ regardless of their place of origin or nationality. Of note also, is that racial categories will be capitalized in all study related documents to connote the formal role of individuals identified by these descriptors as participants in the social organization discussed in this study.

Research Design and Methods

Design

The study used ethnographic methods including participant observation and embedded interviews to: 1) explore the experiences of Black trauma patients in an urban academic medical center, 2) describe the nuances of patient-clinician interaction and processes of racialization which might affect increased vulnerability to poorer outcomes, and 3) explicate the perceptions of both injured patients and the clinicians who care for them in this setting. The purpose of ethnography is to generate research that explores the in-depth world-view and experience of participants (Cook, 2005). This design emphasizes flexible data collection strategies and is particularly well suited for investigating intimate experiences and interpersonal interactions of patients and clinicians in a complex hospital system (Cook, 2005; Jorgensen, 1989; Kaufman, 2005; Rich, 2009).

With the theoretical orientation provided by CRT, this inquiry was guided by Carspercken’s methodological framework for critical ethnography (Cook, 2005). Critical ethnography is based on traditional ethnographic methods but emphasizes study of forms of cultural power dominance and socially marginalized participants (Cook, 2005; Soyini,

2011). The critical ethnographic research process is comprised of five components which include: observation, analysis of observational data, interview related to observational data, analysis to describe relationships between individuals, groups, and systems, and exploration of the relationship between analytical findings and social or structural theory (Cook, 2005). An adaptation of event analysis (EA) was used refine and manage the amount and content of data collected during observation and embedded interview. Analysis of the data included the inductive development of thematic and categorical codes to illustrate participant experiences and the way in which these experiences reified or conflicted with the theoretical underpinnings of the research.

Setting

Participants were recruited from the Regional Resource Trauma Center at the Hospital of the University of Pennsylvania (HUP), a 700 bed quaternary academic hospital. This hospital is accredited by the Pennsylvania Trauma Systems Foundation as a Level I Regional Resource Center for Trauma. Patients are triaged to the Trauma Center via a well-established pre-hospital system. Patients arrive via ambulance, police car, self-transportation or helicopter (that delivers patients from the field and transferring hospitals). Near to 2000 seriously injured patients are evaluated at the trauma center yearly.

The Trauma Service is staffed by attending trauma surgeons who provide in-house 24-hour coverage. Trauma fellows, house staff, and acute care nurse practitioners comprise the trauma team. Nursing staff on trauma-designated units are specialty trained and educated. The experiences of Black trauma patients were observed during all phases of trauma care once they consented to participate throughout trauma departments in the

hospital including the Surgical Trauma Intensive Care Unit (SICU), the trauma surgical inpatient unit, and the outpatient trauma clinic.

Participant selection

This research focused on understanding the experiences of urban Black trauma patients who comprise the largest group (over 70%) of patients characterized as being of racial or ethnic minorities treated for traumatic injury the HUP. A purposeful sample of English-speaking Black patients at least 18 years of age were recruited for observation and interview following the acute resuscitation of their injury. Patients under arrest or incarcerated at time of injury, those with self-inflicted injury, brain injuries, preexisting diagnosis of a major psychotic disorder or whose injuries would otherwise preclude verbal communication (i.e. prolonged mechanical ventilation), were excluded.

The focal participant of this study was the patient, however, given the participant observation nature of this study, nurses, nurse practitioners, physical therapist, and physicians, who care for these patients were also observed and interviewed. Purposive sampling was used to select clinician participants involved in the care of patient participants. Multiple clinicians were observed during the course of observation. Selection for interview was based on clinicians who had a clear tie to critical events under study. These clinicians were nurses, nurse practitioners and physicians. Clinicians were asked to consent for interview based on their relative contribution to patient-care processes and in circumstances in which capturing their perceptions built a better understanding of the motivations and decision pathways that constructed patient–clinician interactions.

Procedure for Data Collection

Approval to conduct this research was obtained through the University of Pennsylvania Institutional Review Board. I received permission to conduct fieldwork in the trauma units of the Hospital of the University of Pennsylvania from the Chief of the Division of Traumatology, Surgical Critical Care and Emergency Surgery. To ensure that the purpose of my research and role as a researcher was clear to hospital staff, I met with the nurse managers on all of the trauma-designated patient care units at HUP to introduce the scope and conduct of this study. In consultation with nurse managers and leadership in the trauma department, I provided all clinical staff on trauma-designated areas of the hospital with information about the research and a brief description of data collection strategies, through email and presentations at staff meetings.

There are several admissions to the Trauma Service on a daily basis. I recruited participants in HUP's Trauma Intensive Care Unit (ICU) and Trauma Floor early in hospitalization but following the emergency treatment of their injuries. Initial introduction of the study to potential participants was carried out by a member of a trauma patient's clinical care team (nurse or nurse practitioner) who appraised the extent to which a potential participant had achieved medical and psychological stability required to provide informed consent for inclusion in this research. Patients who met study inclusion and exclusion criteria and who were hospitalized but medically stable were asked if I could speak with them and inform them about this study. If patients refused, I made no further contact. Patients who agreed to participate were provided a verbal and written description of the study, given an opportunity to ask questions, and invited to participate. Participants who met eligibility requirements and consented to participate were asked to provide basic demographic (age, gender, race) and contact information

(Appendix A), provide written informed consent (Appendix B) and describe their experience of injury.

After being provided with information about the research, 13 patients declined participation, citing pain and fatigue as primary reasons for non-participations. Twelve English-speaking Black patients (10 men and 2 women) between the ages of 22 and 74 were recruited for observation and interview following the acute management of their injury. A brief narrative describing each participant is included as an Appendix to Chapter 2 (Paper 1).

Data collection strategy

Qualitative Event Analysis (QEA) is a technique adapted from anthropology for nursing research by Kaiser-Jones (2002) and refined for use in hospital settings, like ICUs, by Happ, Swigart, Tate and Crighton (2004), where the goal of research is to: “achieve a thick description and explanation of phenomenon in a complex clinical setting.” This technique permits focused and detailed collection of observation and interview data around a ‘critical’ event that occurs repeatedly in a clinical setting (Happ et al., 2004). The definition of a critical event is flexible and open to the interpretation of the investigator and guided by the needs of the research questions that comprise a particular inquiry. Events require human interaction and description must include features like time, physical setting, equipment, key participants in the interaction and patterns of behavior (Happ et al., 2004). The events that comprised this inquiry were not delineated prior to initiation of fieldwork, but began with the experience of a patient describing their entrée to the trauma care system at the hospital. Events that became part of data collection activities and areas of exploration included: transitions between hospital

settings, communication and treatment of pain, hunger, fatigue, and psychological reactions to injury and hospitalization, interactions between patients and clinicians regarding clinical status and plan of care, interpretations of patients by hospital staff, and interpretations of hospital staff by patients.

Description of observed events was enhanced through interviews with participants. The location of observation and interview of events was guided by where participants were admitted in the hospital setting. As the goal was to understand the full range of experiences a Black trauma patient may have during hospitalization, care was observed on at least one day at each of the trauma designated units of the hospital to which the patient is admitted. The timing of observations and interviews varied and included both daytime and nighttime hospitalization experiences. The length of observations and interview also varied from a little as thirty minutes to several hours in duration depending on the context of the events that were being explored and participant's desire to be observed and interviewed.

During observation I spent time like a 'visitor' in participants' hospital rooms, the Trauma Units' Nurse's stations, hallways and in other parts of the hospital to which participant travelled during the course of their hospitalization (i.e. the Physical Therapy Gym). At times in which interviews did not interfere the course of care and with respect for patient's physical privacy, I elicited patient perceptions and evaluation of experiences of their hospitalization using simple, open-ended questions and probes. A description of the sample interview questions and probes is illustrated in Appendix C. During fieldwork, the tone and content of interviews was guided by the overall intent of this interview guide, but changed in each fieldwork experience to explore the particularities of what

participants were experiencing in the course of their recovery and how they wanted to talk about their injury and hospitalization.

I used both embedded and retrospective interview to elicit the perceptions of clinicians about the care of patient participants. Because I had been granted permission to collect observational data through the Trauma Program at the HUP, written consent for observation was not collected from clinical staff. However, clinicians were asked to verbally consent for confidential participation in the study when approached for interview. This required obtaining both prospective and ongoing consent activities. At the time of consent, clinicians were asked to provide a brief description of their professional role and level of experience. Open-ended questions, such as those illustrated in Appendix D, were used to initiate dialogue with clinicians. On trauma units and floors where patients are managed for longer time periods, clinician interviews were often embedded in the observation experience, but in a clinical area that was not within visual scope or earshot of patient participants. If clinicians were too busy to be interviewed during the course of their workday, we met in a private meeting space at a time in which they were free of clinical responsibility.

Data Management

Data were collected using field notes, audio-recorded notes and interviews that were recorded concurrently or immediately following each field observation. Field notes were written in condensed, abbreviated language to capture interactions as closely as possible (Happ et al., 2004) which were expanded through verbal dictation as audio notes following observation. Field notes also include observations of the clinical environment in the form of written descriptions. These notes were transcribed and stored in a password

protected server at the University of Pennsylvania, School of Nursing with routine back up. During transcription, participant or informant identifying data were replaced with pseudonyms and other proxies to protect confidentiality. Audio notes summarizing observation experiences and recorded interviews were reviewed and transcribed as the first step in data analysis.

Transcribed notes were organized and coded with the assistance of NVivo v.10 software for qualitative data management. Memos and other investigator reflexive insights that arose during field immersion or in the process of data analysis were also entered and stored using this software.

Data Analysis

Each participant's experience was viewed as an individual case. The field notes and interviews from each participant were analyzed to identify how participants experienced their injury and hospitalization, interactions between clinician and participants in the clinical environment, and how the structure of hospital life shaped these experiences. These cases, contextualized by the extent of their complexity and nuances, were analyzed comparatively (Strauss & Corbin, 1990). Themes that emerged from one participants' experience were compared to the greater body of experiences described in the data.

Early in the research, observation and interview technique was open and flexible, which permitted the inductive development of what would be labeled as critical events and then interpretive themes (Jorgensen, 1989). As data were examined in analysis, the context of observation and interviews was refined to explore recurrent themes in participant stories, or to explore in more depth experiences and interactions that

seemed to counter the greater body of data. In using comparative and interpretive analysis, there was no predetermined number of observations or categories required to tell the story of Black injured patients in the hospital. Data collection continued until the themes that emerged in early analysis were sufficiently reinforced and contextualized by the observational and interview data that emerged later in fieldwork.

Rigor

The credibility of research findings was established by engaging in regular expert debriefing, critique by a peer qualitative analysis collective, and the creation of a codebook to organize analysis. I met with dissertation committee members to discuss the clarity and adequacy of the data I collected and the interpretative analysis I conducted. To establish dependability I shared field notes and coding schemas at regular intervals throughout the study with a peer qualitative research collective of fellow doctoral and post-doctoral students. This collective meets weekly to review, critique and reinforce each other's qualitative analyses and related findings. I met with my dissertation committee regularly to discuss challenges in the research process and to elicit a full range of expertise as I conducted fieldwork and analyze data. To maintain transferability (the ability to demonstrate replicability of analysis process), a careful record of procedure and rationale for coding schemas was recorded in a code book (Glaser & Stress, 1967; Strauss & Corbin, 1990). This codebook is described in Appendix E.

Maintaining reflexivity and ethical research practice

As part of ethnographic work and in keeping with the critical theoretic foundation of this research I examined the way that that my own power, privilege, biases and personal habitus (as a student, researcher, and clinician who identifies as White) emerged

in the way that data were collected and interpreted (Soyini, 2011). To examine my positionality and perspective in this work (Finlay, 2002) my personal reflections, emotional responses to observations, and the ways in which I understand my own biases and experiential perspective as a nursing professional within the clinical environment was recorded in field notes. Understanding my positionality as researcher, helped me recognize my own subjectivities as I collected and analyzed data. More importantly, this process facilitated acknowledgement of the many dimensions of the research process and products, in which, I shaped and developed the lens through which participants' stories were told.

Open and explicit communication of research intent, study procedure, and reinforcement of the participants' right to refuse interview questions and stop observation at any time was maintained throughout all data collection activities. Black patients with injuries have expressed a sense of mistrust of healthcare clinicians in other qualitative inquiries (Liebschutz et al., 2010; Rich, 2009). Mistrust and suspicion of my intent was a potential challenge to recruitment and open communication with patient participants (Halbert et al., 2006). I acknowledged that as a White female nurse who has never experienced a traumatic injury, I may have been conspicuously different from the patient participants I sought to understand. I was very conscious in my efforts to establish rapport and trust by explaining that all observation and interview data were confidential. I also reinforced that research activities were unrelated to contingencies of hospital care or, if relevant, criminal or other legal investigation.

Human Subject Considerations

Human Subjects Involvement and Characteristics

Data were collected from patients who were hospitalized for traumatic injury and clinicians who cared for them during hospitalization. The patient was defined as any Black individual (based on appraisal of clinical staff/trauma registrar at time of first treatment in the ED) over the age of 18 who was admitted for treatment for any severity of traumatic injury from the ED of the HUP. Patients with both single and multi-body system injuries were eligible for inclusion. Exclusion criteria included: (1) patients under arrest or incarcerated at time of injury, (2) patients with self-inflicted injury, brain injuries, preexisting diagnosis of a major psychiatric disorder, (3) any other individual whose injuries would otherwise preclude informed consent (including requirement for mechanical ventilation beyond the trauma resuscitation area of the ED). These exclusion criteria were selected to ensure that participants who took part in this research were fully capable of providing informed consent and acting autonomously in their agreement to participate upon entrée into the trauma care system.

This study collected data from clinicians who cared for injured participants. Clinicians were defined as nurses, nurse practitioners, physicians, and physical therapists who were employed in patient care roles at the HUP. The interactions of clinicians as they cared for study participants were directly observed, but the patient was the focal participant from whom consent for observation was obtained. Institutional permission for observation of the healthcare environment including clinicians was obtained for this research within the trauma units of the HUP. Clinicians provided verbal consent to participate in individual interviews. This was in line with the procedures of the

Institutional Review Board (IRB) of the University of Pennsylvania that allows verbal consent for interviews that are not associated with specific informant identifiers.

I applied rigorous standards to protect the confidentiality of both patient and clinician informants. All field notes and transcribed interviews used aliases to describe informants and any other people referred to within the ethnographic data. Any demographic and identifying social histories that were collected from informants were connected to field notes by these aliases only. As notes and interviews were transcribed, all other personal identifiers were removed or exchanged with proxy information. Original recorded interviews and notes are stored in password protected research server for the University of Pennsylvania's School of Nursing. Signed informed consent documents along with contact information for patient participants are stored in a locked cabinet separate from any of the study data in an office at the University of Pennsylvania School of Nursing.

Potential Risks

There were different risks associated with being a patient or clinician participant in this study. A potential risk to patients was that psychological distress could occur when speaking about their experience of hospitalization and injury. Patients also could be afraid that participation in observation and interview would alter the care that they received, threaten their privacy, and/or be an added stress in the activities and procedures that comprise their injury recovery.

Clinicians who verbally consent to interview provided confidential data about the experience of caring for participant patients in the ICU, trauma care department, and trauma outpatient clinic. The potential risks of participation included fear that their

responses to interview questions placed their professional status at risk or caused them to be labeled as a racially biased individual by speaking about socially taboo subjects like racial biases, distrust, blaming and judgment in the medical arena. Another potential risk was psychological and emotional distress that could occur as clinicians described troubling or challenging aspects of their clinical role in caring for Black trauma patients.

Protections Against Risk

As a trauma nurse and acute care nurse practitioner, at the time that fieldwork was conducted I had over six years of experience working with the traumatically injured people and clinician colleagues in the trauma care setting. I used this experience to guide an assessment of if, and when, participation in data collection activities constituted a burdensome psychological or emotional stressor for participants. At the commencement of each observation experience and interview, patients were reminded that their participation in this study was voluntary and completely unrelated to the care they are receiving in the hospital. They were also reminded that they could decline answering any interview question or questions and could choose to stop the interview process or observation at any time. To protect the clinician informants, prior to interviews, I emphasized that their participation was confidential and voluntary. Clinician participants were made aware that they could decline answering any interview question or stop the interview process at any time. In addition, if during direct patient care with the patient participant, clinicians felt that observation threatened the privacy, wellbeing or normal course of clinical care, I would leave the immediate patient care area as requested.

In all publications and written reports generated from this research, site information and patient and clinician identifying information are replaced with aliases and other proxies to protect anonymity and confidentiality.

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CHAPTER 2

(Paper 1)

“Not as a patient but as a person”: Black patients’ experiences of injury and
hospitalization at a major trauma center in Philadelphia

Authors

Target Journal: Qualitative Health Research

Abstract

In America's trauma systems Black patients, particularly those without health insurance, are more likely to suffer poorer outcomes after traumatic injury, including increased mortality. Framed by Critical Race Theory, the purpose of this ethnographic inquiry was to create an in-depth description of the experience of Black injured patients, from their point-of-view, at a Trauma center in Philadelphia. Fieldwork entailed observation and interview of twelve Black patients (10 men and 2 women) with violent and non-violent injuries during their hospitalizations from December 2012 through December 2013. Data from fieldwork were analyzed to interpret the ways that participants experienced their injury and hospitalization and how these experiences influenced perceptions of recovery. Pre-hospital and emergency department (ED) interactions shaped how participants regarded the life-threatening nature of their injuries and interpreted judgements of their personhood and character. Participants understood the extent of their recovery in early hospitalization through embodied experiences of pain, hunger and fatigue. Over time, participants reflected on the consequence of being injured through their psychological and emotional pain and the losses they anticipated in the context of their life worlds made complex by poverty, violence, underemployment, lack of health insurance, and disenfranchisement from local healthcare institutions.

Introduction

At 2pm on a Tuesday in December, Taalib dropped his son at daycare and was heading toward his mother's house. As he was sitting on a stoop next to a corner grocery a group of three teenage boys approached him and asked for money. In a moment of confusion, Taalib reached out to shake one of the boy's hands. Another, in the back of the group pulled out a gun and shot Taalib several times across his upper body. The police officers who responded to the shooting brought Taalib to one of Philadelphia's largest trauma centers. There, a team of surgeons and nurses stabilized Taalib, removed bullets from his chest and abdomen, diverted his upper colon to an ostomy and sent him to the ICU to recover. The attending surgeon recalled that Taalib was "lucky." None of the bullets hit any vital organ, though one came dangerously close, just millimeters, from his aorta.

Taalib shared a sense of blessing. "They saved my life...I told them what happened...They accept me for that...Brought me to their bed. I am too overwhelmed." Taalib understood his life-saving surgery and place in a hospital bed as a privilege. He felt fortunate that the hospital staff seemed to accept him. As he recovered, his wounds were agonizing. The muscles that defined his role as an athlete shrank with inactivity. He missed his two-year-old son and experienced nightmares and panic. He did not expect his caregivers in the hospital to help him through these aspects of recovery - that was his work. In Taalib's words, "when you come, you are taken away from your family. You have to be strong mentally. You know? I lay in the bed with things beeping all day. I have to get used to all that. Suck up all that. Have to absorb all of that to make it comfortable for me. Cause I know I have to be here."

Taalib was one of twelve Black patients with traumatic injury who participated in an ethnographic study of their experience of hospitalization and recovery. The purpose

was to understand how injury and hospitalization is experienced by a group of Black injured patients in Philadelphia and the factors that shape this experience through their eyes.

Background

The inequitable burden of injury risk and injury mortality in racial minority populations in the United States is illustrated by numerous epidemiologic studies. Black people, in particular, experience a disproportionate number of injuries that result from gunshot wounds and other forms of interpersonal assault (CDC, 2009; Kalesan et al., 2014). Complex social factors like concentrated poverty, unemployment, poor educational systems, and racial segregation create conditions that place Black individuals at increased risk for violent injury particularly in urban settings (Smith, Richardson, & BeLue, 2009).

Once injured, Black patients who enter hospital trauma systems are less likely to survive when compared to other racial groups (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Haider et al., 2008; Haskins, Clark, & Travis, 2013; Shafi et al., 2007). In a study that used over 200,000 encounters recorded in the National Trauma Databank, a disproportionate death rate for patients characterized as Black or African American persisted even after adjusting for many factors that might confound the relationship between outcome and race. These included: age, gender, comorbid health conditions, injury severity, payer, median income of zip code of residence and trauma center designation (Arthur et al., 2008). A similar analysis found that both insured and uninsured Black patients were more likely to die from their injuries when compared to insured and uninsured White patients (Haider et al., 2008). Black patients are also less

likely to receive post-hospitalization care like rehabilitation services despite comparable injury characteristics and severity (Englum et al., 2011; Shafi et al., 2007).

The etiology of differential outcomes is hard to explain. Race, insurance status, and socioeconomic status (Ali et al., 2013) independently predict inpatient mortality after severe injury. Yet it is perplexing that injury outcomes would be mediated by a social category like race. Trauma care is arguably one of the most protocolized and routinized care processes in contemporary medicine. In fact, trauma centers are accredited based how closely care processes match standardized guidelines developed by expert trauma clinicians (Committee on Trauma, 2014). It is argued this guideline-driven and algorithmic approach to patient care is more or less resistant to differences in treatment based on social factors (Glance et al., 2013; Millham & Jain, 2009) such as racial discrimination, clinical uncertainty and stereotyping which might drive racial disparities in more discretion-based healthcare encounters (Balsa & McGuire, 2003).

Racial disparities in hospital mortality have been attributed to the cumulative effects of social and health inequalities experienced by Black people over the course of their lives (Ferraro & Shippee, 2008). Operationalizing the lived experience of race for the purpose of research is complex. It requires contending with important intersections in the relationship between patient experience and dimensions of socially-ascribed race, gender, socioeconomic status and geographic stigmatization (Smedley, 2012). Recent qualitative studies begin to illustrate this complex relationship in the lived experience of race and recovery in hospitalized trauma patients. Liebschutz et al. explored the range of experiences Black men had during recovery from violent injuries, like stab and gunshot wounds in a Boston hospital (Liebschutz et al., 2010). These patients expressed their

sense of disconnectedness from the predominantly White clinical staff. They perceived that care was motivated by financial gain and felt unjustly criminalized by police interrogation that was permitted to occur in the clinical setting. These experiences increased patients' sense of vulnerability which was already heightened by the extent of their physical injury and fueled institutional mistrust.

Rich and colleagues (2005) explored the way trauma and violence intersect the lives of young Black men admitted to the hospital for the care of violent injuries in another Boston hospital. It was common for these men to have symptoms of traumatic stress and an altered sense of safety (Rich & Grey, 2005). This work highlighted how medical treatment focused primarily on physical interventions for injury and was insufficient in addressing the complex psychological, social and public health dimensions of healing (Rich, 2009).

The ethnographic research described in this paper explores how Black patients who survive violent and non-violent injuries in Philadelphia experience trauma care in an urban hospital. Ethnographic study in the hospital offers a unique field in which people are removed from their day-to-day lived experience and thrust into the often unfamiliar system of medical treatment and patient role. In the hospital, "questions about the ultimate concern and encompassing meaning present themselves with more urgency" and offer a "condensation and intensification of life in general." (Long, Hunter, & Van Der Geest, 2008) This study focuses on the description of injury and care in the hospital as it is interpreted by patients to uncover the ways that this interpretation is influenced by the social, economic, geographic and psychological dimensions of their lives.

Design, Method, and Participants

The precepts of Critical Race Theory (CRT) guided research design. CRT postions race conciousness and discrimination and as a persistent features of US society, which influence the experience of people of color in daily life and in interactions with institutions like hospitals (Delago & Stefancic, 2001; Ford & Airhihenbuwa, 2010). From this theoretical stance, the voice of Black patients is privileged, rather than compared to any other socio-political referent, so that Black patients are given opportunity to ‘name their own reality,’ (Delago & Stefancic, 2001) in their injury and hospital experience.

Black patients at least 18 years of age admitted to the hospital for an injury were recruited at a Level I Trauma Center that serves a predominately Black population of trauma patients from the West and Southwest regions of Philadelphia. Patients with self-inflicted injury, brain injuries, or other injuries that impaired ability to provide informed consent and those under arrest or incarcerated at time of injury were ineligible for inclusion. Patients were defined as being Black from the point of view of the healthcare system- by the way they were racially characterized by clinicians who recorded demographic information in their hospital record. Use of the term Black as opposed to African American was purposeful in order to include all persons who are raced as ‘Black’ regardless of their place of origin or nationality.

Twenty-five patients were approached to participate in this study. Twelve patients (ten men and two women) between the ages of 21 and 72 years of age, in the ICU and trauma floors consented to participate from December 2012 to December 2013. Six participants were hospitalized for gunshot wounds, three had been injured in falls, and the remaining three were injured in a stabbing assault, an illegal boxing match and a dirt bike collision on a city street. A brief narrative description of each participant is provided in

Table 1. It was particularly difficult to recruit young female trauma patients. The primary reasons eligible patients did not participate was fatigue and pain. There were no financial or material incentives provided for participation.

The Institutional Review Board of the University of Pennsylvania approved this study. Patients were approached for consent early in their hospitalizations but when they were medically stable and able to provide informed consent. Data collection included observation and embedded interviews that began on the day of consent and continued on subsequent days of hospitalization and during follow-up appointments. Fieldwork was conducted in a trauma ICU, two trauma and surgical care units or ‘floors’, a physical therapy gym and at an outpatient trauma clinic.

S.J., a doctoral student, who had several years’ experience as a trauma ICU nurse at the site, conducted the fieldwork. She ended her employment at the hospital prior to commencing fieldwork to mitigate ambiguity that might arise between her roles as a clinician and researcher. Although some clinicians knew her from her work as a nurse, she was clearly identified as a researcher and wore ‘street’ clothes during fieldwork and interviews. The majority of fieldwork was conducted in areas of the hospital in which she was relatively unfamiliar - trauma and surgical floors and in the outpatient clinic. A total of 124 hours of fieldwork was conducted. Fieldwork ended when themes that emerged were sufficiently supported and reified by the experiences of participants recruited later in the study.

Data were analyzed inductively through multiple readings and the development of key themes and storylines. Participant stories, contextualized by the extent of their complexity and nuance were analyzed comparatively for thematic content (Jorgenson,

1989). Themes from specific stories that countered or seemed contrary to the overarching body of data were further explored in fieldwork or re-interview until conceptual clarity and resonance with the overall thematic framework were established.

Data collected for each participant in the form of transcribed interviews and field notes were managed using N-VIVO version 10 software. All names were changed to aliases, chosen by each participant, and other identifying information was altered to protect the anonymity of participants and their friends and family.

Regular expert debriefing and critique by a peer qualitative analysis collective was used to check the credibility and saliency of themes identified in analysis. A record of procedure and rationale for coding schemas was recorded in a codebook. In addition, field notes recorded reflections that would permit examination of the positionality and perspective of the primary researcher and its potential influence on the process of analysis (Finlay, 2002).

Results

Participants shared memories of being injured and entering the hospital and offered interpretation of ongoing hospitalization and injury care. Participant stories illustrate the ways that pre-hospital and emergency department (ED) experiences shaped how they interpreted the severity of their injuries and negotiated power and trust with first responders and clinicians. During hospitalization, patients focused on their physical and somatic experiences like pain, hunger, and fatigue. As these physical experiences became less distressing or more familiar, psychological suffering from the trauma of the injuring experience, anticipation of loss and relating current injuries to previous life experiences influenced the way that patients envisioned the enduring consequences of their injury.

“I just wanted help”: Complex Interactions with first responders

When asked about what it felt like to be injured, participants often began by describing their injury story. This included details on how and why they were injured, who was around when the injury occurred and details of their transportation to the hospital. Memories of the immediate events following non-violent injuries were conveyed in matter-of-fact detail. As Ray describes, “There is this small piece of linoleum that sticks up on the stair. I just tripped and then fell down the stairs. I was lying at the bottom yelling for my son. I don’t really remember everything, the pain was so bad. When the ambulance came, they were even shocked because my foot was in a different direction from my leg.”

Participants with violent injuries shared stories of the particular challenges they faced in accessing emergency medical care. These stories offer evidence of the important role that first responders occupy in establishing trust with injured people and the complexity of social interactions that can occur even before some patients reach the ED. For some, getting help required the dual task of demonstrating to bystanders that they had been injured and proving that they, themselves, did not perpetrate the violence. The first thing Bill did, for example, after being shot was to offer public evidence of his ‘innocence’ by disrobing and showing onlookers that he was bleeding from a gunshot wound. “So I took my upper clothes off to show the people that I was trying to get to take me to the hospital, to show them that I got shot. They thought I shot somebody. So they was like ‘no I’m not getting involved in that.’ But I’m like, ‘I got shot.’ I took my clothes off to show them.”

Other than bystanders, police officers were often the first responders after violent injury. Taalib perceived that the police who were the first to respond to his multiple gunshot wounds prioritized their task of gathering event-related information above assisting him to emergency care. Taalib recalled begging the police to take him to the hospital while they asked him questions about his assailants and the circumstances of the

shooting: “I can’t answer you right now; I need to go to a hospital. I’m getting ready to die.” When an ambulance had not arrived after several minutes, the police officers drove Taalib to the hospital in the back of their car. At the door to the ED’s trauma bay Taalib remembered falling out of the car to the ground. “I came out and got on my knees...When I laid on the ground, I looked up, the stretcher was coming out. They helped me up and put me on the stretcher. They started clipping my clothes off. That was all I remembered.” Taalib interprets what happened before he arrived to the hospital as a reflection of how he was viewed as a person. “When something happen to someone in the streets...it always seems that you’re categorized, categorized as a bad person....it’s like just because the neighborhood you in, they scoop you up off the ground. ‘You a bad person.’ I don’t have a record. None of that. I just wanted help. Get me to a hospital. Get me there and we can talk.”

For Brian, previous life experiences that involved police and injury care changed the way he accepted help for his gunshot wound. Brian chose to wait at the scene of his injury for an ambulance rather than being driven to the hospital by police, despite feeling like his “whole bottom leg was like falling off.” He recalled hearing the police talking about “throwing” him into the back of their car. Brian refused: “Cause last time, last time, they put my cousin in a cop car and he died. Aww man, I did not want to go in no cop car.” Even when he was urged by one of the responding officers, he persisted, “I knew him and he was like ‘come on, come on.’ Trying to grab me. And I was like ‘get off me. Naw. Y’all did the same thing to Timmy. I’m not going in the back of no cop car, man. I’m a wait for the ambulance.”” When the ambulance arrived, Brian described feeling patient and cautious, rather than sharing the urgency of those around him. “I mean I’m normal like everybody else. I just don’t. I just, certain things I just don’t be scared of. Cautious. They was just cutting my pants. Cutting my stuff off. Trying to find out where I was hurt at.”

Like Brian, Hakeem did not trust first responders and felt particularly vulnerable during transport to the hospital. Hakeem was bleeding from a stab wound when a neighbor called the ambulance. As they waited for the ambulance to arrive Hakeem remembered, “My chest got tight. I was losing breath. I was getting drowsy.” When an ambulance had not arrived after several minutes Hakeem re-called 911, and “laid them out on the phone. I was very dramatic.” When the ambulance arrived he was reluctant to trust the Emergency Medical Technicians (EMTs.) He refused to lay down in the ambulance and he and an EMT began to struggle for control over Hakeem’s position on the stretcher. To Hakeem, lying down was not important for managing his wound and would be like “giving my life over.” He recalled thinking that the EMT’s questions about his mobility and his pain were intrusive and nonsensical. He didn’t answer the questions. “He asked me if I could move my legs and stuff like that... He asked me dumb questions. You seen me walking.”

When the ambulance arrived to the hospital Hakeem told the paramedics from the ED that he wanted to walk into the trauma bay. “I was thinking of other things. But when I got here, they wanted me to lay on a stretcher to push me in. But I was going to walk... But they was like, ‘we got to put you on a stretcher,’ so we had a confrontation because I wanted to walk. I wasn’t going down.” This resistance emerged from a personal, traumatic childhood experience. Unbeknownst to those trying to transport him, the ‘other things’ that Hakeem was thinking of was his father’s death. “Long story short, my father got stabbed in the back and he died, so I didn’t want to be on a stretcher. To me, that’s like giving up. I wasn’t getting on no stretcher. I was going to walk this thing out. They didn’t let me, so I sat up on that stretcher. I didn’t lay down.”

“Chaos”: trauma bay memories

Initial assessment of an injured patient in the ED is highly protocol-driven, rapid, and involves many clinicians working together to evaluate the extent of injury and

stabilize the patient. Participants with memories of their time in the trauma bay described the experience as chaotic and out of their control. The chaos was heightened by the number of people in the space, poor understanding of the roles and responsibilities these individuals occupied, and ambiguity in understanding the progression or purpose of trauma care processes. These memories informed how patients understood the severity or life-threatening nature of their injury.

Dave remembered, “Once I got here, I see the doctors or whatever. They had to wait to get the bullet out. But they processed me and everything, X-rays to see where it was at, to make sure my organs wasn’t hit. And I was happy it wasn’t. So they had to put me to sleep in order to get the bullet out. I’m happy I was asleep.” This time was chaotic, because he didn’t know what to expect. He analogized his care to being ‘processed.’ It was “Crazy. Crazy cause that was my first time getting shot. So I just saw people coming in and out.” He remembered seeing “a lot of doctors” and the number of doctors led him to wonder if he might die. He remembered being asked questions like where he lived, his age, if he knew the person who shot him, and whether he was allergic to anything. Dave interpreted all the people in the room as “doctors” and felt that everything that was asked of him was so: “they could get a good picture of who I was.”

Storm recalled, “It was kinda crazy. A lot of pain and confusion.” He remembered being angry. He attributed this anger to his disorientation and inability to reconcile the events that surrounded his injury. Storm remembered arguing with a belligerent man outside a bar and then suddenly being shot and losing consciousness. He awoke in the trauma bay which was frightening and disorienting. “There was doctors. Chaos. I was hollering... I didn’t understand what was going on.”

For Ray, who had an open fracture of his ankle, the trauma bay was similarly chaotic but easier to interpret because he was fully conscious from the time of injury

through emergency treatment. Communication lapses during the whirlwind of procedures and assessment imbued Ray with a sense of mistrust for clinicians, in particular, trauma surgeons. Ray interpreted the use of rectal exam that is a routine procedure in the rapid assessment of penetrating traumatic injuries as an experience of sexual violation. Ray recalled that there were people all around him turning him “this way” and “that way.” “All of a sudden one stuck a finger in my ass.” Ray talked about the sense of shame that remained with him several days later. “I understand if I was shot, if I was stabbed, and maybe was bleeding, but my ankle was broken. What were they looking for?”

Bill and Hakeem, on the other hand, remember comforting and reassuring interactions with clinicians in the trauma bay but were disturbed by police interviews that occurred. Bill describes: “While they putting tubes in my side. ... Like I see them cutting me open. But I can’t feel it. Cause I’m falling asleep. But like, the detectives keeping me up. ‘Do you know who did this to you? Do you know who did this to you?’ Like he’s keeping my eyes up.” He felt like, “Yo, I’m in pain, I can’t talk right now.’ I could barely breathe....This is all going through my head. Why can’t you let me get healed first before you question me and all this? I’m not going to forget what happened to me. This is something serious that happened to me. I’m not going to forget it. Let me recover. You want to do this while I feel like I’m getting ready to die. You want to sit here and ask me questions while I’m getting ready to die. Like that just showed me you don’t care nothing about nobody’s health.”

In the trauma bay Hakeem insisted on taking off his clothes and getting on the exam table by himself. He trusted that the doctors and nurses were there to help him. He recalled feeling particularly reassured by a nurse who talked him through his chest tube insertion, “Just like ‘it’ll be ok,’ and ‘you have to move this way’ and they was telling me why they was doing what they were doing, why they were putting in this thing (*to chest tube*). I was just cracking jokes the whole time.” After the chest tube was in place and he was breathing easier, Hakeem was waiting to go to the ICU when detectives came to talk to him. “They was getting on my nerves.

Cause they try to make you say something that you don't want to say. They keep going over it... I felt that they shouldn't have been asking me questions there. They should have waited till I got to a room or something. So when I told them. I was upset. I told them to get out of my face."

"I'm not going to cry or nothing. But it hurts." Pain

Memory of the injury events and ED care shaped how participants perceived the life threatening nature of their injuries and began to determine trust and rapport with providers in the hospital environment. During inpatient hospitalization, patients understood their wellbeing and recovery through physical sensations like pain, fatigue, and hunger/lack of appetite. Pain was particularly significant and it was common for the experience of severe pain to overwhelm all other sensations and concerns. Participants attributed pain to both the injury and other aspects of hospitalization. As Dave describes: "The needles. The catheter. The after-effect. Everything. The pelvis. Part of my pelvis broke off, so it's a lot of pain."

Some participants found relief in prescribed medications. Others felt ignored and unsafe in the hospital environment when pain persisted for long periods of time despite frequent complaints to clinical staff. Persistent pain also changed how participants believed they were viewed by the hospital administration. The open fracture in Ray's ankle resulted in episodes of severe neurological pain that were not effectively treated by the narcotic medications delivered via a patient-controlled anesthesia pump. Ray described his pain as "spikes." During a spike, his body would become rigid and shake uncontrollably and sweat would soak through his hospital gown. He often held his leg suspended in the air or would pull at the bandages around his splinted ankle, seeking relief. He experienced unremitting pain episodes for over a week despite frequent changes to his medication regimen. After the first few days, his beseeching declarations

of “I can’t take this” and frequent attempts for attention from nursing staff turned to anger and resignation. Ray accepted that he would be in severe pain and began to believe that he was being kept in pain on purpose. He was suspicious that hospital staff had financial motivation for repeated cancellations of his reparative surgery and that his pain was being used as a justification for additional hospital days which would result in higher insurance payouts.

Access to pain medication was interpreted as a negotiation of power, in which participants viewed themselves as subordinate to their nurses and physicians. Joe was open about the fact that he had used illegal drugs in the past that changed his tolerance to pain medication. He believed that his nurses were “telling stories” to keep him from getting the pain medication that he wanted and saw the hospital staff as beholden to rigid policies that wouldn’t address his needs. “I have the pain but they have the medicine. I have a tolerance level. They don’t understand this. They just use their formulas.” He threatened to get pain medication from outside of the hospital, if he had to endure more days of uncontrolled pain. Bill, unlike Joe, felt that the medication he received was adequate but felt frustrated with the repeated act of representing his pain numerically, on a scale of 0 to 10, every time he needed pain medication. He perceived that to do so, meant that nurses didn’t trust his evaluation of his own pain. He recalled a conflict he experienced with a nurse when he refused to qualify his pain level numerically: “I’m telling you I’m in pain and I can’t get my medicine. It’s passable. It’s bearable. But you know what I’m saying, it hurts though. I’m not going to cry or nothing. But it hurts. I guess it’s not a ten. I don’t know. I don’t know how to rate the pain. So she catching an attitude cause I’m telling her that. Like I’m getting smart about it. I’m just being real with her.” The nurse refused to dispense medication until he relented and provided a number.

Hospital staff members were interpreted as “caring” or “nice” when their actions demonstrated that pain consciousness was a priority. Reece evaluated the beneficence of clinicians based on the way they touched him. Reece described: “She just grabs onto me with full force. Because you know I’m a big guy. I understand that. But my body is hurting. If you give me a second I will catch myself. Like you understand what I’m saying? Like all you have to do is guide me. And then like I’m asking her to put her hand on my shoulder or on my arm, somewhere where it’s not sitting directly on my side or my incision.” In contrast, Reece described the physical therapy technician who brought patients to and from the physical therapy gym as: “... he was very nice. Very nice. He helped me all the way, without...he just thought about my pain before he thought about what he was doing.”

Pain relief also extended meaning to the way patients interpreted judgment on the basis limited economic resource or culpability in the circumstances of their injury. Reece described his favorite nurse Lisa as especially good: “She always brings me my pain medication on time and ice packs when I ask for them.... Thing you got understand, people are coming in here for trauma and for bad situations, but a nurse if she could only do her job and actually take you not as a patient but as a person that’s actually trying to heal. You get, you get so much better care from them. It’s not like you just get brush to the side and then like flitted away as you see I don’t have insurance. Understand it’s not because....I work, but not for a job that has insurance and I’m having a hard time finding one because in the construction field it’s really hard to get a job, a legitimate 9-to-5 job.” Reece’s girlfriend, Kia, or his sister insisted on being at his bedside throughout the day and night because they believed it was the only way he would get adequate pain medication. Kia, felt that many nurses and doctors didn’t believe Reece about his pain and treated him unfairly because he was young, Black and had a gunshot wound. “Yeah he’s young. But he’s a family man and we’re trying to prove he’s not a hoodlum this whole time.”

“This really messes up your head:” Trying to Sleep

Fatigue worsened all other experiences and contributed to a sense of vulnerability in hospital space. In often-shared hospital rooms, patients awoke several times in the night from pain, noise, procedures, and nightmares. Sleeplessness was worsened by institutional policies such as scheduled blood draws and vital sign assessment in the middle of the night. Taalib typically expressed gratitude for nursing care, but lost patience as his exhaustion increased, which changed the way he related to his nurse. “Last night was the worst night I’ve had here. This nurse. She was.... I can’t remember her name. But she came in at 2-3 in the morning and I told her that I was tired and wanted to rest. But she just kept coming back saying that she needed to get blood and put in an IV. So she tried like 4 or 5 times.” Bill described being woken several times overnight, but judged non-painful procedures like vital sign assessment as tolerable and part of a learned routine. To describe the vital sign assessment that occurred every four hours throughout the day and night, he closed his eyes and held his arm outstretched above his head: “Yeah. I be asleep, they come in I just be like this.” Bill distinguished between being awakened for this type of assessment, which was tolerable, over a painful procedure like a needle stick which was more distressing.

Virginia was kept awake at night from her urostomy leaking urine onto her body and bed. She had lived with an urostomy for several years after surgery for a bladder defect, but now that she was injured and outside of her home environment she was unable to create the necessary seal on her skin. Her nurse tried to help her but when the leak persisted Virginia became resigned to the fact that she would not sleep. Virginia perceived that because she was poor, she should not expect high levels of support from the staff, particularly for issues that were not directly related to her current injuries. In her perspective: “Hospitals are not for you to recuperate, they are treat you.”

Many participants with violent injuries struggled with sleep because of recurrent nighttime experiences of disorientation, frightening thoughts and nightmares. Storm slept lightly and would feel his heart race when he woke and tried to figure out where he was. “I wake up and then have to look around and notice the TV and the clock and then I remember where I am.” Bill could fall asleep but would wake several times in the night when he sensed that others were walking through his shared hospital room. “I think from me getting shot. I don’t know. I’m just dealing with my Ps and Qs...I wake up and pay attention to everything going on, everywhere they move. They move back here I’m watching. They move over here, I’m watching. I’m watching everything. In the bathroom, I’m watching. Like I don’t know.” For Hakeem, thoughts of death prevented sleep early in his hospital stay, “I really didn’t sleep. It wasn’t nothing that the ICU did or nothing, it was just stuff that I was thinking of myself. Like I said, I have a father that was killed, so I was just telling myself that if I closed my eyes I might not wake up.”

Dave talked about reliving the shooting in his sleep. “I mean, you have nightmares or whatever. Being shot, like, reliving it over again.” Taalib’s nightmares were intensified by dreaming that his son was with him when he was shot. Taalib described waking covered in sweat with and a racing heartbeat, ‘like I was running...couldn’t get to sleep....Pain was hurting. I had a dream that my son was getting shot at. My little son. With him. With me.’”

“Filling me up with medicine and no food:” Food

Participants found hunger and loss of appetite in the hospital difficult to endure when its rationale was not clearly understood. Pamela had entered the trauma bay in a semi-conscious state with a high level of alcohol in her blood after a fall. Over 24 hours after admission she was still “NPO” (nothing by mouth). Although she had not examined Pamela for several hours, her nurse practitioner was worried that Pamela was at risk of choking on her food. Pamela was frustrated by her hunger and her inability to make sense

of the food restriction. She interpreted it as being ignored. “My ribs got nothing to with me eating. I am about to cuss someone out now. They keep giving me medicine and I got to eat. Filling me up with medicine and no food. I’m in pain so I’ll take the medicine...They don’t care if I starve or die.”

Joe was unclear about why he was not allowed to eat but interpreted it as a purposeful denial. Surgery for Joe’s jaw repair was cancelled two days in a row due to over-scheduling and emergencies in the operating rooms. Prior to each scheduled surgery, Joe was not permitted to eat. With delays in surgery, Joe had been hungry for two days. Joe didn’t understand why he wasn’t able to have food and analogized to hunger experience to solitary confinement in prison during which he was “lucky to get a glass of water.”

For the first ten days after injury Storm endured his hunger quietly. Yet, his ability to eat was meaningful in terms of how he interpreted the extent of his recovery. Storm did not ask nurses or other clinicians about when he might eat and what might be the criteria that would allow him a meal. He believed the best way to survive his injuries was to do what was asked of him without questions. As he recalls: “I came out of surgery and I still couldn’t eat. They act like they were giving me, but they were confusing. Said if I did one type of thing, I could eat. I was just losing my mind cause I couldn’t eat.” A week later he still hadn’t been able to eat, but was unsure of why, other than “my stomach isn’t right.” He was reluctant to be excited by the prospect of eating because he remembered being disappointed after surgery. He kept his expectations low and avoided excitement around the possibility of eating because, “It don’t help.”

Reece was allowed to eat but he did not have an appetite. Reece’s room was covered in old food trays that he told the hospital staff to leave in place. When he could convince a nurse, Reece would take himself in a wheelchair to the cafeteria to buy food.

His family members also brought in food to help Reece regain hunger and overcome constipation. Reece felt that food was one part of his experience that he had some control over. He could choose food and try to make himself feel better through his choices. Despite this, his lack of appetite persisted and made him worried that there was something wrong with how he was recovering.

“Feeling depressed about it”: Interpreting the meaning of an injury in the hospital

Participants understood their psychological reactions to injury and hospitalization in the context of their personal histories. The challenge of making sense of a life threatening experience and imaging the long term consequences of injury was contextualized by the economy, environment, social support and life philosophies that shaped their daily lives. Taalib, for example, often analogized his injuries to a “wake up call” for changes in his life. On the same day that he lamented his injury as “a crazy situation that no-one should go through,” he described how he planned to change himself now that he survived. “Things happen for a reason sometimes. You know, cheese steaks. All that greasy food, eating that. But now with all this done, I’m starting over again. I’m going to eat a lot of fruits, baked food, vegetables.” He saw his experience as an opportunity to find strength and to correct a perceived deficit “Malcom X. Martin Luther King. They went through a lot to understand. You need to withstand and then you’ll be heard. But you have to go through a lot. A lot...Maybe I made money a god and forsaking that god should be my number one priority...By god not protecting me that day, it’s a wakeup call to learn that I need to decrease my relationship with money or else that something else should come about because of this, but I can’t see it right now.”

Reece felt deep resentment for the man who shot him but also felt compelled to find meaning from his pain and anticipated losses. “I don’t know why this happened to me. I didn’t ask to be shot, I didn’t ask to be shot, I didn’t ask to be shot....I know that the guy who shot me is in

jail. But jail is a mental thing and what I have to deal with is a physical thing.” Reece was thinking about the reason for his injury and wondered if god was punishing him for putting too much emphasis on his construction work and “worshipping money.”

For many participants who spent more than a few days in the hospital, psychological distress became more troubling than physical distress. While participants would address their physical symptoms with clinicians, none thought to speak to their nurses, doctors, or social workers about the fears, anxiety, and sadness they were experiencing. “The pain doesn’t keep me awake. The pain, I can take it. They’ll tell you there are times when they come with something for pain and I don’t take it. I can deal with pain. It hurts more to know that I got stabbed than to feel the physical feeling” With less emphasis on his physical pain, Hakeem was able to think more deeply about the connection he felt between his stab wound and the stab wound that had killed his father several decades earlier.

Reece called on the chaplain to pray with him because he was “just feeling depressed about it.” He had felt depressed before in his life, but, “this is different- seems hopeless...I have all these questions about my foot that they can’t answer.” Reece worried the nerves controlled the movement in his foot wouldn’t heal and he wouldn’t be able to do construction work. “I won’t even be able to play ball with my sons.” Reece also worried about loss of his sexual function and masculine identity. “A man shouldn’t cry but every time I think about it I can’t help tears come to my eyes.” He was embarrassed to talk to his doctors about but thought that because of where the bullet hit and went through his pelvis he wouldn’t be able to father any more children. “I don’t even know if my manhood was taken away.”

A heightened sense fear and insecurity changed how participants planned to negotiate interaction with the neighborhoods and home to which they would return. Dave spoke of his neighborhood as dangerous and unpredictable. “Today, people just want to do

something, just to do it. Especially, if they run with the wrong crowd. They gonna do something just to do it. You just got to watch. You just got to watch. Everything. Everything. Watch everything. Even little ones. You just have to watch everything. And that's how, I mean, I wouldn't assume I wouldn't get shot tomorrow, just catching up with someone. Got to watch." Prior to being shot, he spoke of always watching his back. Now, "I'm going to have to do, I guess, more. Mirrors...After being shot, you get a little paranoid." Dave recognized that the extent of his emerging fear was a product of both his current injury and a long history of vigilance in a threatening environment. "I'm battered, cause growing up, you don't want to grow up like that. You know, always, basically it's like you paranoid, like you waiting, you know something gonna happen. You just waiting for that. I say battered."

Bill and Taalib both planned on staying indoors at their homes for the foreseeable future. "Like I ain't going from in front of my crib. Less I'm with my family or something. Like I don't know, I don't even want to walk nowhere with my family. I don't even know where the bull be at like that. So you know what I'm saying? I could be walking anywhere and he see me, he don't know where my mindset at, he don't know if I want to retaliate or not. So I know he already paranoid. He's prolly walking around strapped now. You know what I'm saying?"

Some fears reflected the economic insecurity with which participants lived, such as poverty and loss of livelihood as a result of injury. Pamela was concerned about the cost of her hospitalization especially because she was unemployed. "I know they going to send me a bill. And I don't have it. I don't have it to pay em. I'm just being straight up. I would like to talk to a social worker. I'm not working right now. I don't have it. I'm waiting for a job." Ray was worried about how his injury would set him back in the home improvement work he would be able to do. Like Reece, he worked contract to contract and so his ability to bring income into his home was contingent on his ability to work. Prior to his injury, he had received a job contract that would pay \$1500.00, which would be very meaningful for the

economics of his household. Ray saw the loss of his potential to do this job as a devastating deviation of his path towards “doing better.”

The expression of fear, anticipation of loss, and sadness was not universal to all participants. Brian interpreted his gunshot injury and hospitalization as yet another difficult situation in his life that he had to endure - that this injury and all the distressing aspects of hospitalization- was a natural part of his life. In his interpretation, even potentially traumatizing moments, like witnessing the death of other patients in the trauma bay, were understood as commonplace in the context of his lifetime experiences of violence. This is exemplified in Brian’s description of his trauma bay memories: “All I hear is them trying to revive his heart. Trying to revive both of their hearts. And one of them, they revived his heart and he survived. Other one, they said ‘1:50’ .’ So I knew what that meant. . . .It’s how it goes. It’s real. It’s definitely real. My own, Nafis Washington, he died in my arms. He got shot in the head, accidental. I was 6 years old he died on my arms. So I been through a lot. I’m not the only one in life who been through a lot. There’s just certain things I’m used to.”

“It is what it is”: The wounds that remain

Only Storm, Taalib, and Hakeem agreed to meet after being discharged from the hospital. After hospitalization, Storm, Taalib and Hakeem interpreted the lasting impact of their injury and hospitalization in different ways, but all offered evidence that the impact of the experience was enduring. Just as in the hospital, physical pain or difficulty was addressed with healthcare providers, but psychological distress was not interpreted by these participants as something worthy of care or, for which clinicians involved in their injury care could help.

Four days into rehabilitation at a nearby facility, Storm was regaining mobility in his leg. He was “really alright,” and was particularly happy that his 10 year old son could

visit him without being afraid. He felt very positive about the recovery of his leg but was anxious to finish rehabilitation so that he could move his family out of the environment in which he had been shot. The experience scared him and he believed he needed to relocate as the only way he could re-establish safety and protect his children.

At his first clinic visit after recovering at home for three weeks, Taalib talked about “doing great” and being thankful to be alive and to the people who saved his life. Within minutes of sitting with his girlfriend, Yadira, in private exam room, he was sobbing. Taalib explained he was terrified of the pain of having the feeding tube that he had lived with for two months removed from his stomach. He recalled the pain of having other “tubes” pulled out of his body before he left the hospital. He felt debilitated, weak and with little energy or desire to leave the house. He couldn’t, “get on the floor and play with Elijah,” his two year old son. Taalib became increasingly afraid to eat knowing that his ostomy would fill with stool and gas. His “bag” had become the object of his compulsive attention and desire keep it free of content. Every time he felt the bag fill he wanted to check it and clean it. “Every two minutes I’m down on my knees over the toilet.”

During the appointment at the outpatient clinic, the surgeon told Taalib that if he didn’t eat he wouldn’t be strong enough for a surgery to reverse his ostomy. Taalib’s desire to be free of his ostomy made him willing to eat more. Six weeks after this visit, Taalib said he was more used to his ostomy and starting to focus on getting stronger, or “getting my weight back up”. He did push-ups and arm exercises at home to increase his strength, but he did not return to work. He didn’t want to be outside to interact with people he described as “not positive.” On the few occasions he had visited his mother near the scene where his injury had occurred, he described a state of hyper-vigilant awareness

as he moved through the neighborhood. “I’m like that everywhere now and I know not to carry money.”

In the months that followed, Taalib began to re-establish his social life and returned to the home that he had lived in before his injury. He joined a social group with other “positive people who like to do things for the community.” Even among new friends he trusted, he remained embarrassed of his ostomy and when offered the opportunity for a reversal surgery, he agreed. As the surgeon described what the surgery would entail, he began to cry out of fear that being in the hospital again would lead to similar experience from his initial hospitalization - pain, tubes, scars, medication, and diminished strength. “I’m scared, scared. But what can I do about it. I can’t live like this.”

Following surgery to reverse his ostomy, Taalib spent an additional 10 days in the hospital almost a year after his gunshot injuries. “I was doing good, putting on weight, jumping up and down, playing with my son. And now, I am stooped over again. I was doing good I don’t know why I just didn’t go on with the bag. If I knew it would be like this I wouldn’t have done it. I feel dead. I feel dead.” During this hospitalization, Taalib was easy to anger and sleepless for the first few days. It was as if his threshold for tolerating hospitalization had diminished, even though his recovery was much faster and the result would be a fully functional bowel. Weeks after discharge he was happy to be free of the ostomy and realized that his ability to reestablish a physical routine was much faster than his first hospital stay. He talked about working again, but realized that the past year had diminished his confidence and strength. Nonetheless, Taalib had hope about returning to his pre-injury life, “trying and I’m hoping. I might be injured but I’m not out.”

Hakeem was similarly focused on reestablishing his athletic physicality and he pushed himself beyond what his clinicians recommended. “I want to see what I can do.” He

had persistent pain in his chest at the spot where he was stabbed and a hard time breathing when playing basketball but thought that this would resolve with more exercise. Whereas Taalib was focused most on the lasting physical aspects of recovery, Hakeem was most concerned about his inability to sleep since leaving the hospital. Hakeem used video games to deal with insomnia. He was afraid to sleep because lying in the dark he would think about how he could have done things differently so “it wouldn’t have happened.”

Hakeem said that his family members were worried about his mental state because he was avoiding people, which was so unlike him. His aunt in Ohio had him visit her so that he could meet the man who stabbed and killed his father (a relative of Hakeem’s cousin). His aunt reasoned that coming face to face with this man, who continued to be a family acquaintance, would relieve Hakeem of his preoccupation with comparing his current experience to his father’s experience. He described the meeting as “it is what it is,” and that he didn’t know how to react.

A month later, Hakeem’s chest pain was mostly resolved although he had moments where he couldn’t take a deep breath. Although he was more active with his friends and in the life of his young son, he continued to have difficulty falling asleep. He couldn’t get his mind around his survival, when his father had died from the same injury. He felt compelled to identify the reason he lived. “It was in the same spot. And with a bigger knife. Why didn’t I die?” Hakeem spent a lot of time trying to figure this out and it troubled him these many months after the injury. “Maybe he gave up and that why he died. When I was stabbed, even when I was covered in blood and the ambulance drivers said I lost so much blood. But I said ‘I’m going to walk on my feet. I am not lying on a stretcher.’ I had in my mind that I was going to live for my son. Even covered in blood and crying I wanted to walk into the hospital.”

Discussion

The stories of twelve injured people at one trauma center in Philadelphia offer perspective on what patients endure before, during and after treatment for their injuries. These narratives support what previous naturalistic inquiry in urban US hospitals suggest. First, Black patients and particularly those with violent injuries enter the hospital from complex life worlds often shaped by economic insecurity and community violence exposure (Rich, 2009). Second, trauma treatment can be perceived as dehumanizing when patients don't understand the rationale for care practices, are permitted to suffer physically and emotionally without perceived redress, and are not protected by the institution from outside agents like police officers and detectives during the intense vulnerability of their injured state (Liebschutz et al., 2010). Third, the psychological and social consequences of a traumatic injury extend well beyond the repair of patients' bodies (Lee, 2012). Inattention to the psychosocial dimensions of healing alienates patients from asking for and receiving the additional support they may need, may put injured people at further risk for re-injury (Rich & Grey, 2005) and fail to attenuate the psychological consequences of their disrupted lives (Lee, 2012; Lee, 2013).

The design of this research was centered on race and being Black in a Philadelphia hospital. Yet in fieldwork, disenfranchisement from a public institution like the major trauma center was about more than race, it was about life in a social world where race was a factor. The experience of injury for participants in this study was influenced by their personal histories and the contexts in which they lived their day-to-day lives. Like other life threatening illness, the meaning that the experience of severe injury takes on in a patient's lived experience is informed by prior illnesses and injuries,

major life events, and expectations held for the future (Becker, 1997). These aspects of patients' personal histories were shaped by poverty, violence, underemployment, lack of health insurance, and rare or unorganized relationships with the local healthcare institutions.

Disenfranchisement was reinforced for patients when they felt that their individuality and humanity were not acknowledged during care processes. Reece reflected on hospital staff by saying, "You put my life in your hands." His use of "you" as opposed to "I" suggests a perceived social distance between himself and the people that comprise the healthcare institution. Many participants also had a difficult time distinguishing the different roles for which different clinicians were responsible, particularly in the chaos of the emergency management of injuries. Perceived "ruptures" in the interpersonal relationships that develop between patients and clinicians, "have potential to undermine fundamental aspects of personhood" (Bastian & Haslam, 2011). This is meaningful, if at a very basic level, "better health requires clinical encounters where patients (and families) and clinicians present and understand one another's perspective" (Street, Makoul, Arora, & Epstein, 2009). When participants chose not to disclose or were not provided the opportunity to share the extent of their fear and distress, opportunities to mitigate the non-physiological consequences of injury were lost.

The experiences of twelve patients in Philadelphia cannot extend explanation to the significant survival gap that exists between White and Black trauma patients in US hospitals. This research is also missing the stories of young Black women and focuses primarily on the experience of people with current, or past, violent injuries. Yet when looking across the span of participant experience, what emerges most urgently is that all

of the injured patients were in emotional and psychological distress that, at times, rivalled their physical agony. Without a sense of personal and economic agency during hospital care, patients' threshold for mistrust of institution was very low and worsened when disturbing sensations like pain, fatigue, and hunger were inadequately addressed from their point-of-view.

There is a danger in considering that there is something inherently 'special' about Black people's psychological needs after injury, particularly when seeking explanatory factors for race-based outcome disparities. To do so would inherently conflate traits and conditions that emerge from environmental and social conditions with patients' race. Historical racial segregation, economic marginalization, inequitable policing and incarceration and other forms of discrimination touch of the lives of many Black people in Philadelphia (Gibran Muhammad, 2010). And there are well-documented health consequences to persistent exposure to these stressors (Barr, 2008). Yet despite the influence of the health consequences of these injustices, the experience of Black participants in this study demonstrates the everyday, every person, nature of what injured people want and need from a responsive health care system. Patients expressed their desire for care processes that were humanizing, recognized the complexity of their lived experience, and acknowledged that they anticipated returning to homes, neighborhoods, and communities that felt unsafe and frightening.

Conclusion

Participants' interpretations of injury and hospitalization in this study abound with areas for institutional and professional redress. A highly-protocolized and algorithmic approach to trauma care may be important in managing the physiologic and even

psychological consequences of an injury but may blind clinicians to the complexity of life factors and influences shape how patients recover and reestablish their place in the world. It can be argued that other colleagues like psychologists, psychiatrists and social workers should manage non-physiological factors in injury care. Undoubtedly there is a place for these disciplines in a robust trauma care program. However, given the rarity and brevity that participants described in recounting their relationship with the formal healthcare system in Philadelphia, the opportunity offered in the clinical encounters that surround injury care has great potential as a starting point for seeing patients as they are and connecting those with specific needs to long-term primary care and psychological care services. For patients, like those in this research, who lack adequate health insurance benefits or whose access to primary care is limited to public health clinics, there may be need to create and extend new arenas in injury care programs.

Careful consideration of the social ‘distance’ that patients perceive between themselves and their care providers offer other avenues through which a more humanistic and just institutional experience can be created. Perhaps a worthy place to generate shared perspective, especially in cases where clinicians and patients may live in vastly different life worlds, is with story. The ethnographic perspective generated in this research cannot be generalized to all Black patients in Philadelphia or in other urban hospitals. It does, however, offer evidence that patients, even those who may feel disenfranchised or mistrustful of a healthcare institution, are willing to share their perspective and the intimate details of their lives in an effort to be seen and heard in the hospital environment. If clinicians could create space in the course of care processes to let people tell their story, whether it be of the present injury or something else that they

feel is important to express, it may open doors for more meaningful conversations about what patient need after injury and reshape care processes to make people feel seen in the context of the life world to which they will return.

Appendix A: Participant Descriptions

Taalib	Taalib was 42 years old when he was hospitalized for several gunshot wounds to his trunk and leg. He was tall and slim with pronounced musculature. A ring of grey hair circled his bald head. He had tattoos across his arms and legs. He lived in Southwest Philadelphia and split his time between his own room in a shared building and his girlfriend's home with young old son. Taalib had difficulty securing work and for most of his adulthood he was employed as a construction worker. He currently supplemented government assistance by working as a sport coach for young adults. He had a lot of family in the area that called him frequently but rarely visited once he was out of the intensive care unit. Taalib self-identified as "African American."
Bill	Bill was 22 years old when he was hospitalized for a pneumothorax from a gunshot wound to his chest. He was tall and thin with short black hair and a light beard on the periphery of his face. He had dark tattoos on both arms. He lived in South Philadelphia with his mother and was not working at the time of his injury. He was mostly visited by his friends near to his own age. Bill self-identified as "African American."
Brian	Brian was 34 years old when he was hospitalized for 2 gunshot wounds to his right leg. Brian was of medium height with a muscular build. Multiple tattoos covered his arms, chest, and neck. He had been hospitalized in the past for health crises related to heart disease. He alluded to a long period of incarceration during which he also experienced health problems. In the hospital he was visited by his girlfriend, siblings and friends. Brian spoke of his grandmother who was Cherokee, but self-identified as "Black."
Hakeem	Hakeem was 25 years old when he was hospitalized for a pneumothorax that occurred after being stabbed in the back. He was short and thin with a medium length Black hair and a goatee. He was employed at a local sporting goods store and his boss had visited and assured him that he could take the time he needed off to recover. He often had visitors that included friends and family who lived in Philadelphia and visiting family from Ohio. Hakeem self-identified as "African American."
Dave	Dave was 21 years old when he was hospitalized for a gunshot wound to his pelvis. He was tall and thin with short Black hair and a small goatee. Tattoos covered his arms and neck. He had been hospitalized for a week approximately a year earlier for a severe concussion after a car accident and had a facial injury that required emergency room care a few years before this. Dave was currently living with his mother in West Philadelphia and looking for work. The birth of his young daughter motivated him to seek regular employment and stop drinking. He was a cook at a local restaurant but was recently laid off. His girlfriend remained at his side through the majority of his hospitalization. Her mother brought their young daughter to be with them during the day. Dave self-identified as "African American."
Storm	Storm was 37 years old when he was hospitalized for several gunshot wounds to his abdomen, leg, and arm near his home in a town that bordered Southwest Philadelphia. He was tall and heavy with short black hair and a long thin goatee. Faded tattoos covered both of his arms. He had never been injured or hospitalized before. His mother and brother were at his bedside for the majority of the two and half weeks he was in the hospital. For the most part, his mother interacted with the nurses and physicians in the hospital asking questions and taking notes on the plan of care. His children began to visit once he was more awake and interactive. He was discharged to a rehabilitation facility after he left the HUP. Storm self-identified as "Black."
Ray	Ray was 41 years old when he was hospitalized for a right open fracture of his tibia

	<p>after falling on the stairs in his home in North Philadelphia. He was of medium height and build, and had a beard that covered his jaw and chin. His right leg was always braced and elevated on pillows or a prop. Ray had been injured with a gunshot wound to his pelvis twelve years earlier for which he had not been hospitalized but which lead to chronic leg pain. Ray sold drugs for a prominent Philadelphia gang in the 1980s and 90s but had not been involved in gang activity for over a decade. Ray was incarcerated for 4 years during which he took courses on various aspects of home building and engineering and was self-employed as a contractor. Ray’s wife of twenty years visited daily when she wasn’t at work. Often she had their 8 year old daughter with her. Ray self-identified as “African American.”</p>
Joe	<p>Joe was 46 years old when he was hospitalized for a jaw fracture after participating in boxing match. He was of medium height and build. The visible portions of his arms and legs were covered in faded tattoos. His face was swollen and reddened from his injury. He was restless and would often try to leave his room to smoke. He was relatively familiar with the routine of hospital life from several previous hospitalizations. His first injury was a gunshot wound at age 15, and had experiences an additional 4 gunshot wounds on 3 different occasions in his later adolescence and adulthood. He had also been stabbed during a period of incarceration several years prior. Joe currently lived in the South Philadelphia. He was unemployed and did “little things here and there” for income. In the hospital he was visited periodically by his girlfriend, daughters, and a cousin. Joe self-identified as a “native of America.”</p>
Reece	<p>Reece was 26 years old when he was hospitalized for a gunshot wound to his groin. He was tall and athletic with long dreadlocks surrounding his angular face. His left leg was braced to help him flex his foot which he was unable to do on his own due to extensive nerve damage. This was Reece’s first injury and hospitalization. Reece’s mother, girlfriend, or sister stayed with him at all times. When childcare was unavailable, Reece’s girlfriend had their 1 year old son and her 6 year old son with them in the hospital. Reece lived between his mother and girlfriend’s house. He had a passion for electrical work and would work on house restorations and building projects as they were available on a day-to-day basis. Reece self-identified as “African-American.”</p>
Virginia	<p>Virginia was 72 years old when she was hospitalized for arm and neck fractures with signs of mild intracranial bleeding after a fall at her community center. She was short and thin with bright white hair. She had several hospitalizations in her past, and particularly in the past 6 years, after requiring surgery for a bladder malformation. She lived with her sister in the South Philadelphia. She was retired but had always done “manual labor” in the past. Her son and grandchildren lived nearby and her daughter visited her on each day of her hospitalization. Virginia self-identified as an “African American.”</p>
Pamela	<p>Pamela was 54 years old when she was hospitalized for several fractures and alcohol intoxication after a fall. She was small with long braided hair. She had a large abrasion over her eye and her forehead was red and swollen. She had never had been injured seriously before or spent the night in the hospital. She lived alone in a room in the West Philadelphia. She was currently unemployed after being laid off of as a cleaner. For most of the time she was in the hospital, she had no visitors with the exception of a neighbor who checked on her after calling for an ambulance when he found her on the ground. Pamela self-identified as “African American.”</p>
Basil	<p>Basil was 22 when he was hospitalized for multiple limb fractures and a laceration of his liver after being hit by a car riding his bike near his parent’s home in Southwest Philadelphia. He was tall and looked younger than his age. His arms were braced, his</p>

	right leg in traction, and his face and was swollen and bruised. His arms, legs, and neck were heavily tattooed. He had several visitors. His girlfriend was often at his bedside, along with friends and Basil's parents. His cousin who worked as a hospital security guard would also visit and check on his recovery. Basil self-identified as "African American."
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CHAPTER 3

(Paper 2)

“Like I’m locked up”: Space, gaze, and race in trauma care in a hospital in Philadelphia

Authors

Target Journal: Social Science and Medicine

Abstract

Racial disparities in injury outcomes in the United States are perplexing given the legislative protections that require that all people, regardless of insurance status, are admitted Trauma Centers and that accreditation of these Centers requires adherence to strict standards of care. This paper examines the experiences of Black trauma patients in a Trauma Center in Philadelphia to explore the structural and interpersonal consequences of racialization and subjectification of Black Trauma patients in clinical culture using ethnographic data. The observations and interviews for this study were collected between December 2012 and December 2013 from twelve Black Trauma patients admitted to the hospital and the clinicians responsible for their medical and nursing care. Patients perceived their racial and economic status reflected in the hospital space in which care was delivered and their interactions with doctors and nurses. They felt that these aspects of their identity, at times, influenced the way that clinicians judged their character and applied hospital policies to exert authority over their bodies, movement through the hospital, and the visitors at their bedside. Clinicians who were interviewed did not perceive the overt influence of racial biases on their interactions with patients, but illustrated racialized stereotypes through which they characterized Black trauma patients in general, through connotations of race, criminality, poverty, and unstable social networks.

Introduction

Basil was in and out of sleep, bruised, and swollen a day after he had been hit by a car while driving his dirt bike through the streets of Philadelphia. His splinted leg was attached to a pulley that applied traction from the metal frame that caged his hospital bed. With his eyes closed, Basil looked younger than his 22 years of age though the tattoos that covered his arms and neck and a small goatee suggested his emerging adulthood. His mother and father, along with his girlfriend and three other friends were at his side in his room on a surgical care floor at a large city hospital. Basil couldn't find the words to describe what it was like being injured except for that he was in pain. His father offered an analogy, "It's like he's locked up...He can't move, he has to stay still, and no one tells us what's going on." Basil, like many other injured people of color in the city of Philadelphia, was receiving medical treatment at a regional Trauma Center that offers state-of-the-art interventions for injury and recovery. Yet Basil's father was not at ease or reassured. He imagined Basil as imprisoned and felt powerless to access the information he needed to understand the consequence of his son's injuries.

The urban Trauma Center provides a unique setting in which to explore race consciousness and negotiations of power in medical institutions. Contemporary epidemiologic research has documented racial disparities in access to health services, experiences with the healthcare system, and patient outcomes across multiple health conditions (Millard, 2009; Van Ryn, 2002). Patients categorized as Black or African American experience poorer outcomes, including mortality, from traumatic injuries when compared to White referents with the same injury, health characteristics, and insurance

status (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Haider et al., 2008; Shafi et al., 2007).

Large urban medical centers offer highly technical clinical care while simultaneously providing a forum for clinical education, biomedical research, and multiple forms of economic and political exchange with surrounding community, institutions, and extramural funding entities (Sanfilippo, 2010). A medical center that is designated as a regional resource center for trauma care requires 24 hour a day access to a broad spectrum of medical specialists, nurses with special education in trauma care and the organizational and technological capacity to contend with a wide range of injuries. In the acute management of injury, trauma clinicians rely on care guidelines based in algorithms developed by professional societies such as the American College of Surgeons Committee on Trauma (Committee on Trauma, 2014). This algorithmic approach outlines anatomic and physiologic parameters to guide treatment choices. Policies have also been created and enacted to diminish the risk of disparities in trauma care among populations perceived to be vulnerable. For example, the 1983 Emergency Medical Treatment and Labor Act requires that all trauma patients who arrive to emergency departments are admitted and provided care irrespective of proof of ability to pay for services (Shafi et al., 2007).

Given legislative mandates and standards for accreditation, the management of injury is expected to be 'blind' to many of the social and economic factors that often mediate race-based disparities like health literacy (Marquez de la Plata et al., 2007), ability to pay for services (Blanchard, Haywood, & Scott, 2003), and access to highly equipped medical facilities. It is suggested that regardless of the beliefs and attitudes of

healthcare providers who make diagnostic and management decisions, algorithms inhibit the potential impact of racial bias in injury treatment (Willard, 2009). The etiologies of racial inequities in injury outcomes that persist, despite structural protections like facilitated access to care and practice guidelines, remain broadly unexplored.

Perspectives on race in trauma care from the point of view of patients are not well represented in the current body of published research. Liebshutz et al. (2010) elicited the experiences of Black patients with violent injuries treated in the hospital setting (Liebschutz et al., 2010). This study shows that Black males injured by violence are often distrustful of trauma clinicians and presume a connection with the criminal justice system that inhibits patient-clinician communication. Injured Black patients in this and other studies describe their sense of disconnection from nurses and physicians, adding to their insecurity and feelings of dehumanization in trauma care processes (Liebschutz et al., 2010; Rich, 2009).

Patient-clinician interactions are bounded by the institutional environment, norms, and policies in which they occur. While protocol-driven, trauma care is delivered in the context of a clinical culture whereby a “particular subsystem of socially legitimated beliefs, roles, relationships, transaction settings,” are constructed and reflect, “underlying sociopolitical sectors of care and their ideological (cultural) structures (Kleinman, 1978).” Foucault explains clinical culture and power in the hospital through ‘dividing practices’ and the concept of ‘subjectification.’ Dividing practices are forms of spatial and social exclusion, which differentiate the patient from others in the hospital and are institutionally legitimated through scientific rationale (Foucault, 1994). Through these divisions, an individual comes to understand him or herself as the ‘subject’ of medical

objectification and assumes a passive position in the interplay between his or her body and the actions imposed upon it (Foucault, 1994; Rabinow, 1994).

An ethnographic exploration of the experiences of Black trauma patients was carried out in a major medical center in Philadelphia to explore the relationship between race, institutional norms and modes of subjectification in the culture of urban trauma care. The purpose of this research was to describe the socio-structural influence of the urban context on the experience of Black patients recovering from injuries and to explore how race and other social constructions play out in this cultural milieu.

Methods

Critical Race Theory (CRT) and Carspercken's methodological framework for critical ethnography guided the design of this study to purposefully situate the social construction of race as a focal point through which to explore power and culture within trauma care at a major urban medical center (Delago & Stefancic, 2001; Ford & Airhihenbuwa, 2010)). Critical ethnography is based on traditional ethnographic methods like observation and interview, but emphasizes the study of cultural power on socially marginalized participants (Cook, 2005; Madison, 2012). An adaptation of Qualitative Event Analysis (QEA) was used to refine and manage the amount and content of data collected across multiple clinical settings in the hospital. This technique permits focused and detailed collection of observation and interview data around a 'critical' event that occurs repeatedly in a clinical setting (Happ, Swigart, Tate, & Crighton, 2004). The definition of a 'critical event' is flexible and open to the interpretation of the investigator and guided by the needs of the research questions that comprise a particular inquiry. Events require human interaction and their description must include features like time,

physical setting, key participants in the interaction and patterns of behavior (Happ et al., 2004). The events that comprised this inquiry were not fully delineated prior to initiation of fieldwork. Each participant began to explore their experiences by describing how they were injured and entered the Trauma Center. Other events that became important areas of exploration included: transitions between trauma care settings, communication and treatment of pain, hunger, fatigue, and psychological reactions to injury, interactions between patients, their support system and clinicians, communication regarding clinical status and clinical interventions, interpretations of patients and their support system by hospital staff, and interpretations of hospital staff by patients and their visitors.

The fieldwork that informs this analysis was conducted from December 2012 through December 2013 at a regional trauma center in Philadelphia that serves a predominantly Black patient population from communities in the West and Southwest regions of the city. Approval to conduct this research was obtained through the University of Pennsylvania Institutional Review Board and the hospital's Department of Traumatology. To ensure that the purpose of the research and role as a researcher was clear to hospital staff, S.J. met the nurse managers on all of the trauma-designated patient care units at the hospital to introduce the scope and conduct of this study and to disseminate study information across trauma-designated units of the hospital.

Eligible patients were identified for inclusion by a charge nurse or nurse practitioner on the trauma intensive care unit (ICU) or trauma floor of the hospital if they were recently admitted to the trauma service (within 24-48 hours), were identified by hospital staff as 'Black' or 'African American' and were able to provide consent to participate in research. Patients under arrest or incarcerated at time of injury, those with

self-inflicted injury, brain injuries, preexisting diagnosis of a major psychotic disorder or whose injuries would otherwise preclude communication were not eligible for inclusion. After being provided with information about the study, 13 patients declined participation, citing pain and fatigue as primary reasons for non-participation. Twelve English-speaking Black patients (10 men and 2 women) between the ages of 21 and 72 years, with violent and non-violent mechanisms of injury were recruited for observation and interview following the acute management of their medical needs. All participants self-identified as Black or African American in concordance with staff perception.

Observation of care occurred on at least one day at each of the trauma-designated units at the hospital to which the patient was admitted after recruitment. Observation and embedded interviews lasted anywhere from 30 minutes to several hours. The focal participant of this study was the patient, however, given the observational nature of this study, nurses, nurse practitioners, and physicians, who care for these patients were also observed and interviewed. Clinicians were asked to verbally consent for confidential participation in the study when approached for individual interview. At times in which an interview did not interfere with the course of care and with respect for the patient's physical privacy, embedded and retrospective interviews were used to elicit perceptions that clinicians held regarding critical events and care of patient participants.

Early in the study, observation and interview technique and analysis was open and flexible. Time was spent surveying the environments in which care for injury took place to identify the environment, processes and interactions that seemed to define the culture of trauma care and the experience of participants in the hospital. Latter fieldwork, contextualized by the themes of early analysis, guided the context of observation and

content of interviews to focus on critical events that reinforced or seemed unique in their contradiction of other participants' experiences (Pope, Ziebland, & Mays, 2000).

Data were collected using field notes and audio notes that were recorded concurrent with or immediately following each field observation. Field notes included structural and social observations of the clinical environment, descriptions of interactions, and in cases where a patient preferred not to be audio-recorded, detailed recollections of interview content (Strauss, 1987). These notes and audio recordings were transcribed with participant or informant identifying data replaced with pseudonyms and other proxies to protect confidentiality. Transcribed notes and interviews were organized and coded with the assistance of NVivo v.10 software for qualitative data management. Memos and other investigator comments that arose during fieldwork or in the process of data analysis were also stored and referenced using this software.

In analysis each participant's experience was viewed as an individual case. Using Foucauldian theory, each case was analyzed to identify how the interplay of physical and psychological reactions to injury and hospitalization, patient-clinician interactions, and the hospital environment produced specific interpretations of objectification and subjectification from the point of view of patients and the clinicians who provided their care. Themes that emerged from one participant's experience were compared to the greater body of experiences described in the data (Strauss, 1987). Fieldwork and participant recruitment continued until there was sufficient reinforcement and explanation of major themes.

The credibility of themes that emerged was crosschecked through regular expert debriefing, critique by a peer qualitative analysis collective, and the creation of detailed

code book (Glaser & Strauss, 1967; Happ et al., 2004; Strauss A.L. & Corbin, 1990). Field notes and initial coding schemas were critiqued at regular intervals throughout study activities. To maintain transferability, or the ability to demonstrate replicability of the analysis process, a careful record of procedure and rationale for coding schemas was recorded in a code book (Glaser & Strauss, 1967; Strauss A.L. & Corbin, 1990). Interpretive and reflective field notes were also included to permit careful examination of the positionality and perspective of the primary investigator and to uncover potential influence on analytic process (Finlay, 2002).

Results

Observation and interviews focused on the day-to-day lives of Black trauma patients and their predominately White clinicians on the trauma unit of a major urban medical center. We used Foucault's theory of power to examine how dividing practices shaped the institutional culture in which Black injured patients became "subject" to clinicians' surveillance, control and gaze and influenced the racialization of trauma care interactions.

Dividing through space

The physical structure and use of trauma care facilities influenced the way participants understood their role as a patient and power in the direction and content of their hospitalized lives. Participants spent the majority of their conscious hospitalization on the trauma floor of the hospital, Foster 7, following the acute management of their injuries in the emergency department or Trauma ICU. Foster 7 was located in the oldest building in the hospital and was its only inpatient floor. Participants perceived the physical dilapidation and outdated design features of this space as a reflection of their

social and economic status. Brian, a 34-year-old man with multiple gunshot wounds, awoke from surgery on a hospital floor that was not specifically designated for trauma patients. He described this space as having “more luxury” like better TVs and larger, single rooms. Brian believed he was transferred to Foster 7, not solely for trauma care, but when hospital staff realized that he was poor and relied on public insurance.

The shared rooms to which most patients were assigned were crowded and dark. Only one of the patients in these rooms could see through a window at the far end of the room. The patient nearer to the inner hallway was conferred privacy through a set of parallel curtains with only enough room for a chair, table and a hospital bed. Worn beige curtains divided the rooms’ two occupants, although sound and odor moved easily between patients’ spaces. The sounds that entered participants’ rooms from the hallway were hard to interpret but gave the sense that nurses and other staff were close by. Taalib, a 42 year old patient with multiple gunshot wounds, commented, “you hear them out there talking and laughing.” The audible proximity of staff, out of visual range, made participants feel helpless and ignored when calls for attention went unanswered for long periods of time.

Participants who were housed in private rooms didn’t perceive particular advantage to the space they occupied. Basil felt that the manner in which clinicians entered his room violated his privacy and autonomy: “They are always knocking on the door and then come straight through. I don’t say anything and they just open the door and put on the lights.” Bill, a 22 year old with a gunshot wound, described the fear that accompanied his loss of control over the medical procedures and the time in which they occurred “It was the worst. It’s like six in the morning. They walk in. At first I thought they was detectives. They doctors? They detectives? I

don't know what they about to tell me. They just come in. Raising the bed up. I'm like, Ho. What's going on? They were about to take the chest tube out. The chest tube? At this time? It's too early."

Features of the technology used to survey patients' physical condition subtly reinforced a perception of confinement. Bill spoke of the wires used to telemetrically record his heart rhythm: "over my face, all tangled up. I had to stay still like this (*straightens his body rigidly*) I was staying still like this anyway cause I was on an IV. Know what I'm saying? Gave me Morphine every five minutes. So was asleep most of the time. But when I was finally waken up, I was like, damn I can't even fix these wires a little bit. It's making me feel worse. Like 'can you straighten these?' I want to be able to move, change position and all that. Like I'm scared to move..."

In addition to the loss of control that participants expressed in the confinement of their hospital rooms, participants noticed the ubiquitous presence of police and prison guards throughout Foster 7's hallways. Pairs of police officers in dark blue uniforms with city insignias sat just outside the rooms of patients under arrest or awaiting arraignment. Prison guards in orange bullet-protective vests stood at the bedside of patients who had been incarcerated at the time of their injury. Both police and prison guards displayed weapons at their hips. This presence created a uniquely carceral feel to the trauma care floor.

Though none of study participants was under arrest, all of those with violence-mediated injuries like gunshot wounds described interactions with police during the course of their hospitalization. These interactions were often in the emergency department or early in hospitalization. Participants, like Bill, felt dehumanized and resentful when police interviews were permitted concurrent to medical treatment in the emergency department. "This is something serious that happened to me. I'm not going to forget it. Let me recover. You want to do this while I feel like I'm getting ready to die. You want sit here and ask me

questions while I'm getting ready to die. Like that just showed me you don't care nothing about nobody's health."

For clinicians caring for participants, the presence of the police or prison guards was interpreted as a normal but challenging feature of the trauma care setting. Ann, a nurse with over ten years' experience was accustomed to the presence of police and prison guards to the extent that they had become invisible to her: "it's been over so many years that these nurses have worked there, the older ones, that they almost don't even see the police. Because I don't. I forget." Lisa, a trauma nurse with only two years' experience felt aligned, but conflicted, with the presence of the police in the trauma units. "It's difficult because I know they're on my side and protecting us but sometimes they interfere with the care." The trauma surgeon who cared for Taalib reflected on the presence of police in the emergency room as a typical but disruptive feature of trauma resuscitations. "The police will sometime come in while we are working in the Bay and ask questions about how many bullets or where the bullets went. Its chaos. I have to yell that if there is anyone who is not directly involved with saving the life of this patient either get out or shut up."

For participants, the carceral quality of the trauma floor was reinforced by rigidity of policies that hospital staff used to limit patient's movements. This was particularly so for participants who had been incarcerated at some point prior to being injured. The first thing Bill said when asked about his hospitalization was, "I'll tell you how it feels, it feels like I'm locked up." He attributed part of this sense of imprisonment to the physical environment. "You can't smell no air." The loss of autonomy he experienced during hospital care processes reinforced his sense of captivity. "You got to stay in this bed. If I got to poop, I got to call someone to tell them I got to poop. You know what I'm saying? I don't know. I can't move on my own. Like I'm saying not being able to move, that sucks. I can't get up and go to the store. Can't eat good food. Food kinda nasty. Got to have somebody tell me what I can drink. Stuff like that."

Reece, a 26 year old with a gunshot wound, articulated how it felt to be divided from one's support system in the course of hospitalization. He attributed the enforcement of policies that isolate patients from their support system, like visiting hours, to the way that trauma patients were viewed as people. "People are social animals, like you understand what I'm saying? Like they're like a socialized animal and therefore we need that socialization. When you break people off, like from, because of their class or their demeanors, you know what I'm saying? If you separate those people, that's where they get worse into that. Like that's how I really feel." When the nurse who was caring for Reece described how she felt about family presence for trauma patients in the hospital, she perceived: "There is a lot of anger, especially with the moms or the baby mama or what they call it. But I think it's because they're trying to be protective."

Patients who challenged hospital policies or clinicians' directives were labeled as problematic and subject to additional surveillance. Joe, a 46 year old with jaw and rib fractures, actively resisted being confined to his hospital room and was labeled by the nurses on Foster 7 as "difficult" for this resistance to hospital rules. Joe analogized the hospital to a prison because he was not permitted to go outside to smoke cigarettes. It was medically risky for Joe to smoke with the collapsed lung that resulted from his rib fractures. Rather than explain the medical rationale, Joe's nurse who was overwhelmed by his attempts to leave the floor told Joe that he couldn't go outside because the unit was on "lock down" due to a death threat made to another patient. While Foster 7 was indeed being monitored by Philadelphia Police due to a threat, Joe's nurse wanted to prevent him from going outside because she presumed he would use intravenous narcotics. Joe persisted in his resistance "They can't keep me here... Most of those doctors smoke right out in these lounges and she going to tell me the floor is closed and I want to smoke." Joe 'escaped' the floor

several times as he waited a week for reparative jaw surgery. “They told me I can’t leave with an IV. So I took the IV out. I went out to 7-11 last night and then came back.”

Dividing through information

The use of complex clinical language and lapses in communication obscured how participants understood the rationale for treatment strategies. These obscurations limited the trust that participants had in the hospital’s clinical staff. When Basil’s clinicians kept their explanations for care brief and cursory, he felt like he wasn’t being given a straight story on why he continued to require an uncomfortable nasogastric tube: “And when you ask these people something, they can’t give you a real answer. They give you like sideways answers. Just cut straight. It’s the easiest way out of it. And they look at you like you crazy.”

Clinicians’ motives were further suspect when details of medical findings and treatment strategies were inadequately discussed in face-to-face conversation. Joe was waiting for surgery to repair his mandible that would leave his jaw wired shut and inhibit speech for at least six weeks. He was afraid to have this surgery before he felt satisfied that his clinicians had a plan to “deal with the liver.” Joe had a copy of a form titled ‘Incidental Findings’ as evidence of his concern. The form that included an indecipherable physician’s signature noted that the radiographic scan used to look at Joe’s fractures identified multiple areas of tumor growth on his throat, liver, and kidney. Joe said that the physician who signed the form had told him to use the form for reference “down the line.” Joe knew that this document meant that something was wrong, but he couldn’t interpret its meaning or what he might do to follow-up on this information once his jaw had been wired.

Serious clinical events during hospitalization were not consistently explained to participants or their healthcare decision making proxies with sufficient reinforcement to

ensure understanding. In these cases participants expressed a sense of confusion and fear about their care but were not able to understand why their perceived needs were not met to their expectation. Ray, a 41 year old with a broken ankle required a reparative surgery, which injured the nerves in his leg and resulted severe and persistent pain throughout his two-week hospital stay. On one day when Ray was in particularly bad pain, he threatened to transfer to another hospital in order to receive adequate pain relief. He could not understand why the nurses and doctors could not treat his pain. Ray's nurse and a surgical resident reinforced that they could only give him small amounts of narcotic pain medication due to his "bad reaction" earlier in the morning. Ray and his wife did not know anything about a 'bad reaction' and thought that the clinicians were simply being evasive and disbelieving of the extent of Ray's pain. Unbeknownst to Ray and his wife, Ray had been found unresponsive earlier that morning and required emergency treatment with a medication to reverse the narcotics in his system. Ray had no memory of these events nor were they discussed with Ray's wife.

Dividing through clinical gaze

The time and task-oriented practice of clinical staff in the hospital communicated a pointed focus on the patient's physical body to the near-exclusion of all other aspects of their personhood. Jane, a nurse practitioner on Foster 7, described Bill as "doing fine. Gunshot wound to the chest, left hemothorax/pneumothorax with two chest tubes." In this description, Bill's health was evaluated, not by the severe and painful wound to his chest, but rather by the relationship between his wound, available treatment, and risk for death. Similarly, Jeanne, the surgeon who evaluated and treated Taalib's multiple gunshot wounds, described her experience caring for him through a discourse of physiology and surgical

tasks. In her description, Taalib's body parts and injuries are dispossessed from his identity: "So I don't know where the bullet is. It could be in subcutaneous space in the front or the back. I don't know. My left chest, I'm draining it and the lung is re-expanded. So at that point I am not worried about the chest but the belly has obvious signs of bleeding in it."

Nurses had more time and consistent interactions compared to nurse practitioners and surgeons and yet nurses appeared to be similarly focused on the physical consequences of their patient's injuries and the specific tasks for which they felt responsible. In extreme examples, nurses did not communicate with patients regarding aspects of hospitalization unrelated to their point of focus. Pamela, a 54-year-old woman who had fallen and sustained several fractures, was preoccupied with her sense of hunger and restriction from eating. Foster 7's charge nurse came into Pamela's room, and explained to her "My leads aren't working." The nurse exposed Pamela's chest and moved the telemetry electrodes to transmit a better reading of Pamela's cardiac activity to the monitors near the nursing station. Pamela told the charge nurse that she was hungry and complained that she didn't understand why she couldn't eat. With focus solely on the telemetry wires and their placement on Pamela's chest, the charge nurse did not offer eye contact or acknowledge that Pamela was speaking.

Non-physical aspects of injury, such as psychological and emotional reactions to traumatic events and loss, were beyond the scope of the clinical focus. A week into hospitalization, Taalib was shaky, drenched in sweat and weeping in his room. In short quiet sentences he described his previous sleepless night, plagued by nightmares about being shot and paranoid thoughts about people in the hallways speaking about him. Taalib's nurse, David, who was new to the Trauma floor, evaluated Taalib's behavior as the result of being "an emotional guy." When David began his shift the woman who stocked

the patient's rooms with medical equipment was talking to Taalib and offered him support through what David called a "freak out." David did not intercede, document the occurrence or offer any additional care because "She looked like she had it under control."

Participants were not unaware or unaffected by the task-orientation and physical focus of the hospital's clinical staff. Basil was bothered by the segmentation of task and responsibility among the clinicians who were charged with different aspects of his care. "I ran into this one guy earlier and you could tell he just, answered a couple of question, right? And then he was done with his job. He don't really care what's going on with me." Reece's girlfriend Kia, had a similar reaction to what she interpreted as impersonal and task-oriented care, "everything's about assembly lines and check boxes."

When interactions were uniquely focused on a certain aspect of a patient's clinical condition or body, this too was perceived as troubling. Dave, a 21-year-old patient with a gunshot wound, had subcutaneous air pocketed in his chest. When pressed upon, the air could be felt popping below the skin surface. At end of shift report, Dave's nurses would show each other the spot on his chest where the air was trapped. Some would bring other nurses in to feel Dave's chest. He was disturbed by their pointed focus and attention on a seemingly inconsequential aspect of his injury: "like I'm a test tube or something."

Participants' response to the limits of the clinical gaze in trauma care can be partly attributed to the rarity of contact between patients and clinicians in the hospital. Whatever brief and task-oriented interactions occurred, they did so against a backdrop of relative non-interaction. For example, Ray's nurse Ella came in for their first interaction in three hours. She asked him if he wanted his Morphine pill. He said yes, she handed it to him, and made sure he had water in his cup. The entire interaction lasted less than two minutes.

Dividing through race

Participants and their clinicians rarely spoke unprompted about the overt ways they believed that race impacted the quality or extent of interactions in the hospital. More commonly, participants explored the influence of racialized features of their lived experience like poverty, use of public health insurance, and exposure to violence, on clinical care and interactions with hospital staff. Virginia, a 72-year-old woman with multiple fractures, described the economic insecurity she had experienced over her lifetime as a “manual laborer” in Philadelphia. When reflecting about her perception of care in the hospital she explained, “the more money you have the more healthcare you receive, and in comparison to people overseas, in Africa, I’m grateful.”

Storm, a 37-year-old man with multiple gunshot wounds, had preconceived notions from what he had seen on “TV” of how a predominately White nursing staff would treat him. He was surprised, and grateful, when he was offered basic nursing care. “Bathe me. Check up on me. They ask the doctors questions about me. They make sure I know everything that’s going on. Make sure I’m clean. Know what I mean? Just make sure I’m focused and not giving up.” Taalib, described clinical staff as “beautiful,” positive, and educated, situating these evaluations in the context of racial difference: “Whether they prejudiced or not... Because I don’t know whether they’re prejudiced. I don’t know whether. But they have job to do. You know what I mean? And then after you sit. After you do your job and you tell a person that you love them. That means a lot. Especially when there’s skin color. You understand what I’m saying? Different.”

A young nurse on Foster 7, Wendy, acknowledged the difference she perceived between herself and the patients she typically cared for on the trauma floor, “but it’s difficult because I’m young and White, it’s obviously a big juxtaposition. Normally they turn around and like me and stuff like that.” There were a few non-White nurses on Foster 7. Ronnie, a Caribbean American nurse with over ten years’ experience, did not openly acknowledge

that race was a factor trauma care interactions, but use relational titles to communicate with Black patients. She referred to Virginia, for example, as “mama” and Virginia’s daughter as “sis” as she discussed the effect of pain medication on fatigue.

Explicit reference to racial discrimination as a factor in hospital interaction was rare but occurred when participants perceived that clinicians were being purposefully neglectful or punitive in their actions. Reece’s mother and sister had argued with nursing staff in the Trauma ICU about what they interpreted as overly ‘rough’ handling of Reece’s body when he was first admitted to the hospital. Reece believed this argument created a precedent for increased surveillance and biased targeting of hospital policy enforcement. Victoria, the ICU nurse who was confronted by Reece’s family, felt that they were overly sensitive and blindly critical of the nursing staff despite efforts to establish rapport. Victoria perceived a commonplace animosity between trauma patients and nurses and was seeking re-assignment to a different hospital unit: “I’m tired of these people, tired of the drama.”

A few days later, when Reece was moved to Foster 7, Reece’s girlfriend, Kia, and their one and six year old children stayed overnight in his room to avoid travel late at night. The night shift nurse brought them blankets and pillows. Reece specifically described her as African American. When a new nurse came in the morning, she told Reece that having children in the room overnight was against hospital policy and unacceptable. Shortly after this interaction, a social worker asked Reece questions about safety in the home. Reece believed that because his children had stayed overnight that he was being targeted for questions about his home-life and children’s welfare. Later that day his nurse practitioner asked Reece questions about the circumstances of his shooting. Reece interpreted this line of questioning, in combination with the morning’s

interactions, as evidence that the hospital staff were racist and judged that he was a bad father.

When clinicians spoke about the influence of race on their interactions with trauma patients, they did so in broad categorical terms, which illustrated the way that race was conflated with criminality, poverty, and unstable social networks. Ann, a nurse and clinical educator on one of the trauma units, referred broadly to trauma patients, as “these guys”. In her mind young Black men with violent injuries were emblematic of the general trauma patient population, although they only represented a fraction of the injured patients treated by the Trauma Service each day. Ann described how she made decisions about her interaction strategy and empathic tone with trauma patients based on how she perceived the combination of their race and mechanism of injury: “... with some patients you can be sort of matter of fact. You know if they were in a fight or shooting or something like that. And they’re like a little bit tougher or you know they had multiple problems with the law. As opposed to some guy who is coming home from work and got hit or was shot in the wrong place wrong time. Who is from a good family and really had a lot of aspirations. And dreams. And then they get shot and it changes their lives. I may be a little more sensitive to the latter.”

Lisa described how she struggled to respect her Black patients with violent injuries because of the way she understood their “lifestyle.” “I try to keep treating them with respect even though I don’t have much respect for them. I know it’s a whole system thing. Like their life, it really sucks. Unless it was like really innocent like, ‘I was mugged.’ Which we don’t really have.” For Lisa, the automatic overlay of criminality and culpability of Black patients with violent wounds, extended interpretation beyond the walls of the hospital. “I’m just scared that the patients that I see, it’s those type of patients that I’ll see on the street, and I didn’t used to think that when I first moved here. I guess it’s working here.” She believed that other hospital staff shared her fear of Black male trauma patients with violent injuries. To support this claim, she described how

nursing staff taped over the surnames on their hospital badges to prevent patients from being able to identify them after hospitalization.

Discussion

Little is known about how race consciousness influences treatment and recovery in urban Trauma Centers. In Philadelphia, Black people are more likely to live in segregated neighborhoods with high levels of violence, experience poverty, have lifetime experiences arrests and incarceration, and are less likely to have access to healthcare and health insurance, and employment opportunities (Anderson & Womack, 2013). Patient perceptions of care in a Trauma Center in Philadelphia illustrated the interwoven nature of this socio-structural context within their interpretations of clinical culture.

Participants saw their racial and economic status reflected in the hospital space in which care was delivered, the interactions they experienced with doctors and nurses, and the clinical focus on the physical consequences of their injuries to the exclusion of the other ways that that they suffered. Participants felt that these aspects of their identity influenced the way that clinicians made character judgments and applied hospital policies to exert authority over their movement through the hospital and the visitors at their bedside.

In the current historical context of the United States in which discrimination is illegal and socially unacceptable (Jackson, 2011), it is very difficult to study the place of race and other social identities in trauma care through the investigation of overtly discriminatory behaviors (Bradby, 2010). The absence of overt discriminatory behavior, however, does not sufficiently capture the potential impact of disavowed or subtler behavior, symbols and communication that can contribute to the persistence of racially

inequitable processes in the course of injury care. In this study, race emerges as both a conscious point of difference between patients and clinicians and a construct that mediates fear and avoidance in clinical care. For some clinicians, race further acts as a physical and visual representation that is conflated with other social categories like poverty, criminality and aspiration for social and economic mobility.

Presuming criminality or culpability in the events around an injury is particularly problematic because this can negatively influence the care that patients receive (Balsa & McGuire, 2003). At a biological level, the regulatory mechanisms for compassion have been shown to directly correlate to the extent to which a victim is perceived to be responsible for their circumstances (Fehse, et al. 2014). In a social psychology experiment, individuals seen as contributing towards the circumstances of their injury were more likely to experience prejudice, less social interaction, and inhibited helping behavior from experienced nurses (Linden & Redpath, 2011). These findings support earlier research findings that healthcare professionals expressed significantly more negative attitudes and less intention to help patients who were blamed for the etiology of a brain injury (i.e., had positive toxicology screen in the context of a motor vehicle accident) (Redpath et al., 2010).

In this Trauma Center, the physical features of the clinical environment reinforced stereotypes that patients and clinicians constructed of one another. Goffman's work on the social processes of stigmatization emphasizes the importance of physical setting (Goffman, 1963) in stereotype activation. Waquant uses Goffman's theory to explain how ghettoized areas of urban environment convey a message of social worthlessness through symbols of dilapidation like abandoned buildings, crumbling streets, and

overflowing sewers. In parallel, trauma care space that is dark, outdated, confining, and lined with police and prison guards can demoralize those who are cared for within it and simultaneously reinforce a “stigmata of race,” poverty, injury and criminality to influence the perceptions and judgments of surrounding citizenry (clinicians, other hospital staff) (Waquant, 2011).

Negative stereotypes of Black male trauma patients that emerged from some clinicians in this study were that they were criminal, poor, and dangerous, and their support systems were “drama” and “baby mamas” (which in and of itself suggests a stereotype of Black women’s childbearing as a form of degeneracy (Kwate, 2014)). The ease of stereotype activation in trauma care may have been reinforced by clinicians’ rushed and task-oriented practice which limited interaction and inhibited the focus of attention on non-physical consequences of injury and each patient’s unique personhood.

The perpetuation of stereotypes of Black male trauma patients as deviant or criminal has structural consequences. At the institutional level, these stereotypes blind clinicians to a social and physical environment that is dehumanizing and thus detrimental to healing, inclusion, and the development of mutual trust. At the individual level, perceptions of stereotypes can induce a stressful level of vigilance as patients feel challenged to identify the extent to which they are safe and accepted by clinicians as social equals (Kwate, 2014). It can also increase rumination on feelings of exclusion and vulnerability, which has been shown to contribute to the development of depression (Kwate, 2014). Factors that worsen psychological distress during trauma care are important to consider because of the well-described relationship between mental health and injury recovery. In the general population of trauma patients, psychological

symptoms like stress, anxiety, and depression predicts poorer recovery and extended disability after injuries (Cooper, Graham, Goss, & DiGuseppi, 2011; O'Donnell, Creamer, Elliott, Atkin, & Kossmann, 2005; Richmond et al., 2009; Richmond et al., 2011).

The themes that emerged in this ethnographic study must be interpreted with the limitations of this type of research in mind. First and foremost, this ethnographic study captured the stories of twelve patients who were admitted to the Trauma Center over the course of one year and the clinicians who provided their care. Participants' reactions to the Trauma Center structure and culture are specific to their experience and cannot be generalized to all Black trauma patients who may be hospitalized for injury in the hospital and at other medical centers in Philadelphia. Participants were mostly male and suffered violence-mediated injuries like gunshot wounds. The experience of female trauma patients with violence-mediated injuries is missing in this inquiry, and may detract from the nuanced way that gender and other identities intersect (Collins, 1998) in this exploration of urban trauma care.

Conclusion

The care of Black patients in a Trauma Center in Philadelphia reflects the intersections of social and racial marginalization and violence in this urban environment. Young Black men are injured in violence at rates disproportionate to any other group (Rich, 2009). And in this study, they become emblematic for some clinicians of all Black trauma patients that enter the hospital for care. This conflation of race and violence, make injured Black patients subject to stereotypes which in this, and other studies (Rich, 2009),

hardens nurses and physicians to the Black patients with violent injuries they see in their daily work.

Racialization in trauma care processes in this inquiry was not solely the consequence of the biases of individual clinicians. The structure and logic of the clinical environment symbolically reinforced racialized perceptions and stereotypes of patients, who were isolated to small and cell-like rooms that made them feel isolated and vulnerable. Regular and visible police presence in the hallways of the trauma floors served as a consistent reminder that patients could be dangerous and culpable for the circumstances of their injuries. Clinical assessments and interventions focused on participants' bodies and the physical consequences of their injuries, to the exclusion of the psychological or social ways that they suffered. This too, contributed to the ease of negative stereotypes, by concretizing avoidance of the human and relatable experiences that participants go through as they contended with a life changing injury.

Participants in this study perceived the stereotypes to which they were subject and interpreted these judgements as a reason to maintain emotional and social distance from clinicians. When patients felt that clinicians recognized their humanity it was important way in which trust was established in this contentious and complicated clinical space. As Reece describes, "like you see I'm laying here, I'm like partially naked. I don't even feel together in my head. My hair's not done. But they're actually making me feel like a person instead of making me feel like a burden. That's really the whole thing to me." The challenge set forth from the interpretation of the stories of the patients and clinicians included in this inquiry is to find new ways to face one another towards a common goal of healing and working in a place of trust, and to find ways to come closer to what Reece understands as the "whole thing."

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CHAPTER 4

(Paper 3)

The insight and challenge of reflexive practice as a nurse-researcher conducting an ethnographic study of traumatically injured patients in Philadelphia

Authors

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Abstract

Clinically applied interpretations of critical anthropologic research can be used to improve clinical care, nursing practice, and patient experience. This paper discusses the insights and challenges of reflexive practice in conceiving, engaging, and analyzing an ethnographic study of the hospitalization experiences of Black trauma patients in an urban academic medical center in Philadelphia, as both an insider and outsider to the clinical environment and among the participants whose experiences were the focus of inquiry. The insights of reflexivity became a secondary source of data. In fieldwork, I learned that my nursing habitus was a durable disposition that structured my way of being in clinical space and facilitated a particular level of interpretation of, and participation in, clinical culture. In analysis, reflection on the subjectivities through which I designed this ethnographic research allowed me to see beyond my preconceived and theoretically informed perspective to permit unexpected features of the 'field' to emerge. Finally, reflexive practice guided my reconciliation of key practical and epistemological differences between clinical ethnographic research and the Anthropologic tradition in which it is rooted.

Introduction

The integrity of a naturalistic inquiry is quickly diminished by avoiding the subject of self and one's own subjectivities in the research process. And yet allowing oneself to "fall into an infinite regress of excessive self-analysis at the expense of focus on participants (Finlay, 2002)" risks losing sight of the purpose of research all together. Recognition and integration of self-subjectivity at different phases of research can be difficult, especially for those entering the 'field' for the first time as a novice investigator (Baumbusch, 2011). In this paper, I discuss the processes through which I learned the insights and challenges of reflexive practice in conceiving, engaging, and analyzing ethnographic research, as both an insider and outsider to the clinical environment and among the participants whose experiences I sought to understand.

Throughout 2012, I conducted fieldwork for an ethnographic study of the hospitalization experiences of Black trauma patients in an urban academic medical center in Philadelphia. The purpose of this research was to explore how race consciousness and other features of the urban social context influenced the process of recovery. I became interested in this line of inquiry through my experiences as a trauma nurse in Philadelphia caring for injured patients who lived within the low-income, predominately Black neighborhoods adjacent one of the city's major Trauma Centers. The trauma and violence that impacted the lives of many of the patients I cared for was striking. Research on racial disparities in injury illustrate that Black people, particularly in urban settings like Philadelphia, endure a disproportionate risk for violent injury and its physical and emotional consequences (Rich & Grey, 2005; Smith, Richardson, & BeLue, 2009). Once hospitalized, Black patients are more likely to die from their injuries when

compared to other racial groups with comparable injuries, economic characteristics, and geographic proximity to trauma care services (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Haider et al., 2008; Haider et al., 2012; Shafi et al., 2007). The etiological factors that underlie the relationship between a social category like race and injury recovery in the context of protocol-driven trauma medicine are poorly understood (Gooberman-Hill, Fox, & Chesser, 2011).

Background

Use of critical ethnography through which the stories of Black injured patients could emerge in detail and in their voice was ideally suited to the study of the social context from which racial disparities in injury recovery arise. The ‘critical’ in critical ethnography does not imply departure from traditional ethnographic approaches to a field of interest. Rather, it signifies that the focus of research is to address processes of injustice or unfairness within a particular social dynamic (Cook, 2005; Soyini, 2011). This framing draws on Foucault’s notion of critique, where the purpose of research is to challenge the epistemological certainties within institutions, systems of knowledge, and disciplinary practices that: “limit choices, constrain meaning and denigrate identities and communities (Soyini, 2011).”

Critical race theory (CRT) informed the focus and initial approach to data collection. This theoretical stance positions racism as an endemic feature of the U.S.’s social and political landscape and requires interrogation of claims of positivistic, neutral, knowledge that is accepted in isolation of historical and social analysis (Vaught, 2011). Application of CRT in studying trauma care meant paying particular attention to the ways in which racialization influenced patient experience, knowledge production, and the

relationship between the culture of trauma care and broader society (Ford & Airhihenbuwa, 2010). CRT also advocates that the lived experience of people who are particularly vulnerable to racism be privileged in research (Delago & Stefancic, 2001) rather than made subject to comparison in a Black-White binary which oversimplifies the social and political realities through which racial categories are culturally produced. For this reason, the experience of injured people who were identified as Black or African American by hospital staff, became the sole focus of research.

As a White researcher studying the experience of Black trauma patients and as a nurse attempting critical analysis of a familiar healthcare institution, reflexive practice was essential to the integrity and interpretive quality of the research that I produced. Reflexive practice or conscious self-awareness opens up the ways that the researcher's position, perspective and presence are integrated and influential within the research process (Finlay, 2002). Rigorous self-examination and self-disclosure can be used to understand the way that the product of research (viz. field data in the context of an ethnographic study) is co-constituted by the participants, researchers, and their relationship (Finlay, 2002). Essentially, I needed to think about the ways in which the story I was told and tell about the experience of Black trauma patients in a Philadelphia hospital was co-created by the identities both I and study participants represented and expressed. Reflexivity in this research was a fluid and encompassing process; it required examination of the subjective and inter-subjective during and in retrospect of all phases of research from conception of the research question through the analysis of the data generated during fieldwork (Finlay, 2002). In the narrative that follows I describe the process and discoveries that emerged through my practice of reflexivity as I contended

with the influence I had on this ethnographic inquiry as a nurse, as raced, and as a researcher.

Designing the research

From 2005 through 2012, I worked as a trauma nurse at a major medical center in Philadelphia. I inferred that race consciousness was a present but unexamined factor in the interactions and rapport that occurred between the predominately White clinical staff and non-White patients in the course of every day practice. In my clinical experiences, overt discussion of patient race was confined to how patients were described ('24 year old African American admitted for gunshot wounds to the chest') or as an explanatory factor for underlying pathophysiology of a critically ill or injured individual (for example, chronic high blood pressure in an older Black person). More nuanced racialized discourse occurred when nurses and physicians insinuated presumed relationships between patient race, violent injury, and criminality ('he's tough enough to be a thug, he should be tough enough to get out of bed.'). I felt compelled to understand if and how the ways that patients were racially categorized and characterized could influence the care that is provided and the way that hospitalization is perceived.

In conceptualizing how I would conduct research in the clinical setting in which I was professionally familiar, I considered the benefits and disadvantages of this position. Nurse researchers have use ethnographic methods to explore the context and dynamics of clinical space (Robinson Wolf, 1988). Familiarity with the field can filter out some of the complexities of clinical world, which may be unavoidably distracting to a non-clinician investigator (Kaufman, 2005) and permit specific attention to other domains of interest. At the same time, alliance with a particular health discipline or set of disciplines may

hinder the ability to see the ways that disciplinary norms influence, or even mask, race consciousness in clinical culture and tradition. I attempted to mitigate the influence of my clinical orientation by ending employment and formal clinical practice prior to data collection. I tried to avoid interpretation of the hierarchical relationships between clinicians as I understood them as a nurse, so that I could be present in experiencing a different understanding of clinicians and their relationships, from the point of view of participants.

As a nurse-researcher conducting health research in a hospital using anthropological methods, there was some ambiguity in the way I planned to combine the practical and ethical norms of biomedical research with those of the social science methodology I employed. The participatory nature of ethnographic study required that I create a participatory identity in the context of this work. In other hospital ethnographies, researchers have assumed a participatory stance by positioning themselves as a patient, clinician, or visitor (Van Der Geest & Finkler, 2004). I choose to ‘participate’ as a visitor with a clinical background. My clinical background would offer a certain level of insider knowledge of the hospital, an institution that non-clinician anthropologists have referred to as an “out-of-this-world place. (Kaufman, 2005)” Knowledge of the everyday nature of hospital life includes familiarity with professional routines and rituals, specialized language, medical and institutional technology, and “what counts as normal and ordinary in terms of the progress of disease, medicine’s responses, co-workers activities, and institutional procedures. (Kaufman, 2005, pg. 12)”

To meet the challenge of conducting research on this ‘margin’ between visiting researcher and clinician, I prepared my research plan according to the counsel provided

by Hoeyer, Dahlager, Lyncoe (2005) in the conduct of anthropologic study within medical institutions. It was particularly important to establish a fair balance between informed content and the study of trauma care in the hospital in its natural state. First, when introducing my research and the broad purpose of the study, I made clear that my role was as a researcher and not a clinician (Hoeyer, Dahlager, & Lynoe, 2005). I always wore 'street' clothes and not scrubs or any other garments that would suggest alignment with a clinical role or responsibility. Second, I observed and interviewed clinicians enacting the same ethical obligations as I did for patient participants, with respect for their anonymity and autonomy (Hoeyer et al., 2005). Clinicians were made aware of their position as subjects of research during observation and prior to any interviews. I also decided that I would not specifically talk about race consciousness in introducing the purpose of my research but rather describe the exploratory nature of the inquiry that sought better understanding of the experience of Black trauma patients and their interactions with the clinical environment.

In data collection

Ways of knowing the field

My alliance with nursing and my consequent clinical knowledge provided the opportunity for a particular level of participation in this hospital ethnography. In field notes I integrated my nursing-informed observations and the ways that I felt this background influenced interpretation of the clinical environment. In review of these observations, I found that knowledge of the field offered particular advantages in accessing information, interpreting the clinical culture of trauma care, and engendering trust in both patient and clinician informants.

Prior to beginning fieldwork I introduced the aim of my research and recruitment criteria (any recently admitted trauma patients who were: 18 years of age or older, identified as Black or African American, and deemed clinically capable to provide informed consent) through email and presentation to all nursing and surgical clinicians in trauma-designated units in the hospital. When I began fieldwork and was a known presence on the trauma floors, nurses and nurse practitioners helped guide me to eligible study participants. Without exception, I was directed to young Black men with gunshot wounds. Young Black men with violent injuries are well represented in the census of the trauma department of this Philadelphia hospital but they do not make up the majority of hospitalized injured patients. Though I repeatedly reiterated my interest in the experience of men and women, with and without gunshot injuries, specific recruitment of women and patients without violent injuries was required create a more nuanced body of data. This difficulty in recruitment was, in and of itself, an opportunity to interpret the culture of trauma care in the hospital. The consistent identification of Black men with gunshot wounds as emblematic of the trauma patient population at large helped me to understand how race, gender, and violence intersected in a symbolically meaningful way in the Trauma Center's clinical culture.

I learned that insider-status in the clinical environment offered open access to hospital space and information. When I entered the hospital to conduct fieldwork and recruit participants, I always introduced myself and the research, and made certain that my role as a researcher was clearly documented on an identification badge. I quickly learned that in this large medical center in which I carried myself with ease and comfort, no one looked to my badge or questioned either my identity or right to information. I

could move through the hospital and access information, from clinicians, secretarial staff, and security guards easily, if not invisibly. Hurried clinicians were less interested in detailed description of my research intent than they were to quickly offer me the information for which I asked. I also had access to multiple sources of publically displayed information about patients' injuries, whereabouts, and length of stay which likely would have been difficult to interpret as a researcher who had not spent lengthy immersion in the hospital environment. I also infer that White privilege played part in my access to the field. I physically resembled the predominately White clinical staff and it is likely that this offered the social advantages, benefits, and courtesies that accompany being part of the dominant racial group (Delago & Stefancic, 2001) at the top of the hierarchically-oriented structure of the medical center.

Abundant research documents the perception of racism and a mistrust of the health care system among Black patients in the United States (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Dovidio et al., 2008; Nicolaidis et al., 2010; Peek et al., 2010). I was initially concerned that being a healthcare provider would make it more difficult to recruit participants and establish trust in the context of the hospital. I informed patient participants that I was both a nurse and a researcher when I approached them to ask if they would permit observation of their hospitalization and embedded interviews. Contrary to my concern, being a nurse helped patients to accept my presence in the intimacy of their hospital rooms. During fieldwork, my nursing experience allowed me to sustain calm equanimity when witnessing participants' wounded bodies, expressions of pain, struggles with mobility, and emotional distress. Moreover, I was able to maintain conversation and attention despite beeping pumps, overhead pages, and other distracting

features of the hospital. Essentially, I could quiet the noise and influence of the clinical environment to facilitate observation and interpretation of some of the more subtle aspects of patients' experiences.

Another advantage of a clinical background was that I could more easily interpret what patients did and did not understand about their injuries, treatment, and recovery trajectory. Knowledge of the language and technical intricacies of acute medical care allowed me to understand how participants misunderstood or remained uninformed of the important aspects of care they received. This knowledge was useful in establishing trust with participants as well. On several occasions, participants asked me to explain what I had observed doctors or nurses telling them. I was also asked to interpret educational and informational documents on topics like prescribed medications that had been left for patients' review. In these cases I would refer patients back to their nurses and doctors but suggest specific questions that might help elicit the information they sought. The extent to which I was asked for interpretive services allowed me to understand the vulnerability and knowledge gaps that participants in this study felt in maintaining agency and control in the care that they accepted for treatment of their injuries.

When I interviewed nurses and physicians, even in brief conversations in the hospital hallways, the content of our dialogue demonstrated that they believed I shared an insider's knowledge of trauma care. Clinicians were open, causal and disciplinarily specific when offering their medical and social interpretations of participants' recoveries. A nurse who was exasperated with a participant, for example, described him to me as a "pain in the ass" for pulling out an IV and allowing the contents of medication to drip on

the floor of his hospital. I believe her candor was influenced by the extent to which she thought I could sympathize and relate to the cause of her frustration.

Making it better

When I planned for fieldwork, I thought that self-awareness and attention to my subjectivities would supersede the habitus I had developed as a nurse in a medical institution, such that I could learn to observe participants in the clinical environment without interfering or interceding in their experience. I learned my nursing habitus, inculcated through years of professional training and experience, was a durable disposition that structured and generated my way of being in clinical space (Bourdieu, 1977) in very particular interactions with participants. One of my earliest reflexive insights was that I was unconsciously compelled to ‘make things better’ when witnessing participants in severe pain or anxiety. To a certain extent, my experiences having witnessed patients endure extreme forms of pain and suffering as a nurse allowed me to maintain an outwardly calm posture. I was careful not to interfere with or advocate for pharmacological interventions. However, in the many circumstances when the pain medication did not meet participants’ pain needs, I would offer reassurance, sympathy, and relaxation instructions to help participants cope while I was conducting observations or interviews.

As I became aware of the way in which I felt compelled to soothe participants who appeared to be suffering, I also recognized that this nursing ‘impulse’ was part of how I established trust and rapport with participants. Ray for example, was a 41-year-old man who experienced an open fracture of his ankle after falling down stairs. His injury caused severe and persistent neurological pain for the majority of the time he was hospitalized.

When I would spend time with him Ray, he would often have to take breaks from our conversations to endure the “spikes” of pain that ran from his ankle up through his hip with severity sufficient to cause him to yell out or shake violently. I would suggest breathing and visualization techniques to help calm him. Once Ray knew that I could witness his pain and talk him through it, he began to open up more to me and share the details of what he considered to be his life’s “struggles.” The stories he shared included very sensitive and intimate details of his life like how he was abandoned by his parents, affiliation with a notorious Philadelphia gang, experiences of violent injuries, and what he endured during incarceration for a violent crime. He spoke in detail about how his current injury renewed his deep anxiety that he wouldn’t be able to provide sufficient income to support his family. Ray referred to our interviews as “helpful” and “therapy,” though he understood that my role was of a researcher and not a clinical care provider.

Supporting Taalib, a 42-year-old man who had experienced multiple gunshot wounds, through a painful experience was similarly instructive. Taalib and I developed a strong relationship over the course of a year, both in the hospital and at his outpatient clinic visits. On one visit to the outpatient clinic, Taalib was having his gastrostomy tube pulled out of his abdomen. In the outpatient clinic, clinicians did not have access to pain medication other than a local anesthetic and Taalib was terrified of feeling more pain. Though reassured by the surgeon that the removal of the tube would only take a moment, he began to cry and tense his body in fear. His girlfriend became too upset to witness the procedure. He looked desperately scared. I offered to hold his hand. After he agreed, I talked him through the procedure and rubbed his arm to soothe him as he wept for several minutes after the tube had been removed. This scenario was one in which I had

participated in many times in my clinical practice. As a researcher, it was beyond the bounds of how I had planned to participate in patient experiences.

My motivation for shifting from a visitor-participant to clinician-participant in these examples stemmed from both research interest and an empathetic imperative. I was able to provide something to Ray's and Taalib's experience that I might not have been able to as a non-clinician doing the same work. These moments in which my clinical instinct compelled me to "nurse" were also essential for helping me to understand the ways in which patients' needs were not being addressed. I learned that my nursing impulse, rather than being an impediment to understanding the field in its natural state, was like a miner's canary in its ability to signal parts of the clinical culture that were neglecting or even creating further injury to participants' recoveries.

The insights of mistrust and conflict

Fieldwork experiences in which it was difficult to establish trust and rapport with participants despite my clinical orientation were equally as instructive. I disrupted the tenuous trust that I had established with Brian, a 34 year old man with multiple gunshot wounds, when I was not thoughtful about how I applied my clinical knowledge to my actions as a researcher. Initially Brian was eager to participate in research and share the story of his injury and hospitalization. He told me that he liked being part of research and had participated in a study of his "childhood and lifestyle" several years prior when he was incarcerated. On the fourth day in which I would observe Brian's experience, I was able to interpret the hospital navigation board to know that he was due to be discharged home later that afternoon. I walked into Brian's room and casually noted that he would be going home. I didn't know that Brian was very angry about being discharged home,

rather than to a nursing home, which in his interpretation would provide the care he would need to contend with his injury. I also was unaware that his behavior was erratic and “confusing” to the nurses who had cared for him overnight. After I told Brian that I saw he would be going home, he told me he didn’t want to participate in an interview, turned his back, and immediately called a friend. As I attempted to find closure in the conversation, he referred to me on the phone as a “this White lady” that wouldn’t leave him alone and told me that I was making him angry.

I left Brian’s room feeling unsettled and regretful of the extent to which I realized he didn’t trust me or my intention as a researcher. This interaction yielded two important interpretations. First, clinicians doing research in a clinical environment need to be vigilantly conscious and thoughtful about how we communicate taken-for-granted clinical knowledge to patient participants. Second, my perceived race as a researcher had meaning for how Brian interpreted whether he should trust me and how I was aligned with the predominately White clinical staff by whom he felt disregarded.

Virginia, a 72-year-old woman who had suffered several fractures following a fall at church, similarly interpreted that I had a connection with her clinical care team and was therefore hesitant to trust me. Virginia had a complex medical history that included multiple hospitalizations in different Philadelphia medical centers. She consented to participation in the study but would share her interpretations of her interactions with clinical staff in hushed tones and when she felt assured that none of the hospital staff could hear her. After two days of observation and interview, she would only speak to me for brief periods of time and unlike her earlier interviews, would offer simple platitudes about her experience in the hospital. “I think they are upset that I am talking to you,” she

explained. At the time, I was frustrated and felt that I had failed to explain the intent of the research in sufficient detail to gain Virginia's trust. When I reflected on this experience, I recognized that I had interpreted the situation centered on my sense of rejection. When shifted perspective to what Virginia was telling me, I realized the importance of her interpretation that participation in research would threaten the care she received. Her belief that care was contingent on acquiescent and non-judgmental expressions of hospital care processes illustrated the vulnerability she felt in her agency and power as a patient in the hospital.

Following up

Of the twelve participants I enrolled in the study only three responded or could be contacted for interviews after they had been discharged from the hospital. Joe, a 46-year-old man who had a jaw and rib fractures from a boxing match, called to ask me to explain a message he had received from a nurse at an outpatient clinic. Among the medical discharge paperwork he had received, he could only find the informed consent document in which my phone number was listed. He was confused and frustrated when I told him that I couldn't help him make any arrangements with the hospital. Two weeks after this interaction, I called to see how Joe was recovering. Joe's phone number was disconnected and I never heard from him again. Albeit brief, this follow up allowed me to recognize that disorder and disenfranchisement that would influence Joe's trajectory for outpatient care and long-term recovery.

Taalib and Hakeem each made themselves available for interviews and observation after they had been discharged from the hospital. For both of these participants, being part of ethnographic research offered an opportunity for support and

disclosure of aspects of their injury experience that they did not want to share within their social and familial networks. Taalib called me to invite me to every outpatient visit that followed his hospitalization and continued to call me to discuss his recovery for almost two years. For Taalib, I was a witness and supportive presence throughout his recovery. Taalib introduced me to his girlfriend as his “news reporter.” He showed me on his phone that I was listed as “Nurse Sara.” He expressed how much it meant to him that I was always “there for him” and “listening.” Taalib felt shame about the way that his injuries had disabled him and changed his body, so much so that he preferred that friends and family not visit him in the hospital or see him during clinical visits. As a nurse and someone outside of his social support system, he felt that it was safe for me to see his injured body and witness the distress and fear that he felt around medical procedures and in the clinical environment.

Hakeem was a 25-year-old man who suffered a penetrating stab wound. After Hakeem was discharged from the hospital, he and I would meet near his workplace to discuss how he was recovering. For Hakeem, participating in research allowed him to describe some of the feelings that he had about his injury freely without maintaining the “always smiling” affect he believed his family and extended support system expected of him. Hakeem’s aunts and extended family had raised him after his mother had abandoned him and his father had been killed by a stab wound when Hakeem was young. Months after his hospitalization, Hakeem was haunted by the parallel he felt between his injury and the injury that killed his father. He was glad to have the opportunity to talk about the insomnia and repetitive thoughts that continued to impact his day-to-day life, even though he was back at work and outwardly “recovered” from his injury.

In data analysis

Analyzing the ethnographic data I collected during fieldwork offered different opportunities to practice reflexivity and contend with the ways that my subjectivities influenced this research. The advantage to the flexibility of ethnographic research is that I could learn about how hospitalization was experienced by participants from multiple vantage points and with extension into areas of life that might not have been reached had interviews or observation been more circumscribed. However, the data that emerged from each field experience differed in tone and content, which was a challenge to compare across time and participants. I also had very different relationships with each participant so the subjectivities that influenced my interpretation, also changed from day to day and person to person.

I chose to transcribe all of my recorded interviews and field notes personally as a first step in analysis in order to contend with the challenge of the volume and variability of the ethnographic data I collected. Close listening to the conversations and interpretations that emerged in early fieldwork allowed me to adjust the intent and construction of future interviews and observation to explore consistent or counterfactual content across participants' experiences. The process of listening to recorded interviews also helped me understand the tone and content through which I structured interactions with participants. I realized, for example, that silence seemed to make me nervous and would motivate a jump in topic whether or not a participant might have completed their line of thought. This was useful to encourage more mindfulness during future observation and interviews, to allow for silence to exist, unmitigated, and create the more space for in-depth and unexpected conversation to emerge.

I analyzed transcripts and field notes from the first few participants to reflect on the ways I established trust and rapport. I realized that I often used positive affirmation, like “of course” or “that’s understandable” to encourage participants to share their stories in more depth or detail. I also noticed that I often referred to the hospital’s clinical staff as ‘they,’ as in, “what did they tell you about your surgery?” to establish alignment with the patient perspective and distance myself from connection to the hospital staff. In later fieldwork, as I became more aware of my own way of being during fieldwork, I was able to maintain more self-consciousness in these areas. I tried to resist qualifying participant responses and deferred alignment or departure from other clinicians so that I could privilege how and what participants described and understood about their own experiences with hospital staff.

Reflexive practice was most important when I found that my analysis yielded a story that was not satisfactorily explained by my preconceived interpretations of race and trauma care and the critical theory from which I planned my research. This study was designed to explore race and racialization in trauma care processes. The experiences I interpreted offered a much more nuanced story about what it is like to be Black and injured in a Philadelphia hospital. The way that patients understood their injury and experience with hospital staff was informed by their complex life-worlds. These life-worlds included their race but were also influenced by previous injuries, poverty, residence in segregated communities with high levels of violence exposure, and persistent psychological and emotional distress. To some extent patient-clinician interactions in the hospital environment demonstrated race consciousness. However, interactions seemed similarly influenced by the dehumanized and disembodied way that trauma care

processes were applied and evaluated as a matter of clinical and institutional habit. The patient's life world, beyond their physical body, was rarely the object of attention from clinicians and other hospital staff, leaving recovery from the many psychological and social consequences of a traumatic injury, only partially addressed.

Discussion and Implications

Reflexive insights guided the design, data collection, analysis and interpretation of this research to explore the experience of Black traumatically injured patients within the clinical culture of trauma care in Philadelphia. These insights were as important as any observational and interview data I collected. In keeping with the critical foundations of my ethnographic inquiry, I recognize I, with all of my subjectivities, co-created the story that I tell about experiences of the Black injured people and the clinicians who care for them. Our co-creation is a dialogue of my subjectivities with subjectivities of my participants. The process of that co-creation is a relationship and a discourse that generates the “cooperative and collaborative nature of the ethnographic situation (Tyler, 1986).”

Being a clinical insider was one form of subjectivity that I brought to this ethnographic research. Rather than attempt to separate my clinically informed interpretations in memos, I allowed my nursing-informed observations and inferences to be part of the ethnographic record as data. I took notes on what captured my attention both from what participants expressed to me and what I saw during observation of a clinical environment with which I was familiar. I learned that these clinically informed interpretations could only have emerged in my position as a researcher. The time and tempo afforded by the ethnographic research process allowed me to see patients,

clinicians, and hospital environment in new ways. For example, as a nurse with a defined set of daily and normative tasks, I had never noticed the extent to which patients are left alone and isolated in their hospital rooms. Conducting this research then prompted me to ask patients to describe how their injury and hospitalization made them feel about themselves and the extent to which they felt marginalized or supported during trauma care processes. I also came to understand that in such a deliberate and careful examination of patient experience, my clinical instincts were not a barrier to understanding how patients felt. Rather they served to signal particularistic critique of the way that trauma care in the urban environment is currently enacted.

The learning curve of reflexive practice in ethnographic research is in and of itself an extra data set and, in a way, a secondary inquiry (Hess, 2009). It creates the opportunity to understand positionality and subjectivity, not as a static state of being, but as an evolving field of influence on research and its products. With careful attention to subjectivity at each phase of research, the specificity and consciousness with which data is collected and understood can be used to explore emergent analytic insights.

Reflexive practice is also important as a source of motivation when contending with the practical and epistemological differences that divide clinical ethnographic research necessarily completed in the biomedical context, from ethnographic methods and an Anthropologic tradition in which it is rooted. Many clinical ethnographies completed by nurses do not afford sufficient time and resources to create a robust and reflexive ethnographic recording of the inquiry. As in other qualitative inquiries, there are also challenges to aligning the practical and ethical framing of research with the standards of human subject protection as interpreted by biomedically oriented

Institutional Review Boards (IRBs) (Opsal et al., 2015) . For example, I had to assure participants that that my intent was to ‘simply spend time talking to them and observe their experience in the hospital’ after reviewing with them a six page IRB document including that they would be subject to the risks of participation and receive “no benefit.” Finally, the small sample sizes, concerns over lack of generalizability and use of interpretive analytic techniques similarly fall beyond the bounds of what many in clinical disciplines label science.

Interdisciplinary clinically relevant applied interpretations of critical anthropologic work nonetheless hold important advantages for improving clinical care, nursing practice, and patient experience (Messac, Ciccarone, Draine, & Bourgois, 2013; Hopper, 2013). Such work often privileges problems in institutional and public healthcare that might otherwise be overlooked or considered unmeasurable using the tools and gaze of quantitative sciences grounded in apolitical empiricism. Reflexivity reminds us to value that feeling that something is not humane in a clinical situation, the knowledge inherent in an unconscious drive to ‘nurse’ and intercede on someone else’s behalf, and the ways that those tugs of consciousness have a story to tell.

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CHAPTER 5

Discussion

The goals of this study were to explore the experience of Black injured patients in a major Trauma Center in Philadelphia from their point of view. Interest in this area of inquiry developed when I worked as a trauma nurse in one of Philadelphia's busiest Trauma Centers. The time I spent as a clinician in this setting led me to believe that there were institutional and cultural processes that challenged the healing and handling of Black trauma patients, such as biased enforcement of visiting hours and avoidance of Black patients with violent injuries. I also felt that my colleagues, a group of predominately White clinicians, did not recognize the extent of the race consciousness that influenced their interactions with Black patients or privilege that distanced them from the complexity of the lives, homes, and neighborhoods in which many patients were injured. With these subjectivities in mind, this inquiry was designed using Critical Race Theory (CRT) to guide how and among whom I would study the place of race in Trauma Care in Philadelphia. This transdisciplinary social theory contends that race consciousness and racial biases, whether overt, disavowed or unconscious, are part of the cultural fabric of US society and social institutions, and influence the experience of people of color in their everyday experiences (Delago & Stefancic, 2001; Ford & Airhihenbuwa, 2010a; Ford & Airhihenbuwa, 2010b).

Epidemiologic studies illustrate that Black injured patients, as a population, are more vulnerable to outcome disparities during hospitalization despite structural and legislative protections (Arthur et al., 2008; Arthur, Hedges, Newgard, Diggs, & Mullins, 2008; Crompton et al., 2010; Haider et al., 2008; Marquez de la Plata et al., 2007; Shafi

et al., 2007). Yet, the voice and perspective of Black trauma patients are not well represented, even within naturalistic inquiries on Black patients' experiences in hospitals. The few naturalistic studies that are published in this domain focus solely on Black men with injuries incurred from acts of violence due to gunshot wounds and other forms of assault (Lee, 2012; Liebschutz et al., 2010; Rich, 2009; Rich, 2009). These studies provide an important perspective but do not elucidate the influence of race consciousness on the practice and processes that shape experience of all Black trauma patients, regardless of gender or mechanism of injury.

In the biomedical paradigm, patient satisfaction surveys and retrospective interviews are traditional methodological approaches to study how patients perceive hospitalization and healthcare encounters. The application of these methods to examine the influence of race and other socially constructed identities on trauma care processes is limiting. These methods cannot capture subtleties in patient-clinician interactions. They also overlook the way that perceptions of medical and nursing processes are constituted by the structural and institutional culture in which they occur. Results can spuriously create the illusion of non-racialization in healthcare interactions when analyses do not yield findings that are overtly and demonstratively racist or discriminatory (Johnstone & Kanitsaki, 2009).

Critical ethnography is an interpretive methodology that can be used to explore of racialization in trauma care in its naturalistic setting. This method uses traditional ethnographic techniques from Anthropology and Sociology, emphasizing the study of forms of cultural power in the experience of socially marginalized participants (Cook, 2005; Soyini, 2011) through observation, interviews, and analysis of interactions in the

setting in which they naturally occur. Critical ethnography is also self-reflexive and well suited to the study of clinical culture and disciplinary norms; it provides an analysis of the clinical environment to generate, “narratives and scenarios to refocus our attention, which make us visible to ourselves by representing us and everyone as cast into the midst of a world full of irremovable strangeness’s we can’t keep clear of (Geertz, 1990, pg.190).”

My intent in conducting a critical ethnographic study of trauma care in Philadelphia was to contextualize some of the etiologic factors that perpetuate inequities in injury recovery among Black injured patients. Each of the papers in this dissertation is a different part of the interpretive analysis of the field data I collected. In Chapter 2 (Paper 1) I explored how Black trauma patients who participated in this inquiry perceived their early injury experiences, interpreted their physical and psychosocial responses to injury during hospitalization and understood what being injured meant in the context of their complex life worlds. In Chapter 3 (Paper 2) I illustrated how the social and structural context of hospital, influenced by the racial, economic, and political dynamics of the city-at-large and the clinical culture, shape the experience of Black injured participants. Specifically, this paper explored how race and other social constructions like assumptions about criminality and deviance play out in the cultural milieu of hospital-based injury care. This paper includes perspective from both patients and their clinicians and critical interpretation of the culture in which their interactions occur. Chapter 4 (Paper 3) is a methodology discussion paper in which I explored the processes through which I learned the insights and challenges of reflexive practice in conceiving, engaging, and analyzing a study of patient experience using ethnographic methods. I

describe the ways in which I attended to my subjectivities and clinical assumptions as a novice researcher who was both an insider and outsider to the clinical environment and among the participants with whom I co-created this research.

This inquiry was centered on race and race consciousness. However, when I analyzed how participants experienced their injuries, understood hospitalizations, interpreted the clinical environment, and situated these findings in light of clinicians' perspectives, I recognized a more nuanced story. Both patients and clinicians alluded to race as a factor in the quality of interactions that occurred during hospitalization. However, participants also interpreted their injuries and hospitalizations through other factors in their life-world including: economic insecurity, residence in violent neighborhoods, histories of previous injuries, incarceration experiences, and disenfranchisement from the healthcare system at large. Most participants lacked health insurance and if they did seek healthcare services it was in the city's public health centers or hospital EDs. Disenfranchisement made being in the hospital for the treatment of injury feel exceptionally vulnerable and isolating. It was difficult for participants to decide whom to trust in the context of changing hospital settings and different care providers. Most participants did not have a clear understanding of the specifics of their injuries, their course of treatment, and expectations for the long term consequences of their injuries. Many participants also demonstrated psychological suffering from their injuries like nightmares, paranoid thoughts, and depressive symptoms. Observation of clinical care and perspective from participant interviews did not yield evidence that their psychological and emotional suffering was ever subject to a formal or structured response by their clinical providers during in their recovery process.

Fieldwork offered new insights into a clinical environment with which I was familiar. From my observations, I interpret that trauma care is provided within an institutional context that makes patients' lived experiences, and consequently their humanity, very difficult to recognize. Care at the Trauma Center focused almost entirely on the physical aspects of injury, to the exclusion of the psychological, emotional and social ways that injuries cause suffering, and relied heavily on a siloed, task-orientation through which to deliver medical and nursing care. Patients were divided from clinical staff and all others in hospital through physical partitions and policies that limit movement outside of circumspect 'patient care' areas in the name of safety. The common spaces of the Trauma Units, like the hallways, included the ubiquitous presence of police and prison guards which added a carceral quality to the institutional feeling of the inpatient environment. In the relatively infrequent opportunities during which patients could communicate with their nurses and physicians, the focus of conversation was often clinical and complicated by medical jargon and technological language. Participants described how this made them confused, resentful and unequipped to ask questions or assume greater control of the care they received.

For some of the clinicians included in this study, their regular interactions with Black patients with violent injuries, police presence in the inpatient environment and a clinical culture that focused on patients' physical bodies, reinforced racialized stereotypes that conflated being Black, young, and male with criminality and deviance. Even during recruitment for this study, it became clear that Black men with gunshot injuries were emblematic of the Black trauma patient population. This characterization was tied into a stereotype that "these guys" were culpable in becoming injured and somehow less worthy

of empathy. Participants with gunshot injuries in particular, were sensitive to this characterization and it deepened the vulnerability they described when seeking care and comfort in the hospital. These characterizations dehumanize patients on two levels. Black men are subject the historical stereotypes of their race and gender; positioning them as racial others who are “impulsive and prone to criminality and can tolerate unusual amounts of pain (Haslam, 2006).” At the same time, all patients are subject to modern medical care, which in and of itself neglect patients’ individuality, “with its lack of personal care and emotional support, its reliance on technology; its lack of touch and human warmth; and its emphasis on instrumental efficiency and standardization (Haslam, 2006).”

As descriptive and interpretive research, extrapolating findings to make recommendations for direct clinical applications, such as training goals or directed protocols, would be atheoretical and reductionist. Nonetheless, I am compelled to highlight the importance of providing a platform from which socially marginalized patients can speak about their lives and experience. Many participants described the therapeutic quality of participating in this inquiry as an opportunity to share their story. The stories they shared began with descriptions of their injury or hospitalization but often shifted toward some other part of their life in a narrative that began with their childhood and extended through their contemporary lives in Philadelphia.

Participants described the opportunity to share these aspects of their lives as “like therapy.” As a researcher, embodying the role of witness and listener, allowed participants to trust me with intimate details of their lives. I also contend that sharing their story offered the opportunity to be seen or known as a complex and historied human

being in the context of the isolation and coldness of the clinical environment. It countered the ways they felt dehumanized and offered recognition of the vulnerability and fears they held about the impact of injuries on their lives and livelihoods. If patients don't feel seen or understood as people, why would they trust clinicians' recommendations, follow-up at outpatient visits to prevent re-injury and complications, or invest time to seek a meaningful relationship with the healthcare system at large?

Making space for patients to tell their story in a complex clinical culture like a Philadelphia Trauma Center, offers a counter-narrative the stigma of deviance and guilt too frequently attached to Black injured patients, in particular Black men with violent injuries. I describe the participants in this inquiry as I came to know them, not as patients but as children, fathers, mothers, and people in loving relationships. I explore the way that participants were not simply hardened to the segregation, poverty, and violence of their neighborhoods, but rather felt brutalized and victim to the environment in which they were injured and to which they returned. Their perspective also illustrated that the 'hospital' was not viewed a singular institutional reality. Participants evaluated clinical space and interactions with individual clinicians with sensitivity and distinction.

Patients' nuanced view of clinical space and interactions can be used to generate ideas for restorative places and practices in trauma care. The hospital environment, in general, often includes noise, lack of privacy, and interactions with clinicians who fail to identify themselves. This intensifies the stress and vulnerability of ill and injured patients during hospitalization (Detsky & Krumholz, 2014). The physical dilapidation and outmoded design features of the Trauma Center added to these traumatizing features of hospitalization and contributed to participants' sense of isolation, invisibility, and

vulnerability. As in previous research on the experience of Black trauma patients in the hospital (Liebschutz et al., 2010), institutional permission granted to police officers and prison guards to be present in common space on the trauma care units and during emergency medical care in the ED imbued the units with a carceral tone and made participants feel like their health and wellbeing was secondary to the priorities of the criminal justice system. Finally, the way that nurses and physicians spoke to and touched participants imparted either inattention or empathy. Other research has highlighted the importance of communication behaviors and staff conduct as foundational to the preservation of patient dignity (Manookian, Cheraghi, & Nasrabadi, 2014). These aspects of clinical culture are all amenable to re-invention.

Just as the thematic content of the analysis of this ethnographic study must be interpreted in light of its inherent limitations, so too must any practical and policy oriented recommendations. The narratives of the twelve participants in this inquiry generate attention to factors that shaped their experience of hospitalization and recovery. These perspectives are not generalizable to all Black trauma patients that entered this Trauma Center for treatment. Nor can participants' stories elucidate care in the clinical culture at other Philadelphia hospitals or medical centers in other urban US settings. Patients who were admitted to the hospital had more serious injuries than those discharged directly from the ED. Observing patients with more serious injuries was important in understanding the range of patient-clinical interactions in the hospital, but only captures more acute end of the continuum of injury care. While this inquiry included patients across the age spectrum, perspective of men with violent injuries made up the

majority of participants, and different stories and interpretations might be generated from ethnographic research with additional patients with non-violent injuries and women.

This inquiry leads to several areas for future research. The voices of young Black women with violent injuries, who were difficult to recruit, are conspicuously absent and are important to represent. Participants describe that pre-hospital interactions and ED care were meaningful in their interpretations of their injuries, but this perspective was filtered through partial and chaotic memory of the events that immediately followed becoming injured. Inquiry that examines the impact of place and interactions on the ‘street’ and in the ED trauma bay, could offer a better description of how early and emergency care influences patient experience. The presence of police as first responders and throughout the Trauma Center changed the way that participants with violent injuries understood their power and personhood. Study of how the presence of police and prison guards shapes hospital care and patient-clinician interactions would offer needed exploration of the relationship and potential contradictions of law enforcement and medical care in injury treatment experiences.

Finally, from a health service and social medicine perspective, it of interest to consider the consequences of healthcare disenfranchisement in predominantly Black, economically marginalized neighborhoods in Philadelphia to understand its impact on the use and perception of emergency injury treatment or conversely how better linkages with a primary healthcare system and the protections of health insurance create different realities in the context of injury care. It will also be interesting examine whether the Patient Protection and Affordable Care Act (PPACA) which has the intent of extending insurance coverage and access to health services to underserved populations

(Rosenbaum, 2011), changes the healthcare experience of traumatically injured patients before they are injured and after they are discharged from hospital-based care.

This research demonstrates the complexity of the social, political, and economic realities, which create the conditions in which racialized health outcome inequities are perpetuated. While the findings of this inquiry do not offer explanation for disparate outcomes in injury mortality, they do illustrate the inextricability of the socio-structural context of urban life in Philadelphia and clinical care in a Trauma Center in the city. In this complexity, it is difficult to concretize or strategize the most effective ways to build racial equity in injury recovery. Perhaps we must continue to generate a close and critical description of our clinical culture, by “looking internally at our institutional structures” (Bassett, 2015, pg. 2) and the social conditions that bring patients to the ED door. A healthcare system that is just and openly contends with race and our intersecting identity politics in the healthcare encounter requires us, as Anthropologist John Jackson writes about U.S. society overall, “to accept our fates as vulnerable observers, realizing our collective future depends on mutual trust and recognition (Jackson, 2008, pg. 211).”

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APPENDICES

APPENDIX A

Patient participant Information Tool

Name:

Address:

Phone number:

Alternate contact:

Phone number:

Age:

Race:

Gender:

Injury:

Place in hospital at point of recruitment:

Phenotypic impression:

Pseudonym:

APPENDIX B

Title of the Research Study: The Experiences of Black Trauma Patients
Protocol Number: 816540
Principal Investigator: Sara Jacoby, Claire Fagin Hall, 418 Curie Blvd., Rm. 327B, Philadelphia, PA, 19146. PHONE: (215) 573-4729. EMAIL: sfjacoby@nursing.upenn.edu
Faculty Advisor: Dr. Therese Richmond, Claire Fagin Hall, Rm. 330, 418 Curie Blvd., Philadelphia, PA 19146, (215) 573- 7646, terryr@nursing.upenn.edu
Emergency Contact: Sara Jacoby, (215) 573-4729

You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. I am going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends and family.

If you do not understand what you are reading, do not sign it. Please ask me to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form. It has contact information and answers to questions about the study. You may ask to have this form read to you.

What is the purpose of the study?

The purpose of the study is to understand what it is like for you to be in the hospital for your injury. The purpose is to understand your experiences with hospital staff you meet during your time in the hospital. This study is being conducted to complete a PhD at the University of Pennsylvania School of Nursing.

Why was I asked to participate in the study?

You are being asked to join this study because you are being treated for an injury. You will help us better understand what it is like to be an injured adult of color treated in the hospital.

How long will I be in the study? How many other people will be in the study?

The study will take place over one year. You are asked to be in this study during your time in the hospital. You may also be asked for an interview after you return home. In this study, your hospital care will be observed. Each observation will last about 2- 6 hours. You will also be asked about your thoughts and feelings at different times in the hospital. Interviews may be part of the observation sessions or at other mutually agreeable times. Interviews will last from 5 minutes to 1 hour. The interview may be recorded using a digital audio recorder. All audio recordings and documents of transcriptions will be stored in a locked cabinet at the University of Pennsylvania School of Nursing. When the study ends these documents and recordings will be stored safely for five years and then destroyed.

You will be one of approximately 30 people in the study.

Where will the study take place?

This study will take place in the hospital. This can include your patient room, places where you go for procedures, the clinic, or anywhere else in the hospital that you spend time in during your stay. You may be also be contacted for an interview after you leave the hospital. This interview can be over the telephone or at a place that is convenient for you.

What will I be asked to do?

You are being asked to allow observation of the care you receive in the hospital. Observation will take place only when you are comfortable with my presence. Observation can be ended your request. You also will be asked questions about your time in the hospital and how feel being a patient.

What are the risks?

Talking about your thoughts and feeling may be difficult or embarrassing. You may feel that by talking about your care, the people who are caring for you will not treat you the same as if you were not in the study. You may also feel that your privacy is at risk by observation and interview.

Observing and asking you about your time in the hospital is your choice. At any point you can ask me to leave your room or end the interview. You can chose to answer or not answer any specific question. Anything you tell me will be confidential. There will be one password-protected file on a secure computer that links your name, telephone number and address with a made-up name. Your name or anything that identifies you in research documents will be replaced with made-up information. What you talk about or allow me to observe will not be discussed or brought to the attention of the hospital staff unless you ask me to. All of your personal information will be available only to the research personnel on this document and the IRB of the University of Pennsylvania and it will be destroyed after the study has ended.

How will I benefit from the study?

There is no benefit to you. Your participation could help us understand how patients of color experience their hospital care. In the future, this may help hospital staff provide better care for patients.

What other choices do I have?

Your option to being in the study is to not be in the study.

What happens if I do not choose to join the research study?

There is no penalty if you choose not to be in the research study. You will not lose benefits or advantages that are now coming to you, or would come to you in the future. Your nurse or doctor will not be upset with your decision not to be in the study.

When is the study over? Can I leave the study before it ends?

The study ends after all participants have been observed and interviewed and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI thinks it is best for your safety and/or health and you will be informed of the reasons why.
- The PI, the sponsor or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime.

You have the right to drop out of the research study at anytime. There is no penalty or loss of benefits if you decide to drop out. Your choice will not interfere with your future care.

If you no longer wish to be in the research study, please contact me, at (215) 573-4729 or speak to me when you see me in-person and take the following steps:

- Ask me to end observation and interviews and end your participation in the study.

How will confidentiality be maintained and my privacy be protected?

We will do our best to make sure that the personal information collected during the course of this research study is kept private. However, we cannot guarantee total privacy. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used unless you

specifically ask to be identified. For example, if your name is David Johnson, you would be called a name like Jon Washington in all study documents.

Electronic Medical Records and Research Results

Your experiences in the hospital are the focus of the study. It does not require that researchers have access to any of your medical records in the hospital or elsewhere. You or your doctor or nurse may talk about the reasons you are in the hospital or about your injury or medical condition. Researchers will not look up this information in electronic or paper medical record.

What information about me may be collected, used or shared with others?

To maintain contact with you I will ask that you give me the following personal information:

- Your name, address, telephone number, and email

To understand why you are in the hospital I may ask you to tell me about the reason for your hospitalization and about your past medical history.

I am observing your care and may interview the clinicians taking care of you, I may ask or overhear information about your medical condition in the hospital, results from exams, tests, or procedures and your past medical history.

Why is my information being used?

Your information is used by the research team to contact you during the study. Your information and results of tests and procedures that are heard during observation experiences will allow us to understand the medical reasons that you are in the hospital and to better understand your recovery process. No one from the research will look up your medical information in any electronic or paper medical chart.

Who may use and share information about me?

Sara Jacoby (the PI) and her faculty advisor (Dr. Therese Richmond) at the University of Pennsylvania School of Nursing are the only individuals who may use your information.

Who, outside of the School of Nursing, might receive my information?

Any information that can identify you (name, address, phone number, email) will be protected by the PI and her faculty advisor. Once any identifying information is changed to protect your identity, details about your medical history and hospital experience may be shared with other researchers who are helping to develop and support this research.

How long may the School of Nursing use my personal health information?

Your authorization for use of your personal health information for this specific study does not expire.

Your information may be held in a research database. However, the School of Nursing may not re-use or re-disclose information collected in this study for a purpose other than this study unless:

You have given written authorization

The University of Pennsylvania's Institutional Review Board grants permission

As permitted by law

Can I change my mind about giving permission for use of my information?

Yes. You may withdraw or take away your permission to use and disclose your health information at any time. You do this by sending written notice or calling the investigator for the study.

Will I have to pay for anything?

There is no cost associated with participating in this study.

Will I be paid for being in this study?

There is no payment for being in this study.

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns or complaints about your participation in this research study or if you have any questions about your rights as a research subject, you should speak with Sara Jacoby, the PI, who's contact information is listed on page one of this form. If she cannot be reached or you want to talk to someone other than someone working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

When you sign this document, you are agreeing to take part in this research study and are providing Research Subject HIPAA Authorization. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Signature of Subject

Print Name of Subject

Date

APPENDIX C

Interview Questions- Patient

Initial introduction: I'd like to thank you for agreeing to speak with me about your experiences during your hospital stay. I am interested in understanding how you feel about your time in the hospital and your interactions with hospital personnel. Everything you say will be confidential. Answering questions is strictly voluntary and will have no impact on the care you are receiving. If at any point, you do not want to be interviewed or answer any specific question, you may stop the interview or ask that any question be skipped. The overall goal is to hear your thoughts about your experience in the hospital after being injured. I may take notes during the interview, but your responses will not be associated with your name or any other identifying information. May I answer any questions before we begin?

Note: The following are components of interview that will be embedded in participant observation, at times that directed reflection on observed interactions are necessary additional open-ended questions and probes may be required.

In the Trauma Units

1. What is it like being injured?
2. What about being in the hospital, was it that like?
3. What have your interactions with the health care providers, like nurses and doctors been like?
(Probe)
 - a. Regarding pain?
 - b. Regarding your injuries?
 - c. Regarding the tests and treatments you are receiving?
 - d. Regarding the next steps in your hospitalization?
4. How has it been being cared for by other hospital staff, other than physicians and nurses?
5. In what ways do you think that being injured will change your life?
 - a. Why?
 - b. What about being in the hospital, can you describe any concerns that have come up for you?

In the Trauma Outpatient Clinic

1. Looking back, what was your time in the hospital like?
2. What was it like going home?
3. Is there anything else about your time in the hospital you think about since you have been home?
4. How has being injured affected your day-to-day life?

APPENDIX D

Interview Questions- Clinician

Initial introduction: I'd like to thank you for agreeing to speak with me about your experiences caring for Mr./Ms. X. Everything you say will be confidential and confidential. You will never be identified beyond your role and level of experience in patient care in any product of this research. If at any point, you do not want to be interviewed or answer any specific question, you may stop the interview or ask that any question be skipped. The overall goal is to hear your thoughts about caring for Mr./Ms. X after their injured. I may take notes during the interview, but your responses will not be associated with your name or any other identifying information. May I answer any questions before we begin?

Note: The following are components of interview that will be embedded in participant observation, at times that directed reflection on observed interactions are necessary additional open-ended questions and probes may be required.

1. Describe your experience caring for Mr. /Ms. X.
2. Is this similar to your experiences taking care of other patients with the same kind of injury? How?
3. Can you describe any particular challenges clinically or personally in this particular case?
4. What challenges do you think that Mr./Ms. X will experience?
 - a. In what ways did you address these challenges?
 - i. Can you describe any barriers/facilitators in addressing these issues?
5. What do you think the rest of Mr. /Ms. X recovery will be like?
6. When you are treating Mr./Ms. X do you ever think about who he/she is, the way he/she lives, works, or behaved, before the injury? Describe this to me.
7. How did you feel you communicated with Mr. /Ms.?
8. Was there anything unique about caring for Mr. /Ms. X?

APPENDIX E

CODEBOOK

Theme/Category	Description
Recalling the injury and hospitalization experience	
<ul style="list-style-type: none"> Recalling being injured 	<p>Recounted stories of the moment of injury, the circumstances surrounding the injuring event, what happened just before and just after injury, what the injury felt like, thoughts at the time of injury</p>
<ul style="list-style-type: none"> Recalling pre-hospital police interactions 	<p>Recollections of interactions and exchanges with police officers outside of the hospital, recollections of police actions as first responders</p>
<ul style="list-style-type: none"> Recalling pre-hospital EMS interactions 	<p>Recollections of interactions and exchanges with Emergency Medical Service personnel at the scene of injury and in ambulance on route to hospital</p>
<ul style="list-style-type: none"> Recalling hospitalization, trauma bay 	<p>Recollections of experience in the trauma bay, interactions with healthcare staff and police officers, the somatic experience of trauma bay care, thoughts and emotions surrounding procedures, witnessing other patient's treatment</p>
<ul style="list-style-type: none"> Recalling hospitalization, ICU 	<p>Recollections of care and interactions in the ICU setting, interactions with healthcare staff, interactions with family and friends</p>
What it feels like to be in the hospital	
<ul style="list-style-type: none"> Enduring passively-Resisting actively 	<p>Expressions and demonstration of compliance, acquiescence, and acceptance of the course of care and clinical advisement OR expressions and demonstration of resistance to, disagreement with, or resentment from course of care and clinical advisement</p>
<ul style="list-style-type: none"> Separation and Surrounding 	<p>Expressions and observations of separation and isolation from clinical staff and/or social support network OR expressions and observations of presence and integration with clinical staff and/or social support network</p>
<ul style="list-style-type: none"> Trust and mistrust of clinicians 	<p>Expressions and demonstrations of trust OR mistrust of clinical staff</p>
<ul style="list-style-type: none"> Understanding respect and disrespect 	<p>How respect OR disrespect is interpreted</p>

Theme/Category	Description
	or perceived
<ul style="list-style-type: none"> • Confinement and Freedom 	Expressions of feelings of confinement and imprisonment OR expression of feeling of freedom and actions of free movement in clinical space
<ul style="list-style-type: none"> • General Perceptions of healthcare staff 	General and summary perceptions of healthcare staff, reflections on role performance and differentiation of staff hierarchy
<ul style="list-style-type: none"> • General feelings about the hospital 	General and summary perceptions of the hospital as an entity or structure
<ul style="list-style-type: none"> • Undergoing procedures 	Reflections on the experience of undergoing procedures
The physical experience	
<ul style="list-style-type: none"> • My body in the hospital 	Expressions and self-observations of bodily sensation and perception during hospitalization, bodily changes, the physicality of injury, embodiment of injury
<ul style="list-style-type: none"> • Pain <ul style="list-style-type: none"> ○ Pain Medication 	Expressions and observations of bodily pain -expressions and observations of the use, acceptance, and action of pain medication, responses to change in pain medication, dialogue with healthcare staff about pain medication
<ul style="list-style-type: none"> • Hunger 	Expressions of hunger or lack of appetite, desire to eat
The psychological experience	
<ul style="list-style-type: none"> • My mind in the hospital 	Preoccupying thoughts during hospitalization, how patients are perceiving their own thinking
<ul style="list-style-type: none"> • Sleep 	Expressions and recollections of sleep, dreams, sleeplessness, waking from sleep
<ul style="list-style-type: none"> • Shame 	Expressions of shame and embarrassment over physical body, physical limitations, role performance deficits and emotional responses
<ul style="list-style-type: none"> • Thoughts of death and dying 	Thoughts of death and dying while hospitalized
<ul style="list-style-type: none"> • Staff responses to psychological symptoms 	Staff perceptive or reactions to patient's expressions of grief, anticipation of pain, worry, thoughts of persecution, recurrent preoccupation with particular bodily

Theme/Category	Description
	sensations
<ul style="list-style-type: none"> Family and friend responses to psych symptoms 	Expressions and observations of patient's friends and family responding to expressions of grief, distress. anticipation of pain, worry, thoughts of persecution, or change in personality
<ul style="list-style-type: none"> Thoughts of loss 	Thoughts about loss of structure or function of body, relationships, roles and capabilities
<ul style="list-style-type: none"> Financial Concerns 	Expressions of worry or concern over the financial consequences of injury or hospitalization
My life story	
<ul style="list-style-type: none"> The story 	Summary statements through which patients describe themselves and their lives
<ul style="list-style-type: none"> Who I am <ul style="list-style-type: none"> Past injuries What's important to me Violent injuries that have touched my life 	Statements of "I am" -Stories of being injured, hospitalized, or disabled -Statements of what I live for, inspirations -Stories of witnessing or being impacted by violent injuries, peers and family members
<ul style="list-style-type: none"> Where I live 	Descriptions of home and neighborhood, expressions of what it is like living in their community, what others are like around them
<ul style="list-style-type: none"> My work and employment history 	Descriptions of work and employment history and embodiment
How I think I'm seen	
<ul style="list-style-type: none"> They think 	Statements and expressions of how patients believe they are regarded or understood by hospital staff
<ul style="list-style-type: none"> Double consciousness 	Du Bois: "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"
<ul style="list-style-type: none"> Insurance status 	Statements about insurance or the impact of their insurance on their care or hospitalization
Integrating into a life story	
<ul style="list-style-type: none"> Why this happened 	Thoughts and reflections on the meaning or cause of injury and hospitalization

Theme/Category	Description
<ul style="list-style-type: none"> • How this will change me <ul style="list-style-type: none"> ○ ○ ○ Need to be more vigilant ○ ○ ○ Learning new things 	<p>Statements and expressions of how patients believe this injury will change their lives, behavior, or intentions</p> <p>-Statements regarding need for increased vigilance against violence and persecution in the hospital and after discharge.</p> <p>-Statements about the educational or directional consequence of injury</p>
<ul style="list-style-type: none"> • Friend and family perspectives 	<p>Statements from friends, family members, and visitors about how the injury should be or will be integrated in the patient's life course</p>
Leaving the hospital	
<ul style="list-style-type: none"> • Thinking about home 	<p>Expressions and statements anticipating what recovery at home will be like, things that are missed</p>
<ul style="list-style-type: none"> • Thoughts on life after injury 	<p>Statements about how patients envision their life after injury, anticipated changes in life after injury, concern about possible long term changes after injury</p>
Life after hospitalization	
<ul style="list-style-type: none"> • Physical changes 	<p>Expressions or observations of physical changes that persist or evolve after discharge from hospital, changes in physicality or function, retained bullets</p>
<ul style="list-style-type: none"> • Psychological and emotional changes 	<p>Expressions or observation of psychological or emotional changes since hospitalization</p>
<ul style="list-style-type: none"> • Pain that continues 	<p>Expressions of persistent pain, long term use of pain medication</p>
<ul style="list-style-type: none"> • Daily life and recovery 	<p>Statements of daily life and social life during recovery after hospitalization</p>
<ul style="list-style-type: none"> • The outpatient clinic <ul style="list-style-type: none"> ○ Communication about clinical plans ○ Procedures 	<p>Observations and reflections on the communication of future clinical plans between patients and clinicians</p> <p>Observations and reflections on procedures that occur in the outpatient clinic</p>
<ul style="list-style-type: none"> • Readmissions 	<p>Reflections on hospital readmissions that occurred after initial discharge</p>
Police interactions in the hospital	
<ul style="list-style-type: none"> • Interrogations 	<p>Recollections of interactions and</p>

Theme/Category	Description
	interrogation by police officers in trauma bay, ICU, and trauma unit, quality and content of interaction, feelings about police in the hospital
<ul style="list-style-type: none"> Clinicians perspectives on police 	Clinicians recollections of interactions with police and prison guards, and the role of these individuals in the hospital
Nurse's Viewpoints	
<ul style="list-style-type: none"> Perceptions of patient participants 	Expressions of how nurse's view patient participants- their character, summary statements, how the injury/illness is understood, progress towards discharge
<ul style="list-style-type: none"> Perceptions of interactions- patients 	Expressions of how nurse's view particular interactions with patient participants
<ul style="list-style-type: none"> Perceptions of interactions- families and other visitors 	Expressions of how nurse's view particular interactions with patient participants' visitors
<ul style="list-style-type: none"> Perceptions of themselves 	Expressions how nurse's perceive themselves as care providers
<ul style="list-style-type: none"> Perceptions of critical events 	Perceptions of events in the hospital in which patient had a major change in their wellbeing
<ul style="list-style-type: none"> Perceptions of other clinicians 	Perceptions of other nurses, physicians, physical therapists, or nursing assistants
<ul style="list-style-type: none"> Perceptions of Black trauma patients in general 	Generalized views expressed about Black trauma patients with whom nurses work
Physician and NP viewpoints	
<ul style="list-style-type: none"> Perceptions of patient participants 	Expressions of how physicians and NPs view and describe patient participants- their character, summary statements, how the injury/illness is understood, progress towards discharge
<ul style="list-style-type: none"> Perceptions of procedures 	Perceptions of procedures ordered for or used to intervene on the impact of patient's injury on their health
Description of Patients	
<ul style="list-style-type: none"> Physical description <ul style="list-style-type: none"> Changes after hospital discharge 	SJ's descriptions of the physical appearance of patient participants
Descriptions of clinical space	
<ul style="list-style-type: none"> Physical description 	SJ's description of the spatial and content dimensions of hospital, patient

Theme/Category	Description
	rooms, hallways, PT gym, nursing stations, units, clinic waiting room, clinic rooms
<ul style="list-style-type: none"> • What the space feels like 	SJ's description of her interpretation of the feeling of the hospital, patient rooms, hallways, PT gym, nursing stations, units, clinic waiting room, clinic rooms
<ul style="list-style-type: none"> • Participant's visitors 	SJ's description of the physical and emotional appearance of participants' visitors in the hospital
Communication between patients and clinicians	
<ul style="list-style-type: none"> • Miscommunication 	Observations of instances where patients misunderstood information, rationale or instructions provided by clinicians
<ul style="list-style-type: none"> • Like family 	Observations of dialogue in which patients or clinicians spoke to one another in familial or family-like terms
<ul style="list-style-type: none"> • In conflict 	Observations of dialogue in which patients and clinicians were in conflict with one another
Participating in research	
<ul style="list-style-type: none"> • Sharing the story 	How patients reflect on interviews
<ul style="list-style-type: none"> • Things asked of researcher 	Questions asked to SJ about her life or the research
<ul style="list-style-type: none"> • Perceptions of the researcher 	Observed ways that SJ is spoken of
Physical therapy	Observations and reflections on physical therapy sessions
Observed interactions with clinicians	General observations of patient interaction with clinicians
Race	Interview segments or observations in which race was discussed directly or alluded to.