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Noncompliance and Patient-Staff Relations

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Carrie Kathleen Alexander

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**RACE, CLASS, AND DISABILITY:
NONCOMPLIANCE AND PATIENT-STAFF RELATIONS**

By

Carrie Kathleen Alexander

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ABSTRACT

RACE, CLASS, AND DISABILITY: NONCOMPLIANCE AND PATIENT-STAFF RELATIONS

By

Carrie Kathleen Alexander

The events and interactions recorded and analyzed in this document focus the anthropological lens on the physical rehabilitation unit as a microcosm of society in which the elements of change, loss, and conflict are forced upon people in a constriction of space and time. Noncompliance is a term used in the health care profession to label those patients who are not following a prescribed treatment regime. When examined through an anthropological lens, noncompliance is illuminated as a function of the relationship between health care professionals and patients. This analysis examines the physical rehabilitation unit as a microcosm of societal conflicts, with a focus on race and class, which are nearly inseparable in the Southern U.S. still today, as this study shows. The critical exploration of institutional structure and its effect on the lives of patients and staff in a physical rehabilitation center provides insight into the lives of newly disabled individuals, their families, and the staff members with whom they come in contact while in the hospital.

Ethnographic analysis is used as the major source of data, augmented by population statistics and historical research. I draw from the literature on an anthropological theory of praxis to address disability identity. I developed an historical perspective on race, with evidence to show that racism persists, although it may have

changed forms in the past thirty years. Differing definitions of racism abound, with many white people being totally unaware of the privilege that whiteness brings.

Ultimately, race is one path institutions take to limiting access to economic and political power. As discussed further in this study, from the beginning of the European colonization of this land to the present day institutional reproduction of culture and power relations, race has been used as a way to support one ideology over another, creating a structure invisible to most individuals.

My description of the structure of the rehabilitation unit begins the presentation of findings of this project. At times, the examples in this study show that race was not a conscious issue with many patients or staff, but the habitus was a silent and ever-present shadow brought to occasional consciousness by a racist statement or action, or by the recognition of the reproduction of the institution. Particular informants, especially technicians, had a unique vantage point: partly in the professional world of health care workers, and partly in the patients' world, blurring the lines between subject and object, and professional and patient. The theoretical foundation of embodiment, political economy, and power is expanded, including a discussion of how these concepts are exemplified in my findings, relating them to institutional policy and reproduction. The concluding chapter redefines noncompliance, and calls for a recognition of the complexity of rehabilitation as it relates to access, agency, and resistance in medical institutions.

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TABLE OF CONTENTS

LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER ONE	
Introduction	1
Contextualizing Myself	5
CHAPTER TWO	
Embodiment: The Body As Living Sculpture	
Literature Review	7
Sequestration of “Races” in the U.S.	11
The Black Underclass	12
Objectivism and Official Knowledge	15
An Anthropological Analysis of Disability	19
Subject/Object	20
Stigma	21
Liminality and Communitas	22
Disability and Cosmology	24
Embodied History: Toward a Theory of Identity	27
CHAPTER THREE	
Methods	
Evaluation of Historical Data	33
Participant Selection and Data Collection	37
CHAPTER FOUR	
Eggshells and Kid Gloves: Race Relations in Madison County	45
The Building of New Barriers	47
Other Aspects of Jackson History	55
CHAPTER FIVE	
The Setting	
Social Networks and the Difficulty of “Getting In”	58

Points of Confluence	65
The Hospital	66
Getting In	66
The Rehabilitation Unit	72
Discussion	81
 CHAPTER SIX	
Theory on the Ground in Jackson	
Anthropological Theory: Praxis Explored in Jackson	85
Acquisition of Embodied Traits	86
Western Individualism Meets Embodied History	88
Political Economy: The Bottom Line Masquerades as Necessity	90
Reproduction Through Objectivism	95
Agency, Resistance, and Consciousness	103
 CHAPTER SEVEN	
Power and Resistance in the Rehabilitation Experience	110
Team Conferences: Findings	112
Voices	113
Josephine	116
Grace	117
Monique	122
A.J.	125
Toni	131
Brief Glimpses	134
Policy and Race	136
Noncompliance	141
 CHAPTER EIGHT	
Discussion and Conclusion	142
Noncompliance: Fault Line Over Deep Rumbblings	148
 GLOSSARY	
153	
 APPENDIX A: Semi-Structured Interview Guide	
157	
 APPENDIX B: Selected Interviews and Cases	
159	
 APPENDIX C: Sample SOAP Note	
163	
 BIBLIOGRAPHY	
165	

LIST OF TABLES

Table 1 - Race, Gender, and Position of Participants in In-Depth Interviews	40
Table 2 - Rehabilitation Patient Statistics (1996-1997)	111

LIST OF FIGURES

Figure 1 - Rehabilitation Unit Lay-out	75
Figure 2 - Rehabilitation Department Organizational Chart	77

CHAPTER 1

INTRODUCTION

“Noncompliant” is a strong word used by health professionals to describe a patient who refuses to follow the advice of medical professionals, and is used freely in medical records and in discussions of patients in the halls of hospitals and clinics in the U.S. When viewed through the lens of medical anthropology, however, noncompliance is transformed from a way to unconsciously blame the patient for the failure of suggested treatments to a complex interaction of misunderstandings, disagreement, and resistance between the patient and the health care professional. This study explores the proposition that noncompliance as a medical phenomenon is most prominent when the patient and the staff differ significantly in factors such as class, race, religion, and personal values. The medical setting of a physical rehabilitation unit is the site where most of this research was carried out to address noncompliance in the context of daily conflicts between patients and staff.

When a person is suddenly beset with a life-threatening and life-changing illness or injury such as a stroke or paralysis and is forced to interact with others while learning new ways of accomplishing personal daily tasks, interactions take on an intensity of purpose and level of conflict not otherwise witnessed in routine activity and encounters. Rehabilitation units are filled with people in transition and crisis, and therefore often involve upheavals in family relations and power struggles of patients with family, friends, and staff. The emphasis of this document is the rehabilitation unit as a microcosm of

societal conflicts, especially in terms of race and class. “Race” is a term used frequently throughout this document, however it does not represent the physiological or morphological meaning of the word, but rather the most common term for ethnicity used within the community of Jackson, and the South in general. For discussion of race as a concept, refer to Chapter Six. Race or ethnicity has been an issue with which I have struggled since childhood, and I have recognized a need to examine my data collection with this influence in mind. I have approached this subject as an advocate for improving race relations and eliminating racism, and have wrestled with my admitted advocacy in data collection and analyzation.

The critical exploration of institutional structure and its effect on the lives of patients and staff in a physical rehabilitation center provides insight into the lives of newly disabled individuals, their families, and the staff members with whom they come in contact while in the hospital. The ultimate goal of this project is to illuminate the socially embedded creation of noncompliance, and to deconstruct the official knowledge and rhetoric of the medical community. Embodiment is explored as a way that conflict arises between patients and staff, employees and employers, and African Americans and whites within the context of the Southeastern United States. Racism exists in many forms, and is still a fundamental concept in comprehending societal conflict, and essential in understanding the cosmology and cultural reproduction of this region. My hope is that this project will help to achieve a deeper and richer understanding of the struggle to be whole in an increasingly fragmented society.

Chapter Two, entitled “Embodiment: The Body as Living Sculpture” explores the literature, and outlines the development of habitus (Bourdieu, 1990) within the context of

anthropological praxis theory. Recent anthropological views of disability are highlighted, with discussion of the socially constructed concept of “handicapped” within this culture.

Chapter Three, “Methods,” Through interpretation and ethnographic analysis, I found noncompliance to be primarily a function of the relationship between the health care professional and the patient, rather than difficult, stubborn, or uneducated patients resisting what is right and logical. Institutionalized racism, economics, education, and social mores all play a significant role in forming the uneven ground on which the social dance of medical intervention takes place. The effect that the anthropologist can sometimes have on the community is considered, with a personal example of how the interpreter is interpreted.

Chapter Four begins the major findings of this project. I present an overview of historical and geographic aspects of the community of Jackson, Tennessee. Class and race relations are reviewed, including critical examinations of how racial discrimination and segregation continue to effect the interactions of various sects of the community. Chapter Five describes the difficulties with obtaining permission for research, as well as the major findings of the project. Challenges to communicating and accomplishing daily tasks highlight my navigation through business, personal, and professional interactions. Perceiving economic and education differences between the black and white communities in Jackson is paramount to understanding the climate of overt friendliness and covert resentment. Signs of hope for narrowing the schism between the communities exist with increasing frequency despite the difficulties.

In Chapter Six, theoretical constructs are revisited and expanded, including how the separation of African Americans and white Americans in this community and others

contributes to differences in perceptions of which problems exist, and how to solve these problems. Individualism, social responsibility, and economics demonstrate the separateness of the rhetoric within the region. Concepts such as political economy, official and unofficial knowledge, and resistance illuminate the environment in which the label of “noncompliant” is born within the hospital. Objectivism is deconstructed as a method of reifying the power structure within a system, and minimizing the legitimacy of active and resistive agents. The lack of room for grief in the physical rehabilitation process increases the possibility of conflict, depression, and resistance.

Chapter Seven adds a deeper context to informants’ voices, with revealing interactions and discussions as the focus. Detailed analyses of several cases demonstrates the effect of institutionalized racism framed as “noncompliance.”¹

The eighth chapter concludes the study, with discussion and analysis of power, resistance, embodiment, habitus, and praxis. Future research is implicated, with emphasis on improving access, equality, and humanity with the rehabilitation process.

¹Institutionalized racism is defined in this document as primarily unintentional actions or policies which guide the production and reproduction of a system, with a functional outcome of exclusion of those of color from benefitting from the system in a variety of ways (Gregory, 1993; Harrison, 1995; Millard, 1994).

Contextualizing Myself

I have crossed many lines. . .

Not another middle class white person on race!

You gotta do whatcha gotta do. . .(My mother)

The task of contextualizing my role in the complex strands of this community should begin with my own origins and aspirations so that they may be scrutinized for biases (“true objectivity” denounced). I have lived in several different regions at varying levels of economic class, beginning with my upbringing in the nearly all-white rural Ozarks of southwest Missouri. There I grew up around poverty, practicality, and unfortunately, racism. Due to the mobility required of my father’s military career when I was a child, and substantially through my parent’s career changes brought about by his injuries and disability, I was exposed to multiple perspectives of cultural regions, educational levels, and economic classes. I began to question the values of the culture within which I had been raised, one of which dealt with my puzzlement and amazement regarding the level of racism against African Americans in an area where there was less than one percent African Americans. In other words, how do people who have never met members of a specific race category develop such an ingrained hatred of them?

I remember the summer of my ninth or tenth year, and how I discovered that, despite what most of the people of the small all-white town in the Ozarks believed, there were good black people in the world. During one memorable camping trip, I lay awake and eavesdropped on my father’s conversation with a an old high school friend in which he discussed his experiences in Vietnam in a way that ten-year-old girls are rarely exposed. I learned that some of the men responsible for saving my father’s life on a rice paddy in

Vietnam were black, and that perhaps they had come back for him because my father treated them with respect.² This planted a fierce belief in my child's mind that bigotry was the root of many evils. It was so rampant in whites that a white who treated blacks with respect was rare enough to warrant acts of decided bravery in order to save him. Although I have yet to answer completely the question of racism and how it became so endemic, it continues to drive my need to discover more about the process of race relations and personal concepts of race.

Later, as an aspiring occupational therapist, I questioned some of the perceptions commonly held about people with disabilities, and recognized the pain and conflict inherent in dealing with the onset of a disability. My parents' discussions of their difficulties in dealing with an occasional self-righteous health care professional during my father's hospitalizations and surgeries helped me to develop a tempered view of "medical authority." I chose to be a medical anthropologist because of the tools and concepts in anthropological research appropriate for understanding the complex perspectives of the medical experiences of my family and others.

²The Vietnam era was in many ways a turning point for civil rights and race relations, and is beyond the scope of this document.

CHAPTER 2

EMBODIMENT: THE BODY AS LIVING SCULPTURE

In this chapter, I review the anthropological literature for themes of biomedical constructs, and I also analyze “race” as a socially constructed concept, with specific examples from Jackson, Tennessee. I draw from Bourdieu’s theory of practice to analyze experiences and data from my fieldwork, focusing on the themes of embodiment, agency, and resistance. An anthropological analysis of disability concludes this chapter.

Literature Review

Pierre Bourdieu has articulated a theory in *The Logic of Practice* (1990) that he intends to reconcile theoretical and practical thought in anthropology. Bourdieu states that:

The theory of practice as practice insists, contrary to positivist materialism, that the objects of knowledge are constructed, not passively recorded, and, contrary to intellectualist idealism, that the principle of this construction is the system of structured, structuring dispositions, the *habitus*, which is constituted in practice and is always oriented towards practical functions (1990, p. 52).

He defines practical sense as “a practical mastery of the sense of practices and objects”, that is, action dominated by the non-logic of everyday activity and habits. The habitus is “embodied history,” and can be described as formed through the social structures and events which influence people as they develop, and which continue to shape the actions of

the person throughout life. Examples of these aspects of habitus include gender, class, family, ethnicity, age, sexual orientation, region, language, nationality, education, and occupation. Embodiment is the incorporation of these aspects into activity and ritual, bodily movement, and ways of thinking about the world. The embodiment of habitus is the expression of the past in the present (1990). Race is a concept consciously and unconsciously applied to all people in the Southern U.S., and figures prominently in the formation of habitus.

Western individualism has been explored through many anthropological and sociological texts (Douglas, 1970; Dumont, 1970; Dumont, 1977; Foucault, 1977; Gaines, 1982; Geertz, 1977; Gordon, 1988; Kondo, 1990; Scheman, 1983; Shweder and Bourne, 1982), with the extreme of this concept found in North America (Gordon, 1988), particularly in the United States. Lock and Gordon (1988) lay a foundation for the Western concept of self in Biomedicine Examined, and how it translates into concepts of the body, wellness, and illness. The distinguishing characteristics of Western biomedicine include Cartesian dualism, the individual as independent from society, the objectification of illness, the power differential between "knower" and "known," the assumption that technology is better, the belief that modern medicine is beyond moralistic judgments and superstition, the concept that the human is a biochemical machine, and the dominance of objectivist epistemology: there is only one way of truly knowing, which is through the scientific method (Lock, 1988).

Western individualism in its extreme version in the United States sees the individual as unitary and completely distinct from society, and often in conflict with society. Society is merely a grouping of these individuals, and the core self is relatively

unchanged, no matter the situation or environment (Gordon, 1988; Kondo, 1990). The self is considered an object, not a culmination of interactions. To be swayed by society or by the group is considered weak and undesirable, with the ideal being the free agent who can overcome society and all its trappings.¹ In hospital settings, this is apparent in the emphasis of occupational, physical, and speech therapy in which personal independence in daily activities and the acquisition of new skills to re-enter society is the major goal of physical rehabilitation, not necessarily the return of a person to a social role or unit. It is also the self's responsibility to maintain or regain health in this cosmology, with individual blame and responsibility for illness as the opposite side of the wellness coin.

An excellent example of this ideology of blaming the patient can be found in the treatment of chronic pain. In the U.S., pain is accepted as a largely physical and biochemical phenomenon, and many physicians prescribe heavy doses of analgesics and narcotics to treat chronic pain.² When a person complains of severe or ongoing pain, both the physician and the patient have a need to find a physical cause which can be treated promptly. This need perpetuates a series of medical evaluations and tests that inevitably rule out acute disease or injury. This practice is further justified by availability and "magical thinking" surrounding the use of more and more complex technology,

¹For an example of "free agent" psychology, see Jean-Paul Sartre's The Emotions: An Outline of a Theory (1948).

²Physical pain is in fact a perception, usually beginning with detection of noxious stimuli by receptors in the skin. These receptors respond by firing electrical impulses along nerves to the brain, which, through past learning and socialization, begins to interpret what might be the source of the pain and how it might be stopped. Pain receptors can also trigger reflexes, such as when an arm jerks away from a hot iron (Morris, 1991).

contributing to fantasies of a simple solution to pain (Barley, 1988). However, when no discernible cause is found, physicians and other health care professionals become uncomfortable with their lack of knowledge. This discomfort, when coupled with the patient's display of behaviors indicative of pain, leads some medical professionals to label the pain as "not real," or "all in your head." A recommendation for psychiatric therapy is often made, which angers the patient. The implication is that the problem is created by the patient, does not warrant serious medical treatment, and could be easily corrected if the patient would just "act normal." More significantly, the patient's motives are most often questioned if financial gains such as disability payments or worker's compensation are being sought.³

Snow (1993) explains how traditional medicine and cultural ideals among a Midwest U.S. African American community may coincide or conflict with physician and nurse recommendations for various ailments. A lack of follow through of recommendations is often labeled as noncompliant behavior, and the patient may be blamed for subsequent health problems. Health care professionals, having been indoctrinated by training into the belief that health is the sole responsibility of the individual, tend to place blame on the patients when the recommended treatment is incomplete or unsuccessful (Ronald Frankenberg, 1992). The patients' actions are thought to be influenced by ignorance and lack of motivation and frequently interpreted as

³These findings of a pattern of responses by health care professionals was repeatedly noted during my tenure as an occupational therapist in chronic pain programs in Charlotte, North Carolina, and Columbia, Missouri, from 1986 through 1991, and in industrial/occupational rehabilitation programs in Columbia, Missouri, and Jackson, Tennessee in 1991 and 1997-1999 respectively.

noncompliant.⁴ Noncompliance, viewed through the lens of the daily experience of people in difficult circumstances, may in fact be more accurately identified as the embodiment of economics (Segar, 1994; Stack, 1974), cultural identity (Crandon-Malamud, 1991; Goffman, 1963), and resistance to an antagonistic health care system (Crandon-Malamud, 1991; Massey and Denton, 1993; Snow, 1993;).

Sequestration of “Races” in the U.S.

In addition to differences in treatment strategies, larger gaps are illuminated between white and African American concepts of self and society. As outlined above, the Western European intellectual concept of self is of the individual who takes complete responsibility for his or her health or illness. According to several ethnographic works, in many African societies, views of the self have been noted to be based more in a socially embedded concept of self, with the person being born into a social web (Comaroff, 1985; Field, 1960; Mbiti, 1969; Bennett, 1988; Devlieger, 1995). This concept of self makes the community responsible for the health and growth of its members, and several authors suggest that these concepts have remained strong within African American communities (Stack, 1974; Snow, 1993; Mbiti, 1969).

⁴For additional readings on traditional medical viewpoints on noncompliance, see Meichenbaum and Turk (1987) and Haynes, et al, (1985).

The Black Underclass

When considering concepts of “race” and class in the U.S., a phenomenon of the black underclass becomes important to understand. The lower economic ranks of the African American community have less social mobility, affecting a wide range of factors, including access to health care. Massey and Denton presented a strong case for the continued existence of housing discrimination as a major factor for the creation and maintenance of a black underclass (1993). By concentrating African Americans in the inner cities, housing discrimination compounded overcrowded conditions and set up black communities for financial disaster when economic downturns occurred. Massive and overwhelming statistics showed that the degree of isolation from the rest of society experienced by blacks in the inner cities is unique among ethnic groups and categorically affects blacks of all classes. When income was controlled in several studies, and when surveys showed that African Americans were knowledgeable about housing prices and supposed availability, the concentration of blacks of all economic levels in the inner cities was still profound. In other words, African Americans of all economic levels can be found in concentrated areas, whereas whites are spread out in different neighborhoods based on economic class. This further indicates that affluent and middle class African Americans are experiencing barriers to living in more affluent or middle class white neighborhoods. Even as recently as 1990, ten million applications for housing and loans were examined nationwide in an audit which also controlled for income differences, and whites were 50 to 100 percent more likely to be approved for housing and loans (Massey and Denton, 1993). Housing discrimination is still alive and well, and conspicuously absent from current

academic and public discussions of race, racism, and poverty in the ghettos of the U.S. (Massey and Denton, 1993).

Other perspectives have been used to explain the existence and maintenance of the black underclass. William Julius Wilson postulated in The Declining Significance of Race and in The Truly Disadvantaged that African Americans are less strongly affected by racial discrimination than by class discrimination. The flight of middle class blacks effectively removed what economic and political power had existed in the black urban communities, leaving the poorest of the poor to live in politically and economically powerless neighborhoods. According to Wilson, this concentration of poverty led to dependence on the welfare system, the breakdown of the black family, and increasing pregnancies among unwed parents. Massey and Denton's statistics overwhelmingly show that discrimination is still an active and major factor, even when income is taken into account. Carol Stack (1974) also refuted the contention that welfare dependency and concentration of poverty led to the change in family structure (the change from mostly nuclear families to 50 to 60 percent single-headed households among African Americans between 1950 and 1980 is well established by Hacker, 1992; Edsall and Edsall, 1992; Massey and Denton, 1993; Wilson, 1987). Joblessness in the inner city (due to the downfall of industrial inner city businesses along with the suburbanization of businesses and wealth) was the major factor in making marriage a disadvantage among poor urban African Americans--a factor further supported by the loss of welfare checks when single mothers married (Stack, 1974; Hacker, 1992; Massey and Denton, 1993). Wilson reluctantly admitted the role of joblessness, but seemed to cling to other explanations of changes in family structures.

Charles Murray has created furor in public rhetoric with his contention that “generous” welfare payments create a lack of motivation to work, that this motivation is automatically passed down to future generations, and that the ghettos are created due to this chain of events (1980). Murray used Oscar Lewis’s concept of the culture of poverty (1968) to establish the barely covert racist contention that “defective culture” is responsible for the plight of inner city ghettos rampant with increasing violence and fatherless children. The history of this skewed view of the effects of poverty can be traced back to D. Patrick Moynihan’s report to the President on the state of the black family in 1968. Moynihan echoed the sentiments of W.E.B. DuBois (1903) in pointing out that poverty was having extremely detrimental effects on the structure of the black family, coining the phrase “a tangle of pathology” (Moynihan, 1968). The swift and harsh criticism by white liberals and black leaders was based on the interpretation that blame was being laid by Moynihan (and hence by much of the dominant white patriarchy) on the victims of discrimination, rather than the perpetrators, and discussion of the problems of violence, crime, and family structure were essentially silenced for nearly 30 years. Moynihan had been misinterpreted, and liberals feared a similar backlash and alienation from black citizens (and ultimately, voters). Hence, present-day liberal discussion of ghetto formation has been reactionary and inadequate to contend with the conservative rhetoric, at best (Edsall and Edsall, 1992; Hacker, 1992; Wilson, 1987). Charles Murray and his followers will continue to dominate the discussion of the roots of the black underclass, with devastating effects, unless academicians, social scientists, and politicians can effectively and proactively refute the popular (among conservative whites) and misleading rhetoric of the day.

These two opposing explanations for the creation of a black underclass (the responsibility of the white power structure as postulated by liberals versus the lack of initiation or over-indulgence of African Americans on welfare as Charles Murray contends) continue to polarize the debate on what is to be done now. Most white Jacksonians do not classify themselves as racist, and are greatly offended when suggestions are made that the white power structure continues to prevent economic advancement of African Americans. When asked to define racism, most informants in this study defined it as an individual who discriminates against people based on race. Occasionally informants would also list "believing some races are inferior to others" as a part of racism. None of the white informants identified themselves as racist, yet were noted to make derogatory comments about African Americans on other occasions. Classism has become an excepted way to categorize the have-nots, but it is often thinly veiled racism when examined closely. Jackson continues to struggle with and deny the racist practices which still exist, and many individuals seem to be consciously unaware of their own racist attitudes.

Objectivism and Official Knowledge

Bourdieu criticizes the artificial division of subject and object in the field of social science:

Objectivism, which sets out to establish objective regularities (structures, laws, systems of relationships, etc.) independent of individual consciousnesses and wills, introduces a radical discontinuity between theoretical knowledge and practical knowledge, rejecting the more or less explicit representations with which the latter arms itself

as "rationalizations," "prenotions," or "ideologies" (1990, p. 26).

By not exploring the objectification of objectivism, science takes no account of the distance it establishes between observer and observed. Objectivists claim to have an "absolute viewpoint, the 'perspectiveless view of all perspectives'" (1990), ignoring the point that objectivism is an ideology. Objectivism "imposes on the object norms of construction" which clouds the understanding of more meaningful, though less "logical" explanations (1990).

Bourdieu uses the example of language to attest to this point. Saussure's study of language is an objectified account which renders the language lifeless:

. . . the tendency towards intellectualism entailed by apprehending language from the standpoint of the listening rather than the speaking object, that is, as a means of decoding rather than a "means of action and expression". . . (1990, p.33)

By making language a study of the relationships between words, Saussure misses the fundamental function of language: to convey meaning and expression between people. Using objectification in this manner asserts "the epistemological privilege of the observer", taking no account of the division between the theoretical and the practical (1990).

Objectivism is a major foundation of the medical field, to the extent that only objectified knowledge receives any serious consideration (Waitzkin, 1991; Martin, 1992; Gordon, 1988b; Lock and Gordon, 1988; Kirmayer, 1988; Lock and Scheper-Hughes, 1990; Armstrong, 1988; Gordon, 1988a; Kaufert, 1988; Koenig, 1988; Barley, 1988; Rhodes, 1990; Bellaby, 1992; Frankenberg, 1992; Pizzini, 1992). Objectivism has its roots in the mind-body dualism proposed by Descarte in the early seventeenth century. In

attempting to justify his passion for knowledge about the body and how it worked, in a religious climate which suppressed non-spiritual explanations of illness, Descarte postulated that the mind (or spirit/soul) and body (the physical shell) were separate entities (Rhodes, 1990). By the 1800s, the scientific method upset the balance (Kuhn, 1970), and became the dominant epistemological process for explaining illness. One of the effects of this ideologically positivist domination has been the delegitimizing of behavioral, emotional, or social ills—all categories which are difficult to isolate to unitary individuals. Social ills or problems, such as racism and its effect on the economy and health of a people, have an especially negative connotation in Western ideology, as these ills would conflict directly with the individualized self concept. The person steeped in the individualized concept of self would be likely to blame the social ills on the weakness of those individuals who were suffering, and who had not been able to pull themselves up by their own bootstraps.⁵ Later examples will exemplify the conflict between individual-oriented self concepts and those who view history as embodied in the present.

Time is a concept which also has multiple interpretations, with the industrialized concept of time dominating the field of biomedicine. In "Your Time or Mine: Temporal Contradictions of Biomedical Practice," Ronald Frankenberg (1992) outlined a critical analysis of time within the field of biomedicine, and concluded that the flexibility of time scheduling was inversely related to status and power within the hospital.

Frankenberg uses the example of the revolt of women against inductions and Caesarean births to illustrate the control over patients' lives through control of time. Since

⁵For more detailed discussion of the Western individualized concept of self, see Giddens, 1991.

most births occur at night, the timetable for inductions and Caesareans has been moved largely to the daytime hours by physicians. Since the "patients" violated the physicians' private time at home, the physicians then felt free to violate the boundaries of the bodies of their patients.

Frankenberg also asserts that the conception of illness is contextualized within each culture by the perception of time and chronicity. Using an example of a tuberculosis hospital, Frankenberg describes a situation of the medical resident who, when confronted with the case of a woman whom he thought had been in the hospital for two years, stated "We have to get her out of here." Upon learning that she had not been in the hospital continuously but had been in and out, the resident changed his mind and argued that the patient should in fact stay longer. In this case, the woman's condition had little or nothing to do with her date of discharge, but the amount of time spent in the hospital (as perceived by the resident) was the determining factor. Frankenberg provides a compelling argument for the control of time by health-care practitioners in Western biomedicine, calling for a renewed critical analysis of time control in all research projects involving illness.

Adams (1992) supports this argument with an analysis of illness within the continuum of time, and how the concept of time is used to judge a person's wellness or competence. She maintains that "Orchestrated cycles of activities when desynchronized or speeded up may best be conceptualized as stress which in turn may result in ill health and accidents." Adams uses examples such as Korsakow Syndrome, depression, and mania to illustrate how loss of ability to orientate within the birth-death continuum can cause a clock-imposed illness category upon the person afflicted. In further development of her analysis, Adams discusses the "non-temporal principle of invariant repetition." Rhythms of

nature "entail repetition with variation, the essence of temporality." When the objectified clock time is used to regulate a factory, for example, the variation inherent in natural time is destroyed. This may result in illness such as repetitive strain injuries from performing a single movement or task over and over at a greatly increased speed. Timeliness and the importance of adhering to the institutional schedule are critical aspects of daily activity in the hospital setting. In later chapters, I will expand the concept of the commoditization of time, and how this is used to reproduce the hierarchy of power in the medical institution.

An Anthropological Analysis of Disability

Self-identity in this society is intimately connected with the body, as illustrated in the extreme by the "disabled" body. The term "disabled" is controversial in the community of people with disabilities, as it tends to identify the person as an objectified disease. The term will be used as little as possible, with more humanizing (and perhaps more wordy) terms substituting as needed.

In many societies, however, the body is much less important than relations with the community and with family. Two major theoretical models of disability have been developed within the social sciences: Erving Goffman's sociological model of deviance (1963), and Robert Murphy's anthropological model of liminality based on the theories of Van Gennep and Turner (Murphy, et al, 1988). While much can be learned from the examination of these illustrations, they remain inadequate when considering non-Western cultural regions. Ingstad and Whyte (1995) offer a cross-cultural perspective on disability, highlighting the differences in definition, social stigma, and self-identity in varying

contexts. Although the theoretical constructs in this most recent work are weak or absent, I relate the accounts to the theory of praxis as postulated by Bourdieu (1990).

Subject/Object

"The anthropologist is a positioned subject, one who occupies a position or structural location and observes with a particular angle of vision. . . . The notion of position also refers to how life experiences both enable and inhibit particular kinds of insight" (R. Rosaldo, 1989, p.37).

My own background predisposes me to the enablement and the inhibition of insight to which Rosaldo referred. My father is a disabled Vietnam veteran who has experienced a gradually worsening physical condition throughout the past 28 years. His experiences as well as my interpretations of them led me to a career in occupational therapy in which I have encountered many people with different disabilities. Through these personal experiences, I am able to capture the subjective point of view to which Bourdieu alluded, while my position within the health care field may inhibit my insights regarding the experience of patients within the hospital milieu. I have attempted to counter these inhibitions through the critical analysis of the Western medical system guided by theoretical models in medical anthropology. My intention is to provide a critical and analytical voice in the field of rehabilitation, in hopes that services to patients will become increasingly meaningful and empowering. My intention in this chapter is in part to provide a preliminary theoretical exploration of disability from an anthropological perspective.

Stigma

Erving Goffman presented a model of social deviance in Stigma: Notes on the Management of Spoiled Identity (1963) in which the person with a disability was marginalized to the extreme. Goffman defined stigma as "an attribute that is deeply discrediting," and researched early Greek writings in which the disabled person was a "blemished person, ritually polluted." Goffman asserted that as we encounter people in daily social situations, we automatically assess their "social identity" which could include such constructs as personal characteristics, social status, and occupation. When encountering a person with an obvious physical disability, the entire social interaction is tainted due to the stigma of disability, which tends to reduce the humanity of the person with the disability. The blemish of the disability is generalized to other characteristics, which further inhibits normalized social interaction.

The stigmatized person in Goffman's model internalizes the category and is filled with self-hate and self-derogation. The person may attempt to "correct his condition indirectly" by relearning sports or excelling in a former activity. According to Goffman, stigmatized persons include all marginalized groups such as minorities, criminals, people with mental illnesses, and women, and they tend to have similar "moral careers":

"Persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self—a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments" (p. 32).

As a person learns of their stigma, he or she will confront prejudice in others and helplessness in themselves. Goffman claims the role of the medical professional as having the "special job of informing the infirm who he is going to be." Goffman posits the

medical professional as the agent of change, rather than the patient who must create a new identity for him or herself. This frame of reference reflects the ultimate arrogance of a medical system at its height of power and autonomy.

Goffman provides a few examples of personal statements from people with disabilities, but does not give voice to particular informants. He often refers to the temporarily able-bodied as "we normals" and to the person with a disability as "the infirm" or "the cripple," which reifies the divisions about which he writes. His emphasis on stigma is illuminating, but his categories of the stigmatized are so broad as to make them useless, and he makes no distinctions between types of disability. Goffman never questions or even recognizes the assumptions he has made about the authority of the medical professional in the identity formation of the person who is suddenly faced with a disability, and in fact never gives an operational definition for self-identity, ego identity, or "normal." Perhaps the greatest problem in this work is the lack of realization that perceptions of disability vary according to cultural context, to which Goffman makes no reference. These problems severely limit any application of Goffman's theory to a cross-cultural or even cross-class, -ethnicity, or -gender study.

Liminality and Communitas

Robert Murphy, et al., outline a model for disability based on the work of Arnold Van Gennep and Victor Turner in "Physical Disability and Social Liminality: A Study in the Rituals of Adversity" (1988). Van Gennep (1960) postulated that life crises have three stages: separation, transition, and reincorporation. Rituals in "traditional" societies were used as an example by Van Gennep, and later by Turner (1967) to describe these stages.

Separation occurs at the beginning of the crisis or of ritual, before which the person has a certain social identity. In the transition stage, the person suspends all former identities and becomes liminal to the group. The final stage returns the individual to society with a new identity. Turner argued that during the liminal stage, social relations are without divisive structures or categories, and that those who are liminal become social equals. Murphy contends that people with disabilities experience this type of liminality with the onset of a disability, but society has no expectation of that person as leaving the liminal state. As Turner would say, "they are suspended in social space without firm identity or role definition" (1967). Murphy, et al., may also be the first group of researchers to use ethnography of the "disabled community."

This model may be more applicable to varying contexts than was Goffman's. Murphy found that the complete authority of the staff and egalitarian relationships between patients were very similar to Turner's traditional societies. Murphy also distinguishes between the stigma of disability and other stigmatized categories, as disability can be acquired by anyone, whereas other categories tend to be "inherited." Murphy criticizes positivistic studies of disability due to the tendency to objectify disability and to make it a static condition rather than a process.

While Murphy has described a stimulating model of cultural symbolism, he has not examined the category of disability as a "Western" construction. European and Western societies are unusual in that they have large numbers of people with adult-onset disabilities (due to the surviving of wars, automobile accidents, and violence through enhanced medical care) and that these societies categorize people according to physical function (Whyte and Ingstad, 1995). Murphy may be correct about egalitarian relations between

persons with disabilities while in a hospital setting, but personal experience has shown me that disability does not erase divisions of ethnicity, class, or gender which people embody throughout their lives. To say that a person is no longer considered primarily of these groups is to say that the person and society has forgotten their social or *embodied history* (Bourdieu, 1990), an argument which I find to be highly unlikely.

Disability and Cosmology

Benedicte Ingstad and Susan Reynolds Whyte have taken an important step by collecting studies of disability from various societies and regions of the world in Disability and Culture (1995). In their introduction, Whyte and Ingstad offer definitions used by the World Health Organization. An impairment is "any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1980), whereas a disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980). A handicap is a "disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual" (WHO, 1980). The WHO made an effort to place cultural context in the picture, but failed to see that the divisions were based on Westernized conceptions of physical function, ignoring "the way in which culture structures whole life worlds, imbuing individual variations of the human condition with significance more far-reaching than the simple ability to perform a given activity" (Whyte and Ingstad, 1995, p.7). It is only through the export of Westernized rehabilitation medicine that *disability* is becoming a more solid category of person in societies where

handicaps are rooted in very different concepts. "Disabled community" may therefore, be a term limited in its use to biomedical systems, and then it must be used carefully, avoiding stereotyping an extremely diverse group of people.

Major differences have been noted in the social identity and relations of people with disabilities in "complex," stratified societies compared to small-scale societies.⁶ Among the Songye of Zaire, physical anomalies at birth fall into three categories. "Ceremonial children" often have special powers such as the ability to heal; these children are usually of an unusual presentation at birth or twins (Devlieger, 1995). "Faulty children" have disabilities such as cerebral palsy or other motor impairments, and are an indication of distorted relationships. "Bad children" are inhuman and come into the world to die; these children include albinos, dwarfs, and children with hydrocephalus. As Devlieger points out, "what is central for the Songye understanding of physical disability is not so much the classification of bodily singularities as the embeddedness of embodied persons in networks of relations" (1995). It is especially important for people of the Songye to determine how and why the child is different (witchcraft, the actions of the mother or father, family relations), so as to determine the category of the child. Ceremonial children are given special treatment, faulty children are cared for, and bad children are "socially amputated" from the society.

The Punan Bah of Sarawak characterize a person's identity based on the socially recognized father, establishing a kinship identity. Illegitimate children (those born without

⁶ "Small scale societies" can include smaller sections or subcultures within larger societies, such as noted by Nora Groce in her study of deafness on Martha's Vineyard (1985).

a social father), twins, witches, and spirit children are all considered nonhuman.

Personhood can only be recognized through marriage and children; therefore, the people with disabilities are found to be cared for and considered a person if they marry and have children or are given children. The person with the physical abnormality is given tasks which they have the ability to complete, and the rest are divided among kin (Nicolaisen, 1995). Talle found similar cosmologies with the Masai (1995).

Handicaps based on individual ability to function are not limited to "Western" societies. Helander found that the concept of personhood among the Somali is based on individual differences and abilities, and on "flexibility, growth, and change; thus infirmity, which inhibits this, is a diminishment of personhood" (1995). This view of the person with a disability was incompatible with the concept of rehabilitation, as the incurable conditions deserved care but were unchanging and therefore unworthy of efforts to improve the disabled person's abilities.

Europeans with multiple sclerosis were found not to be concerned so much with social relations as with their own concepts of the self and the body. Reflexivity was a consistent theme in the narratives (written accounts as well as interviews) and consumed much of the energy of the newly diagnosed person. Biomedicine played a prominent role in the formation of body image and experience (Monks and Frankenberg, 1995). Murphy also provided an analysis of social encounters between people with disabilities and the able-bodied in the United States, emphasizing the culture of the "body beautiful" (1995). These themes relate closely to Giddens's concept of the reflexive modern self in Modernity and Self Identity: Self and Society in the Late Modern Age (1991). Giddens contends that reflexivity is the project of the modern self, while "personal meaninglessness

... becomes a fundamental psychic problem in circumstances of late modernity" (p. 9).

The sequestration of experience is the root cause of this meaninglessness through the separation of the person from existential events, such as illness and death (as illustrated brilliantly in Aldous Huxley's Brave New World). This separation prevents the self from considering the meaning of life and its end, with mediated experience such as TV replacing real events through "reality inversion", in which the soap opera seems more real than actual events.

Embodied History: Toward a Theory of Identity

The collection edited by Ingstad and Whyte (1995) brings together informative ethnographies which have attempted to compare disability categories across many societies. However, Ingstad's point about the concept of disability being very Eurocentric should not be taken lightly. While we should continue to examine disability, it should be within the context of particular societal cosmologies (see Ingstad's work on the export of "rehabilitation" in the name of development in Botswana, 1995). Some authors (Murphy, et al, 1988; Murphy, 1995; Goffman, 1963; Schüssler, 1992) have even failed to recognize that self-identity after disability can differ widely within a cultural region due to differences in gender, class, ethnicity, cosmology, and economics. The habitus of people with disabilities must be explored when explaining how the disability affects self-identity.

The age of the person at the onset of a disability or disease is of singular importance in the development of self-identity in Western society. Giddens's concept of ontological security is based on the development of trust in an ordered existence partly through routinization of daily interactions and activities:

"The maintaining of habits and routines is a crucial bulwark against threatening anxieties, yet by that very token it is a tensionful phenomenon in and of itself. . . The discipline of routine helps to constitute a 'formed framework' for existence by cultivating a sense of 'being', and its separation from 'non-being', which is elemental to ontological security" (1995, p. 39).

If a person is born with a disability such as cerebral palsy (CP), the mobility, speech, and (sometimes) cognitive problems which exemplify CP are incorporated into the daily routine and habits of the person and family, leaving ontological security relatively intact as long as the caretakers are careful to develop this as with other unaffected children.

Giddens appropriately labels this security as the "protective cocoon." With the sudden onset of a disability in early adulthood such as paraplegia caused by an accident, however, ontological security is severely challenged due to the loss of control of the body and a complete disruption of daily habit and interaction: the protective cocoon has been broken.

Giddens's development of the concept of ontological security fits well with the Westernized preoccupation with the body and its functions, but it may not fit so well with cosmologies wherein the person is conceptualized primarily in terms of kin networks. These societies also have daily habits, typical tasks, social interactions, and primary care givers, but why do these not translate into a conception of disability as "loss of bodily function"? Giddens's failure to consider non-Eurocentric cosmologies limits the credibility of his theory as an exploration of "globalization" except as the exporting and commoditization of Western technology and ideology.

Another factor which affects self-identity of the person with a disability is the cause or explanation offered for the disability. The most common cause of disability among young adult men in the U.S. is motor vehicle accidents, many of which are caused by the use of alcohol when driving. The newly paralyzed young man not only has to deal

with his own grief and guilt about having been personally responsible for his condition (or anger at someone who was responsible), but medical professionals and family members often remind him about his role in the accident. Many of these types of injuries are compounded by minor brain injuries, which cause further changes in personality characteristics and cognitive abilities. Ontological security may be not only interrupted, but destroyed for many years.

Religious beliefs may also influence how the person thinks of him or herself, as with the case of a young woman I met during my pilot study in Lansing, Michigan, who had recently been diagnosed with multiple sclerosis (MS). Ruth Wilson was a member of a fundamentalist Christian church but felt that she had not been living up to the high standards in which she believed. During therapy one day, she told me she thought that God had taught her a lesson by giving her MS, as she had been partying and drinking too much on the weekends. Her sense of guilt made her depressed, but at the same time mobilized her to change certain routines in her daily life.

Elderly people in this society are socialized to expect a gradual decline in their faculties and abilities; therefore, the onset of a disability tends to reinforce this concept. The perceived social worth of the elderly in the U.S. is low, and disabilities such as strokes or Alzheimer's disease further compound this tendency. The young adults with whom I have worked in rehabilitation usually conclude that life must still be lived, and want to relearn how to go about daily activities (with varying degrees of acceptance). Many of the elderly people in rehabilitation, however, have given up any hope of return to "normalcy," often deferring to family members for decision-making and for assistance with daily

activities.⁷ Depression and feelings of hopelessness and worthlessness are common in this age group.

Ethnicity may have significant effects on self-identity of people with disabilities through cultural practices and cosmologies, and through the double jeopardy of being of an ethnic minority group *and* being disabled. African Americans, for example, have experienced marginalization and discrimination in U.S. social, legal, and medical institutions (Hine, 1989; Edsall and Edsall, 1992; Dressler, 1991; Massey and Denton, 1993; Thomas, 1992) and have received fewer resources, increasing their mistrust of hospitals and medical professionals (Snow, 1993). The constant scrutiny and awareness of skin color to which African Americans are subjected in this society contributes to mistrust of medical institutions, and folk traditions which are still consistently used remain undisclosed due to this mistrust and to a history of scorn from the medical profession (Hacker, 1992; Snow, 1993; Morrison, 1981; Angelou, 1969).

The identity of being black in this society is ingrained through nearly every interaction with whites, which brings into question Murphy's assertion that former societal divisions are erased when people with disabilities encounter others with similar conditions (Murphy, et al, 1988; Murphy, 1995). African Americans, who already experience the "invisibility" of which Murphy speaks due to their ethnicity in this racially polarized society, encounter increasing invisibility when faced with a disability. The effect on self-identity can translate into an ever-widening gap between the narrative of the self and the

⁷ This may be in part the expectation of elderly working class people that the retirement stage in life is to be used for "resting," not developing a new way of life. This tendency may change as people live longer, and as younger age cohorts reach the elderly years.

"official" narratives of "mainstream" (white, able-bodied) society. This gap not only has far-reaching effects on self-concept, but can further complicate relations between the mostly white rehabilitation professionals and African American patients.

Economic status is drastically affected by the onset of a disability, especially for working class people who depend on manual labor for employment. This group usually lacks long term disability insurance, and may not even have access to medical insurance. The high cost of rehabilitation (\$600-900 per day just for the hospital room and at least three hours of therapy per day for several weeks at \$60-100 per hour) quickly creates a lifetime of debt or bankruptcy, at least until the person can qualify for Medicaid (or the state's equivalent, such as Tennessee's TennCare). The person with a new disability is suddenly plunged into poverty, with little chance of becoming upwardly mobile. Seeking disability benefits can become a new career, requiring hours of paperwork per week applying for disability benefits and insurance coverage. To qualify for benefits, a person with a disability may be encouraged to exaggerate, stretch, or even worsen their own deficits; the payments rarely cover the increased living expenses which the disabled experience (due to the need for special equipment which insurance does not cover, adapted housing, and personal attendants) (Segar, 1994; Whyte, 1995; Sackett, 1976).

I have only touched the surface of exploring the embodied history of people with disabilities in the Midwestern and Southeastern regions of the U.S. An expanded theoretical model is needed in the social sciences to trace the thread of self-identity through the maze of cosmology, ethnicity, gender, class, age, and disability (Steedly, 1993; Kondo, 1990). Goffman (1963) and Murphy, et al. (1988), have provided some groundwork, and Ingstad and Whyte have provided access to ethnographies of people

with disabilities in various societies. The category of "disabled" should not be used, however, without a critical analysis of the concept in the intended context. Further explorations are also needed in analyzing self-identity within subcultures of the U.S., including the African American community, in order to understand relations between patients and staff.

The theory of praxis best accounts for all of the complexities of embodied history when a crisis such as the onset of a disability disrupts the narrative of the self. Themes such as the conception of the body, the objectification of disease, the use of technology, and the reification and reproduction of the status quo through the rehabilitation process also require ongoing study. Self-identity is ultimately embedded in all of these concepts and more, providing a wide field for the illumination of personal narrative, social difference, and individual and collective agency within expanded psychological frameworks.

CHAPTER 3

METHODS

The major research questions I sought to answer with this document included: 1) How was noncompliance or compliance interpreted by patients and staff? 2) Who was labelled as noncompliant, and were there trends in this process? 3) How does the rehabilitation environment reproduce “noncompliance?” In order to address the interpretation issue, daily participant-observation was punctuated with contemporary oral accounts and interviews. Historical data was important to establish the cultural, economic, and social changes which affected the present population of Jackson. Without tracing the history of race relations in this region, it would have been impossible to interpret the current climate of separation and doubt. Empirical data was added to emphasize the inconsistencies between general population statistics and rehabilitation unit statistics. The following pages review methods I used in data collection.

Evaluation of Historical Data

The only written account specifically of Jackson and Madison County area history is the 1946 Historic Madison: The Story of Jackson and Madison County, Tennessee. From Mound Builders to World War I by Emma Williams. This work was originally written in 1946, with reprints in 1972 and 1986. The copy I was able to access belonged to a former assistant to Mrs. Williams. It continues to reflect the common racist views of

the times, and *is still widely respected as the historical account of Jackson and Madison County* (emphasis mine). The book of 534 pages mentions “Negroes” on 22 pages, with all but one account portraying black people as lazy, mean, chronically slow, and in need of discipline. “Miss Emmy,” as the author was affectionately called, taught high school for many years at Jackson Central High School, which was the all-white high school.¹ Her racist viewpoints, especially vocal in comparison to other white citizens, were well-known by those who worked closely with her. I encountered little knowledge or objection in the white community about the content of the work, and the pro-secessionist views are still prominent in the region. “Miss Emmy” served as the county historian for several decades according to her former assistant. The current historian² uses Williams’ book as a major resource for presentations to community organizations, and the local library has an entire cabinet display devoted to this author. Although this viewpoint of the “Negro” was the social norm of whites at the time of its writing, the fact that this account remains the only historical documentation of post-Civil War Jackson, and has continued to be referenced without critique is indicative that Jackson has not dealt openly with its recent racist past. No history of African Americans in Jackson or Madison County has been written to date. I obtained information on history after World War II from various interviews, from The

¹This high school merged with Merry High School (located across the street) in 1970 to form the integrated Jackson Central Merry High School. Though these schools have been integrated for some time, the difference in quality and upkeep of the buildings and facilities is quite glaring. The Central Campus was constructed of stone with a uniform design, athletic fields, and has a large arena on campus. The Merry Campus was constructed of less durable materials, and is still in obvious need of renovation.

²The position of County Historian is appointed by the County Mayor. Emma Williams was the first County Historian. The current Historian is Harbert Alexander, Jr..

Jackson Sun newspaper, The Christian Index newspaper, and from The Metro Forum newspaper.

I reviewed The Jackson Sun daily for 3 years from 1995-1998, and reviewed selected editions from the 1960s which coincided with significant historical events in Memphis, Tennessee, Selma, Alabama, and throughout the South. I chose to review periodicals (The Jackson Sun, The Christian Index) dating shortly before, during, and after historically significant events, such as the Birmingham bus boycott, the Sanitation Worker's Strike in Memphis, or the assassination of Martin Luther King, Jr. The Jackson Sun purposefully did not cover Civil Rights era news, except for the assassination of Martin Luther King, Jr. (the editorial staff was all white, and did not wish to print these stories; stories concerning the war in Vietnam took precedence). The front page story reporting the assassination was not written by a local reporter, but was retrieved from the Associated Press wire. Johnny Malone, a reporter for The Jackson Sun in the 1960s (currently a Senior News Editor for The Jackson Sun), was allowed to print a story on the inside of the paper two days after the assassination announcing a rally of "Jackson Negroes" on the following day. Three days after the assassination, Mr. Malone reported (again, buried on the inside in a column less than 6 inches in length) that over five hundred "negroes" had rallied peacefully in Jackson. No other coverage of civil rights activities were reported in The Jackson Sun until the latter 1970s. The current newspaper staff is ethnically diverse, and has given coverage to Community Treasure Awards, a program recognizing significant contributions of older African Americans in Jackson and Madison County, as well as stories on the church burnings in the past 4 years, and other stories covering race-related issues. When asked about the few civil rights activities (such as this

peaceful rally, or the Woolworth Lunch Counter Sit-In), most African American and white citizens are not aware that these events even occurred (Schneider, 1999; other interviews of informants by author).

The Christian Index was the main periodical for the Christian Methodist Episcopal Church, published and founded in Jackson, Tennessee beginning in 1867. It is the second oldest black periodical in the United States. I again reviewed the paper on selected dates (on microfilm in the local public library). This newspaper (it later became a magazine) rarely printed politically charged articles in its early years, but by the 1950s, occasional editorials regarding civil rights were included. The editorials urged integration and positive regard to white institutions and individuals (Murchison, 1954a; Murchison, 1954b; Murchison, 1954c; Merriweather, 1964).

The Metro Forum is a weekly newspaper published by the National Newspaper Publishers Association³ which targets the African American community in Jackson, was begun in 1989 and is a significant source of advertisement to the black community. I reviewed fifty weekly issues of The Metro Forum from June, 1997, to May, 1998. It is the only local periodical which regularly addresses issues of racism, institutional racism, and inequality, as well as other social concerns of the African American community in Jackson.

³The National Newspaper Publishers Association is an African American publishers association. Each copy of The Metro Forum contains this statement: "Credo of the Black Press: The Black Press believes that America can best lead the world away from racial and national antagonisms when it accords to every person, regardless of race, color or creed, full human and legal rights. Hating no person, fearing no person, the Black Press strives to help every person in the firm belief that all are hurt as long as anyone is held back."

Local librarians, especially those in the Tennessee Room at the Madison County Public Library in Jackson, were helpful with vertical file information, microfilms of newspapers, and recommendations for accessing journal articles. Libraries I accessed included the Madison County Public Library in Jackson, Lambuth University Library in Jackson, Lane College Library in Jackson, University of Tennessee--Martin Library, University of Memphis Library, and University of Tennessee--Memphis Library. Other written sources of the history of West Tennessee included articles in The West Tennessee Historical Society Papers journal, specifically by a local reference librarian and archivist for Union University in Jackson (Baker, 1994 and Baker, 1995). I found voluminous writings on civil rights in Memphis at the University of Memphis library. Very few of these writings or books were available at any of the Jackson libraries. Lane College, an all-black college in Jackson founded by the Christian Methodist Episcopal Church (formerly the Colored Methodist Episcopal Church), had a library rich with historical information on the CME Church, but had no materials on the history of Jackson or civil rights activities.

Participant Selection and Data Collection

Following the approval from the hospital Institutional Review Board for my research project in March of 1997, I was able to begin interviewing patients, families, and staff members. During two and a half years of fieldwork, I was involved in daily participant observation, with 75% of that time spent in hospital or clinic settings as an observer or actively participating as an occupational therapist, 20% spent in the community, and 5% in informants' homes. I selected subjects based on my access to them

and to their therapists during therapy sessions or team conferences. The subjects consisted of the following: those patients who had been labeled as “noncompliant” and the family and staff members connected with them (approximately 100 people), patients who had not been labeled as noncompliant (approximately 100 people), and the general public encountered in a variety of daily interactions as a source of general information about people in the Jackson area. I selected seventeen key informants for more lengthy interviews and observations to represent a variety of class, race, gender, and position (patient, professional staff, non-professional staff, student/intern). These seventeen key informants were selected based on accessibility to me, and I made an attempt to access a variety of informants. See Table 1 for identification of these informants. Eleven of these seventeen key informants were not originally native to Jackson, due to a variety of reasons: 1) informants from Jackson tended not to be very outspoken or willing to discuss difficult issues, 2) my own status as a non-native tended to net fewer natives as informants. It should be noted that the most prominent informants (Daryl Kincaid, Shirlene Mercer, and John Watson) were Jackson natives, and another prominent informant, Toni Proctor, was from Memphis, but had spent most of her life in Jackson. Semi-structured interviews were conducted in a variety of settings, including the hospital, homes, and public places.⁴ Due to the challenges noted here with interviews, I was prompted to use daily interactions in Jackson as major sites for data gathering. Public interactions were numbered in the hundreds over a period of three years.

⁴For a sample of questions used in the interviews, see Appendix A.

Written fieldnotes were the most common mode of collecting data during my participant observation, with historical documents and media as the second most common form of data. Interviews were occasionally tape-recorded. Early in the fieldwork process, I noted that many patients and staff members were reluctant to have interviews recorded, and spoke more freely when interviews were conducted less formally and in a conversational style without a tape recorder. When I could not tape-record interviews, I took more copious notes with care to record specific quotes. My interviews ranged from 1 1/2 to 3 hours, and I observed each patient for eight to two hundred seventy-five hours. As my time between work, interviews, and family became less available, I concentrated my writing to particular events or interactions, organizing my fieldnotes (written one to three times per week) around the theme of race, racism, and compliance, with comparisons made between patients and staff members. I focused my fieldwork on events, conversations, and interviews which brought perceptions of race, compliance, and culture into stark relief against the background of everyday interactions. I avoided physicians as informants, as the dynamics of physician interactions are beyond the scope of this document. While physicians remain an integral part of the rehabilitation team, therapists and nurses interacted with the patients for a vast majority of the time, and physicians had significantly fewer interactions with the patients. Staff members chosen for interviews were selected based on their close working relationships to patients who had been interviewed.

I began the selection of informants for life histories with observation of and participation in team conferences in which patient cases were discussed and reviewed. The team conference was a weekly meeting focused on treatment and discharge planning,

Table 1: Race, Gender, and Position of Key Informants*

Patients

African Americans
Women

Grace Simon

Men

A.J. Porter
Ronald McGee
Darryl Kincaid
Arthur Deaton

White Americans
Women

Georgia Nimke
Josephine McGregor

Men

Charlie Jones
Jim Rochel

Latino Americans
Women

Maria Sanchez

Staff

African Americans
Women

Monique Stapleton
Toni Proctor
Trudy Smith

Men

John Watson

White Americans
Women

Jean Forbes
Jackie Hatfield

Men

Bob Burkeen

*For more detailed information on these participants, see Appendix B.

and involved all therapists, nurses, doctors, social workers, and other professionals participating in each patient's care while in the hospital rehabilitation unit. Team conferences are a requirement of the Commission on Accreditation of Rehabilitation Facilities (CARF), and are held for the purpose of communicating goals of each discipline, and to ensure discharge planning. CARF also requires patient and family input as team members, with documentation to show that this has taken place (1997). This meeting was the most common formal setting for discussion of noncompliant patients.

I selected some informants based on my own observations and experiences working with patients and staff. I also solicited assistance from other occupational, physical, and speech therapists, asking them to inform me of patients who seemed to have issues with compliance. Direct observation of staff and patient observations in departments other than my own (such as going to the physical therapy gym) was not well accepted, unless the primary therapist in question had approached me to identify a particular patient as noncompliant. In other words, the therapists in some departments were very uncomfortable with having their interactions observed unless they had volunteered a particular "problem" patient's name.

The interview questions (see Appendix A) were used as a vehicle for gaining details about the key informant's background, while establishing rapport until the pressing issues were broached. Due to the social taboo against discussing or pointing out negative aspects of life in Jackson, or being critical of people or ideas in general, subjects such as racism, noncompliance, and negative emotions were avoided by most informants. In order to prompt informants to go beyond this "code" to deal with more controversial issues, I spent more time in daily interaction and participation with them to develop deeper rapport.

questioned them more directly as incidents occurred, to explore immediate emotional responses which might later have been suppressed. While the information gained in the interviews was helpful in creating a whole picture of the person's habitus, the bulk of the rich data came from participant observation in the daily life of the community. Weddings, funerals, parades, fund raisers, and school events, as well as daily activities in the hospital, provided insights into perceptions and constructs which would not have been accessible through direct questions. Directness was considered a social flaw in this community, therefore indirect methods of learning were more meaningful in content. The social construction of race, racism, and compliance (or lack thereof) were revealed as nondiscursive constructs during candid interactions and chance discussions.

The themes around which I analyzed the information included race, racism, disability, and compliance. Race was chosen as a theme due to the common view among informants in the community of Jackson that race is a dominant factor in determining past, present, and future circumstances of a given individual. Although this was rarely directly stated, the review of media, interviewee answers, public interactions, and fieldnotes about daily interactions revealed a tendency for people to categorize individuals primarily as one race or another, then added other factors perceived to be less descriptive than race, such as gender, occupation, or neighborhood of residence. When writing my fieldnotes, I wrote a brief analysis of them first, then later reviewed the materials for a more sustained analysis. I then analyzed my data through a full review of my fieldnotes, highlighting passages with the dominant theme present, and began interpreting the actions and statements of my informants.

Racism was also examined as a theme in fieldnotes, interactions, interviews, and media. I collected three years of articles in the local newspapers on stories dealing with race or racism, reviewing them for assumptions, constructs, and trends in reporting. I paid particular attention during interactions when informants expressed racist viewpoints, comparing them to earlier statements made when being pointedly asked about racism. I paid particular attention to comments regarding prominent African American citizens in the community, such as Shirlene Mercer, or Wesley McClure, president of Lane College.

Disability and compliance were constructs that were very important to staff members in the hospital, but were not important or even familiar to key informants who were patients. The staff members immediately categorized patients into disability groups by diagnosis, and most held a coherent view of the patient as a person with a certain type of disability throughout their interactions with patients. The patients seemed largely unaware of this classification system which was so important in assigning of staff team members, room assignment, or types of activities expected of each diagnostic group. For this reason, the construction of disability as an entity unto itself was explored in Chapter Two.

Compliance was also an important construct for staff members, but not necessarily by patients. Compliance or noncompliance was frequently, though not consciously, used to delineate which patients deserved more attention and resources. Fieldnotes were reviewed to determine which passages dealt with which themes, with my own interpretations analyzed as well as interpretations of informants. I selected some passages in their entirety which contained ready examples of the theme, while I reinterpreted other passages or events to highlight nondiscursive constructs.

The methods I used in this study included oral histories and interviews, historical documents and books, newspapers, and participant-observation, with the latter category providing the bulk of data. Very little written history exists regarding Jackson-area civil rights, race, class, or medicine when compared to the strife in Memphis, as confirmed by area historians, librarians, and newspaper editors. The local newspaper was reviewed daily and searched for phrases such as “African American,” “race,” “racism.” I selected fieldnotes and interactions dealing with these themes as well as with disability and compliance, with ethnographic analysis and interpretation heavily emphasized. These methods were selected to reveal the nature of subconscious perceptions and the social construction of race in a Southern community.

CHAPTER 4

EGGSHELLS AND KID GLOVES—RACE RELATIONS IN MADISON COUNTY

“Darryl is the biggest son-of-a-bitch I have ever known. He is horrible to deal with, he cares about nothing and nobody, and he is just out to manipulate the system,” Jackie exploded into my face. Jackie Hatfield was a coworker of mine at the rehabilitation center, and she had noticed Darryl Kincaid waiting to see me in outpatient occupational therapy. Darryl had been an inpatient at our facility a year prior to this encounter, having become a quadriplegic after stealing a vehicle while on cocaine and then crashing it during a high-speed chase with police. The community was experiencing a sudden increase in violent crime, and emotions were running high about this particular incident. Darryl was a young, street-wise, low income, black man who used raw language and emotional outbursts in daily discourse. In contrast, Jackie was a middle-aged white woman therapist from a working class family in the Upper Midwest. It was no coincidence that the rehab staff considered Darryl one of the most noncompliant patients they had ever seen. In cases where noncompliance was an issue, significant differences existed between those doing the labeling and those being labeled. These differences included race, class, education, and geographic origins.

History is a key concept crucial to understanding embodiment, which is the expression of the past in the present. When the embodiment of history, race, culture, and

economic class was expressed very differently between most professional staff members and Darryl, it had a direct effect on his level of care. Two of the technicians (who were African American) had another opinion of Darryl. One labeled him a “jive turkey,” who was mostly bark and no bite, and who just needed to be reminded in a firm, motherly fashion of the priorities. Another tech stated that you just needed to take what Darryl said “with a grain of salt” and go on about the business of taking care of him. She also said that Darryl just needed to have some control over a few choices, and he was “much easier to deal with” when given choices and treated like a human being. The technicians felt that most of the white professionals were scared of young black men, especially of those with the life experiences of Darryl. The history of race relations, economics, and culture in the area has immense effects on interactions between people in this town, and ultimately shapes and is shaped by embodied history.

Historically, Jackson (with a current population of 65,000) was named for Andrew Jackson, whose wife was from the area. It was developed as a cotton growers’ settlement after settlers fought wars and then signed treaties with the Chickasaw and Cherokee people of the region in the early nineteenth century.¹ Many of these settlers (of European descent) were from the older states, such as North Carolina, and brought with them a few slaves to begin clearing and planting for the future economic mainstay of cotton farming. By the mid-1800s, the cotton business was lucrative, and the slave market was increasing in profit as the railroads allowed shipping to Memphis for distribution along the trade routes and ports of the Mississippi River. By the early 1860s, only sixty-one free blacks

¹The Chickasaw people were essentially driven south and the Cherokees to the west by armies and white settlers led by Andrew Jackson.

were known to live in Madison County (Williams, 1986; Baker, 1994). The Civil War and Reconstruction changed everything and nothing. While the slaves had been emancipated, the power and resources continued to be controlled by the white property owners and business people, a trend which continues today.

When the slaves were freed and Reconstruction of the South began, white farmers (many of whom were former Confederate soldiers) were required to pay for housing, clothing, food, and a portion of the harvested crop as salary for contracted laborers called "Freedmen," who were the former slaves. As the economic foundation of the cotton farm was unpaid slave labor, fewer than half of the former slaves were now employed as share-croppers. New laws and restrictions were developed by white politicians to control the black population (Baker, 1994). Bitter feelings developed between the former Confederate soldiers and the Reconstructionist "Yankee" politicians and leaders; the latter were essentially appointed throughout the South by barring former Confederates from voting (Williams, 1986), leading to a long-standing pattern of underground networking and political maneuvering on the part of former slave owners to control the economics of the South (Stack, 1974).

The Building of New Barriers

Inequality between the races developed simultaneously with colonial economic structures in the New World, as slaves became a major commodity for the building of agricultural industries, especially in the Southeastern United States (Smedley, 1993; Thomas, 1993). Reproduction of the economic structure of slavery was further reinforced by the people whose lives and economies depended on this labor, who developed a view

of black people as “Other”: separate, unequal, subhuman (Hacker, 1992; Smedley, 1993). This distancing allowed economic exploitation to continue, and the concept of black as inferior became endemic in the culture of the burgeoning United States. The foundation was laid for long-term racial conflict.²

The Civil War rhetoric was (and is) significant in the South in that it stressed that the issue was states’ rights, not the enslavement of humans. Historians make valid points that the Union had many economic interests, and not necessarily humane social concerns, which led to the war with the Confederacy. The South’s cotton industry was becoming a dominant economic power in the European market, which worried the Northern merchants and industrialists. The Northern politicians were also concerned with the continuing stronghold of Southern politicians (Catton, 1961; Davis, 1982; Nichols, 1961). The continuing conflict over the flying of the Confederate flag above the South Carolina capital building (among other sites) is used as a staging point for century-old arguments over pride in an economic and historical tradition versus the ultimate symbol of enslavement of an entire race of people.

The post-Civil War era was filled with hope in the African American community, and many migrated to the Northern United States for work that was difficult to find in the South. Those who stayed behind faced continued poor living conditions, wages lower than their white counterparts, and racial violence (Edsall and Edsall, 1992; Massey and Denton, 1993; Stack, 1974; Thomas, 1992; Williams, 1946; DuBois, 1903). Even though

²Smedley (1993) offers the most well-supported and in-depth academic study of the origin of the term race, its meanings, and how the perception of race came to be such a dominating world view in North America and South Africa.

the economic structure of slavery had been made illegal in its formal sense, share-cropping continued to exploit the labor of poorly educated black people.

Jim Crow laws began to flourish, forcing the separation of blacks and whites in housing, businesses, and social gathering places. The practice of “redlining” was used to deny black people loans for housing in certain areas, or to discourage white people from buying houses in certain areas (Edsall and Edsall, 1992; Massey and Denton, 1993). When a neighborhood began to be integrated, it was considered unstable, and white flight began to occur. Even in the 1990s, surveys from across the U.S. have shown that most white people say that they believe in racial equality in housing, but statistics show that most white neighborhoods tolerate up to about 20% black occupancy before white flight begins, while blacks prefer a 50-50 ratio. Once an area hits the critical 20%, many whites are anxious to leave, and many blacks are anxious to further integrate in an area that has shown an acceptance of a racial mix. Those who flee a neighborhood because of black integration, or fear of declining property values as many profess, go to areas which are known to be white. This would seem to indicate that there are mechanisms in place to keep certain areas white (Massey and Denton, 1993). These mechanisms are complex and subtle to the outside investigator.

Today, glaring economic disparity continues to exist between African Americans and whites in the South. Foreign nationals, as well as Jackson residents originally from other parts of the country, commented to me frequently and shockingly about the differences between housing and schools for “white areas” compared to “black areas” of Jackson. The school district in Jackson came under Federal indictment in 1980 to integrate the schools, and was again in conflict in 1996 and 1997 with the discovery by a

black school board member of all-black classes at the magnet elementary school. The reason given by the white principal for this resegregation was that *they wanted to avoid making the few white children uncomfortable* (Branum, 1996). Such “consideration” had never been given African American children in traditionally white schools. African Americans account for 40 percent of Jackson’s population; however, the major hospital system (the largest employer in Jackson with approximately 5000 employees), in which I did my fieldwork, employed African Americans in 90% of non-technical, lower paid positions, and only 3% of administrative positions were filled by black people. This pattern of inequality follows those in most urban areas of the United States (Darden, et al, 1987; Edsall and Edsall, 1992; Hacker, 1992; Hine, 1989; Kotlowitz, 1991; Kozol, 1991; Massey and Denton, 1993; Thomas, 1992; Wilson, 1987).

Another more personal scenario highlights the role of landlords in facilitating white flight. My family and I moved into an apartment complex in Jackson in an area which was 10 percent white, 85 percent African American, and 5 percent Latino. The complex housed primarily working class and low income families, but was not classified as a Section 8 (federal low income) business. The apartments were approximately 15 years old, and had originally been considered upscale apartments in a historically white section of town. The current landlord had owned the complex for several years by report of community members, and did the least amount of maintenance possible. The floor of the back porch was rotting, the plaster from the ceiling frequently flaked off and fell to the floor, and poison ivy grew in trees around the apartments. The landlord, Mr. Smith, was a successful white business man who owned several rental properties. He refused to make

some repairs and delayed other repairs for weeks. Several of my neighbors and my family were without air conditioning in the blistering July heat of Tennessee for several days.

Most of the neighbors in the complex were hard working and friendly until Mr. Smith allowed several new renters to move in one week. These renters immediately caused difficulties. The rumor was that Mr. Smith was selling the complex, and was trying to fill it up so that fewer questions would be asked about why there were so many empty apartments. Within a span of ten days, I was awakened by gunfire, one of the new neighbors had stabbed her boyfriend, and a car had been stolen. Suddenly, anyone who had the means was looking for a new place to live. Police officers investigating the recent stabbing informed me that my complex was now on the police force's "worst of the worst" list for trouble. My family and I moved to an apartment complex which had an immediate opening and which was known for its security measures. The new complex required considerable references, and was in the northern, mostly white section of Jackson. Despite only a \$60 difference in monthly rent, none of my other neighbors moved into this new complex. White flight had occurred through a complicated mix of economic advantage and a landlord-facilitated crime wave. Those with economic advantages (including better salaries and better credit) allowing quick mobility into a nicer neighborhood were more likely to be white.

When African Americans get close to these barriers between all-white areas and black areas, and are denied housing through realtor discouragement, withholding of loans, and violence, the black neighborhoods become caged in and are not allowed to expand except into other black or mostly black areas. Over time, this compresses more black people into smaller areas with less and less contact with the white community. Even when

economic levels are taken into account statistically, the compression of African Americans of all economic levels into contained areas in U.S. cities is astounding (Massey and Denton, 1993).

The over representation of African Americans in the lower socioeconomic classes has been well-documented (Darden, et al, 1987; Edsall and Edsall, 1992; Farley, 1985; Hine, 1989; Kotlowitz, 1991; Kozol, 1991; Massey and Denton, 1993; Wilson, 1987). Massey and Denton propose that housing discrimination and hypersegregation³ have been the major forces creating an African American underclass, while Edsall and Edsall outline the political maneuvers which affected economics throughout the 19th and 20th centuries. Wilson argues that African Americans make up a distinct class, much like the castes found in India, limiting economic flexibility and power. Race and economics are nearly impossible to separate in a region where one race is systematically kept contained and controlled through constricted opportunity, poor education, and restricted networking.

The concentration of jobs in cities and the lack of workers during WWI and WWII drew African Americans to fill these openings, and the new workers and their families began to compete more seriously with poor and working class whites. When the Jim Crow laws were overturned through various cases such as *Brown v. Board of Education* in 1954, the Civil Rights Act in 1964, the Voting Rights Act in 1965, and the Fair Housing Act in 1968, the need for housing pushed the blacks into formerly white sections of cities. Whites fought back with violence and police brutality in the mid-20th century, and these trends continue today. African Americans were effectively prevented from moving into

³Hypersegregation is defined as the compression of more and more members of an ethnic group into small, defined areas for housing (Massey and Denton, 1993).

white areas of the cities, even as new waves of migration of African Americans from the rural areas continued. The jobs offered to African Americans were more menial and required fewer skills, and management positions were offered only to whites (for contemporary examples, see Chapter 7). The discrimination in housing and the violence against blacks created increasingly concentrated sections of African Americans in cities and towns, close to the manufacturing and service jobs available to them. This housing demand caused families to take in kin, creating overcrowded and inadequate conditions (Massey and Denton, 1993).

As African Americans continued to apply for jobs with improved wages and opportunities in the 1940s, resentment in the white community began to build. Whites and middle class blacks were appalled at the practices and “uncouth” manners of the black farmers-turned-city dwellers, contributing to stereotypes about black people in general, much to the dismay of established middle class blacks. By the 1950s, violence against blacks frequently erupted along residential borders between white and black neighborhoods, and financial institutions had implemented “redlining,” as noted earlier in this chapter. Block busting also came into practice by white realtors, who would purposefully place newly-immigrated, rural blacks into white neighborhoods, then advertise this fact to the whites who feared the loss of property values. The realtors would buy the white-owned properties at a “fair price,” then rent to poor African Americans at a high price. Neighborhoods quickly turned over along racial lines, facilitated by the practice of loan institutions which denied financing to more liberal whites in these “unstable” neighborhoods, effectively creating and maintaining racial segregation

within the cities (Darden, et al, 1987; Edsall and Edsall, 1992; Massey and Denton, 1993).

The late 1950s and early 1960s brought racial tensions and nonviolent civil movements into the public eye, and new political alliances began to form around the issue of race. From the Civil War to the 1930s, African Americans had traditionally voted on the Republican ticket, siding with the “party of Lincoln.” New Deal programs outlined by Franklin D. Roosevelt in the 1930s facilitated a party change in African American communities to the Democratic party. Friction began to arise in the Southern Democrats against the Democratic line of acceptance of blacks into the party affiliation. White politicians in the South effectively wrestled control of the Republican party from the few African Americans who had come to power in the black communities. As laws such as the Voting Rights Act in 1965 were enacted, the Supreme Court decisions such as the Miranda Act and others protecting the rights of criminals increasingly alienated more conservative white Democrats (Edsall and Edsall, 1992).

Nixon was able to seize the moment in his 1968 election contest against Humphrey (who embraced the acceptance of minorities and women, along with other disenfranchised groups, into the Democratic party) and George Wallace (who had effectively pulled the conservative and overtly racist Southern Democrats into an Independent party). Nixon won due to the split Democratic party, and forged ahead toward re-election plans to win Wallace’s poor Southern whites and Northern working class whites, who were increasingly unhappy with integration of the schools and the increased taxation in support of the Vietnam War and New Deal social programs. Nixon succeeded and started the

swing in political power to the conservatives, which continued through the early 1990s (Edsall and Edsall, 1992).

Residential segregation along racial lines continued to build throughout this period. Milestones such as the overturning of the Jim Crow laws and the Fair Housing Act of 1968 had little effect on the discriminatory practices of financial institutions, realtors, and private citizens due to the gutting of the Fair Housing Act as a political deal to pass it through a bipartisan Congress. The Housing and Urban Development Department (HUD) was effectively prevented from acting on the Fair Housing Act, and individual citizens were left to bring suits with no monetary or legal support. Needless to say, little progress was made in the arena of housing discrimination. When President Reagan attempted to whittle away at the Fair Housing Act, moderate politicians were disgusted with the continual racial divisiveness in the two party system, and passed bills to strengthen the Act in 1988. It remains to be seen if this will have a legal effect on fair housing practices (Massey and Denton, 1993).

Other Aspects of Jackson History

During the much publicized Sanitation Workers' strike in Memphis and other conflicts around the Mid-South region, Jackson remained largely subdued throughout the civil unrest of the 1960s. A very strong taboo against public disagreement existed in Jackson, with the favored public presentation being restraint and congeniality (a trend which has remained largely unchanged). The major newspaper in town rarely reported any news of the black community, despite the fact that nearly 50% of the population was African American. Events such as the *Brown vs. Board of Education* decision and the

Montgomery, Alabama bus boycott received little attention, with interviews of local (white) politicians and leaders downplaying any local effects. Sit-ins occurred at the local lunch counter at Woolworth's department store, which did not allow blacks to eat there. Once the Jim Crow laws were swept aside, Woolworth's closed its lunch counter. Although Memphis is only an hour away from Jackson, their histories are significantly different. While Memphis citizens were rallying and making headlines, Jackson headlines continued to report on the Vietnam war. White Jacksonians were and still are quick to denounce Memphis. When I mentioned Memphis to white Jackson residents in 1996-1999, many of them expressed distaste for the city of Memphis, often relating to me the crime and "dirtiness" of the city. Black citizens had fewer negative comments about Memphis. Few citizens with whom I had contact during fieldwork, black or white, ever spoke of civil rights or the significant role Memphis played in the 1960s.

In 1970, the all-black Merry High School merged with all-white Central High School to become Jackson Central Merry High School. The buildings were and are located across the street from one another, and there is still an appreciable difference in the quality and state of the buildings (Merry's building being significantly more dilapidated). One of the more public disagreements to occur in Jackson was the fight against merging the city and (largely all white) county schools, as well as the forced integration of Jackson schools in 1980. The latter case was significantly supported by the NAACP.

This chapter has reviewed the historical events in the United States which have informed the social development of Jackson, Tennessee. Historical information on Jackson and West Tennessee were included when available. Understanding history, both

local and regional, is imperative in interpreting the daily interactions between people in public and private spaces, especially within the medical setting of a physical rehabilitation center. The rehabilitation center is filled with people in crisis as they begin to grasp their transition: from able-bodied to disabled, from productive worker to unemployed worker, from dependent spouse to head of household. These crises serve to bring into stark relief those characteristics that are so personal and important in this region, such as family unity or lack thereof, independence in self care, a positive self concept, and productivity and worth.

CHAPTER 5

THE SETTING: SOCIAL NETWORKS AND THE DIFFICULTY OF GETTING IN

Jackson, a community of approximately 65,000, is experiencing rapid growth while maintaining its small town character. For native Jacksonians, a comforting familiarity still exists in many areas of the town. For newcomers to Jackson, especially for those unfamiliar with the culture of the Southeastern United States, the town is a perplexing and frustrating lesson in uncovering unofficial knowledge and nondiscursive social structures and cultural patterns.

When approaching Jackson on Interstate 40 from Memphis or Nashville, a series of poorly planned exit ramps (the rural drivers tend to come to a dead stop due to the very short ramps, causing the more traffic-experienced Jacksonians to zoom around them or wait in a line behind them) leads directly onto the two main thoroughfares in Jackson: Highland Avenue and Highway 45 Bypass. The Bypass was built to lessen the traffic on Highland, but has become a tourist and fast-food strip, complete with 20 restaurants and a museum devoted to Jackson native Casey Jones (a famous railroad engineer involved in a major train collision around the turn of the century), all within a single square mile. The north end of town is where the major portion of new residential and business projects are booming, and is largely populated by whites. Driving south towards the center of town (takes ten minutes from the Interstate), well-kept older neighborhoods emerge, alternating with run-down older homes rented out to lower income families. Going past downtown,

driving south on Highland, the former town of Bemis (now a part of Jackson) is still apparent in the old cotton mill structures and shopping centers still bearing the name of Bemis. Bemis was created in the late 1800s by the Bemis Cotton Mill owner operators, who built schools, stores, and housing for former farmers looking for work.

The eastern section of town is considered the center of the black community in Jackson. East Jackson, as it is referred, suffers from lack of close grocery stores and shopping, and neglectful landlords. Industrial parks have made eastern Jackson a mecca of manufacturing, with a large Proctor and Gamble site responsible for Pringles potato chips, Van De Kamp's frozen foods, Pillsbury, Delta Faucets, plastics and metal industries, and sewing factories. A recently added minor league baseball park, Pringles Park, has brought new life to the eastern edge of Jackson.

Little variation exists in the religious life of Jackson, with the Baptist denomination being the most prominent sect. A synagogue exists, but does not advertise its presence, located in a quiet residential neighborhood with nothing but a faint Star of David stain glass window to declare its nature. There is also one Catholic Church in the community, located on one of the main thoroughfares. There are no Buddhist, Muslim, or Bah'ai temples or gathering places. While economic stratification does exist in the black and white communities, most prominent positions are held by white males. Working class people are steadily employed at the numerous factories. Several small colleges are present in the area, all with religious affiliations.

Political wrangling is still the norm in many towns and cities, and Jackson is no exception, even in daily encounters in the community. Jackson is particularly steeped in elusive social networks and unwritten rules. My assessment of Jackson is that of a

stubbornly provincial town which does not appreciate new ideas or transplants that introduce the ideas. When newcomers settled in Jackson in 1995 and 1996, road maps of the town were difficult to locate and outdated, causing problems in finding businesses.¹ Many businesses were not listed in the reference section of the telephone book, especially those owned and operated by African Americans, or those located in the traditionally black sections of town.

One example of the strength of the network was my search for firewood in Jackson. As the winter of 1996-97 approached, I began to look for firewood suppliers to reduce the winter heating bill in our drafty apartment. Only three were listed in the newspaper classified ads, and only two of them would deliver. I called one of the contacts and made an appointment for delivery, but the wood dealer never showed. I repeated the process with another ad. This proprietor also did not show. I began to wonder if my address in a mostly black neighborhood was affecting my ability to receive services. Finally when I mentioned my plight in front of one of the patients at work (who happened to be African American), she offered to give me the name and number of a family member who often cut and delivered firewood. Within the week, I had plenty of firewood at a reasonable price. This networking through people I knew at work and in the community became the only reliable way to receive services or find out where some item could be purchased, providing you used the name of the person making the referral for you.

¹Although newcomers to this area are still a minority, the city is growing rapidly and may soon outgrow its former small town flavor.

When I arrived in Jackson, the separation of the black and white communities in Jackson was immediately apparent and quite solid, though many in the community would have denied (and did deny) this fact. As with many communities nationwide, churches were nearly completely segregated, and residential areas were usually quite separate in most areas of the city. One nearly all-black section was commonly referred to as “East Jackson,” even though it was not a separately incorporated community from Jackson, nor was it listed on any map or in any reference book. The purpose of calling this area “East Jackson” seemed to be to let the listener know that the speaker was talking about a black, generally low-income neighborhood. During the first (very hot) summer in which I lived in the area, I was inquiring about finding a public pool in which I could cool off and take my one-year-old to play. When I mentioned a certain community center to a white patient with whom I worked, he looked around the room and whispered to me that that was a “black place.” He seemed pleased that he had been able to offer this bit of advice to a newcomer, implicitly warning me away from what was perceived to be the certain doom of entering a place separate from my proper societal path. These descriptions are typical of many communities in the United States, especially in the rural south; however many white Americans continue to deny the overt and covert indications of two separate and unequal races in this nation.

The separateness of the races (particularly of whites and African Americans) is a continual struggle for the local school system. In 1975, a federal judge ordered the three elementary schools to be clustered² to integrate these schools. As students reached the

²“Clustering” is the practice of pooling all students from particular schools, then redistributing them with roughly equal numbers of minorities in each school. In this case,

age to move to the 5th and 6th grade school, which was formerly all-black and was still located in East Jackson, the rate of withdrawal of white students to private schools suddenly and rapidly increased (The Jackson Sun, 1988). In 1990, the school system was ordered by a federal judge prompted by the local NAACP to negotiate the terms of a merger with the largely white county schools to ensure integration as the clustering system came to the end of its mandatory tenure (The Jackson Sun, 1990). Numerous private schools still exist and are largely white in composition.

Even today, if not for school integration, young black and white children might not come in contact with each other in the context of play and casual social interactions. The preschool-aged black children in the neighborhood in which we lived had obviously never had much contact with white children, as many would stare at my preschooler and pet his blonde hair upon first meeting him. The children of school age did not behave in this manner, leading me to believe that white kids were nothing new to them.³ Certain grocery stores tended to serve one community or the other, depending on location. Bars were often frequented by either blacks or whites, and some were known risks for African Americans.

Religion, specifically Christianity, was often used as a description which paved the way for interracial connections. For example, when I went to greet a new neighbor

one school was used for K-2, one for grades 3 and 4, and one for 5 and 6.

³Despite the casual interaction provided in integrated schools, it should be noted that black and white children do not randomly mix in structured or unstructured school activities at the middle school and high school level. Informants who have spent considerable time in the public and private schools note that in the lunch rooms, auditoriums, gymnasiums, and hallways, the two races generally keep to themselves.

who was a middle-aged African American man; he said, “No, I’m not moving in here, I’m just helping the family. They are good Christian folks, though, good Christian folks. They’re good folks.” He smiled and nodded his head a lot, and seemed over-eager to make a positive impression. Advertisements depicting child care providers in The Jackson Sun newspaper⁴ often included the phrase “Christian woman will provide child care for your child . . .” When checking for child care in the area, I discovered that this phrase was used for either white or African Americans, but the few African Americans who did advertise as providers almost always used this phrase. White child care providers used the phrase less often.

My interpretation of these and other interactions led me to believe that in this religiously conservative community with a church on nearly every major street corner (and on many minor ones), advertising oneself as “Christian” was an instant way of communicating that this person was more acceptable than those who would not profess this advantage. It was sometimes a way of making black people more acceptable to the white community. The African Americans with whom I came in contact who had need for child care services more often relied on relatives, friends, and neighbors, and did not rely on the local papers or Yellow Pages to find child care. Therefore, I interpreted advertisements in The Jackson Sun by black proprietors to be a primary tool for communicating with the white community. The Metro Forum, a newspaper which targets

⁴The Jackson Sun is the major local paper, and is owned by Gannett News Service. It employs a multiracial staff, and has done so since the early 1980s. It has a largely white readership. Reporting of African American events and news has significantly increased since the Civil Rights era, however there remain complaints that it still does not represent African Americans as well as it should.

the African American community in Jackson, was begun in 1989 and is a significant source of advertisement to the black community.

Jackson experienced substantial growth in manufacturing and the service industry, driving the population up quickly in 1995-1997. The Chamber of Commerce was key in selling Jackson as the home of a stable, reliable work force to incoming businesses (labor is cheap and tends to be union-free). Recently, particular efforts have been made to attract minority owned businesses (Bennett, 1997). The downtown area contained many old and abandoned buildings but has recently experienced a renewed effort to rebuild the county courthouse and other businesses. Many businesses had relocated from the predominantly African American downtown area to the prosperous (and largely white) northern section of town, where new housing was scarcely meeting the demands. Now, efforts are being made to halt the flow of urban flight.

Although the white community is largely unaware of them, a few major historical beginnings or accomplishments of African Americans has occurred in Jackson: The Christian Methodist Episcopal, or CME church (formerly known as Colored Methodist Episcopal) was founded in Jackson, Tennessee, in 1867. Lane College was created as the church affiliated school with Bishop Isaac Lane as its president, and the parents of Alex Haley were educated there. Shirlene Mercer, an African American anti-crime activist in Jackson, was the first person in the United States to institute community anti-crime marches, which has become a nationwide activity. Jackson is also known for home-grown musical talents such as Carl Perkins (wrote "Blue Suede Shoes" which catapulted Elvis Presley into the limelight), the ground breaking blues harmonica player, Sonny Boy Williamson, the blues singer Mabel "Big Maybelle" Louise Smith, and blues band leader

Big Joe Turner. Carl Perkins was a white rock and roll singer/songwriter from Jackson, and was known for popularizing black blues music and presenting “Rockabilly” music to an otherwise unaccepting white community (Meyer, 1998). Dr. Miles Lynk was the first black physician in Jackson, and published the first African American journal of medicine in the United States: The Medical and Surgical Observer.

Civil War societies are common in the Jackson area, such as the re-enactment organizations which sponsor performances every year at nearby Parkers Crossroads. The United Daughters of the Confederacy also has an active chapter, although membership is gradually decreasing due to lack of interest in the current younger generations.

Considerable letter writing has occurred in the local newspaper regarding the use or reverence of the confederate flag, with most letters favoring the continued displaying of the flag. Most area high schools have voted to ban the Confederate flag from school property to avoid racial tension, a decision which seems to have settled well with the community.

The education level of many Jacksonians and the surrounding region remains low; the state is ranked 49th in literacy in the United States, and Madison County has 6,679 adults over twenty-five (out of 48,976) who have less than nine years of education. Fifteen percent of all adults in the state are illiterate, and 39% are at remedial levels in educational measures (Literacy Foundation of Memphis, 1992). Many of the Jackson youth attending college are the first in the family to do so, and they struggle with the adjustment to the college setting with no family role models. The median household income, \$22,434, does not accurately illuminate the gaping chasm between classes and races. The value of the average white housing unit is \$66,242, while the value of the

average black housing unit is \$36,967 (Center for Business and Economic Research, 1991).

Points of Confluence

The black and white communities have made changes which are proving beneficial in the context of race relations. Since the outbreak of church burnings in 1996 and 1997 (a majority of which were within a four hundred mile radius of Jackson), churches across the community have increased communication and activities across racial boundaries. A new interdenominational and multiracial community choir now exists, with community acclaim at recent concerts. Traditionally African American and white colleges have joined in activities and choral performances. Diversity Lunches are sponsored by the city mayor, and take place on a monthly basis. These lunches have allowed prominent African American and white business leaders to get acquainted and discuss matters of importance. Significant African American holidays and events, such as Martin Luther King, Jr.'s Birthday, and Kwanza, are celebrated with positive media attention. The Chamber of Commerce has identified minority businesses as the target of growth in this area. These beginnings are hopeful signs in a community which has historically been divided.

The Hospital

The separateness of the black and white communities in Jackson is apparent in the physical rehabilitation ward at the larger of two hospitals in Jackson. The hospital system is the largest employer in Jackson and in Madison County, employing 5000 people in its

entire system, and occupies a ten-acre campus as well as several off-campus clinics and hospitals. The vast majority of the professional staff members in the rehabilitation ward are middle class, white (with many from other regions of the country and abroad), female, and between the ages of twenty-two and thirty-five, whereas most of the nonprofessional staff are of the working class or working poor category, African American, female, and between the ages of thirty and fifty-five.

Ninety percent of the patients in the ward were white in 1996-97, and ten percent were African Americans, most of the latter being above the age of sixty. Most of the patients were considerably lower in educational and economic levels than the professional staff.

Getting In

I had been an occupational therapist for 10 years in 1996. I had worked in five major hospital systems in a variety of health care settings, providing me with background and depth of knowledge of health systems and policies. This knowledge and familiarity with hospitals and clinics had been essential in gaining easy access to hospital patients in past research or clinical evaluation experiences. I also had interviewed or worked with over 2,000 patients in my career as an occupational therapist. Occupational therapists were in short supply nationwide (especially in the rural South), and I assumed that I would be able to easily find part-time work as an OT while I completed the fieldwork phase of my research.

To my surprise, “getting in,” that is, becoming accepted in my role as researcher in the rehabilitation unit, was time-consuming and frustrating. Hortense Powdermaker

(1939), captured the essence of the introductory phase of fieldwork in any setting, stating that "it is essential that the field worker should in the beginning have some easily understandable and acceptable role, other than that of professional observer." Having been an occupational therapist for ten years, I assumed that I would have less difficulty gaining access to research subjects, especially when a few professional connections could be established. When my husband gained a position at a small college in Jackson as a music professor, I began my search for facilities where I could gather data in Memphis,⁵ starting with an introduction by a local medical anthropologist. This professor warned me that the environment was very closed in this city, especially if the subject involved race matters. I felt, however, that I might be perceived as an "insider" since I was a health care professional, and that this would allow a much improved ease of movement into and within a hospital or clinic. Despite a few significant contacts established in area hospitals and universities, most phone calls went unheeded for months. Life was complicated by my struggle to find part-time work in order to continue my research, and to locate appropriate child care for our nine-month-old infant who seemed to be on the road to chronic ear infections. At the point of having to sell possessions to buy groceries and antibiotics for our son (my husband often travelled as a musician, therefore single-parenting became a role at least three months out of the year), I came to the conclusion that ideological stances regarding separating work from research were a luxury I could no

⁵Although I lived in Jackson, I did not want to pursue research in the same facility in which I was a paid employee because of difficulties encountered in past ethnographic research. Inevitably, the researcher is frequently placed in an awkward position of choosing between loyalty to the research project versus loyalty to a highly competitive health care system, complicated by inquisitive coworkers who want to know why you chose to speak to whom.

longer afford. I plunged wholeheartedly into the search for work which would also provide a population of informants.

Occupational therapists are in great demand in most regions, and I expected to find several openings with the hours of my choice. Once again, my confidence (some might say overconfidence) was eroded when facilities promised home health caseloads that never materialized. Facility managers with whom I spoke seemed curious as to why I wanted only part-time work, and how I came to be in Jackson. As many have experienced in the South, timeliness is not valued, but socially established connections are of the utmost importance. Native Jacksonians took note if one had to ask for directions to get to a business,⁶ and immediately commented on differences in accents. I began to use a more native accent and refrained from giving clues which might suggest that I was from elsewhere. This resulted in quicker acceptance and less curiosity about why I had moved to the area, presumably because I was not initially detected as a stranger. Initial social conversation about local events or people was the normative way of establishing a base for doing business, at which time I could mention that I had a young child. I found it easier to gain acceptance in this “buckle of the Bible Belt” to let others assume I wanted to be home with my child part of the time, but needed part time work. It is no coincidence that I finally found work through a New Jersey native who was accustomed to hiring from outside the area.

⁶Directions often included references to landmarks which may or may not still exist, i.e. “Turn right where the old mill used to be. . .”

Once I finally gained part time employment, I began getting to know the medical director⁷ of the rehabilitation unit in which I was employed. I told him of my dissertation research, and he was very pleased to have someone doing research within his facility. With a letter of support from him and the administrative director, I began the process of research approval within the hospital system. Once again, I was treated as a suspicious stranger when I contacted the Chief of Staff's office, and tried to obtain information on the process of research approval:

CA: "I am an occupational therapist on the rehabilitation unit, and I am calling to get information about doing my dissertation research within the hospital. Is there a board which oversees this activity?"

Secretary: "You have to get approval to do that kind of thing here. You can't just do research without permission."

CA: "Yes, I know. That is why I am calling. I have a recommendation from Dr. C and from Mr. R to begin this process. Can you tell me how I can begin?"

Secretary: "Does Dr. K [chief of staff] know about your research?"

CA: "No, I haven't yet spoken with him. Is he the person with whom I should make an appointment, or do you have an application I need to fill out?"

Secretary: "I don't know about those things. There is a review board which meets every quarter. You need to go through them. John Jacobs is in charge of that."

CA: "Can you tell me where to contact him?"

Secretary: Pause. "He is the Director of the Cancer Center." (This last statement had a note of amazement at my ignorance).

⁷The medical director was a native Grenadian of African ancestry. This may have been a significant factor in gaining approval and support from him for research.

When I contacted this person's secretary, I was given verbal information on what had to be submitted. I gathered the appropriate materials and immediately sent them to the office. After a few weeks, I called back to check on the progress of my approval. I finally spoke to the actual chair of the Institutional Review Board, and he stated that I needed to fill out the application before I could be considered for approval! Trying to keep my frustration from boiling over at a goose chase that had taken several months now, I asked for a copy of the application. I obtained all the necessary materials, and sent them to him. I called to check on the progress, and no return calls were given. Dr. C, the medical director of the rehab unit, continued to ask me how my research was going, and I told him about my frustrations. He made a phone call that day, and the chair of the Review Board called me and apologized for having lost my packet on his desk. He said there should be no problem with my project, and that I could commence with interviewing subjects. A written consent soon followed. After trying for nine months to get research approved, it suddenly came through with a strategic phone call from a doctor and at the seeming whim of the Review Board Chair. No questions were ever asked of me regarding my research from the review board, except to give an annual update on how many subjects I had involved in my study.

This type of process was repeated in many social arenas until I began to slip into the social dance required especially when frequenting white-owned and managed businesses:

CA: "Hi, how are you?"

Proprietor: "Just fine. And how about yourself?"

CA: "Just fine. I was just talking to my friend, Mr. Butchy at ABC business, and he told me that you all do the best work on carburetors in town. Have you got any openings today to take a look at my car?"

Proprietor: "I believe we do. What seems to be the problem? . . ."

Conversation would often turn to community events or weather, and would end with a congenial goodbye. I was careful not to ask for a time line, as this would have pointed me out as untrusting of the mechanic's ability to finish as best he could. "There's no cause for people to get ugly" was a frequent comment encountered regarding anyone displaying assertiveness or (heaven forbid) aggressiveness in business encounters.

Dropping names and giving complements were near essentials in initial contacts. Having little knowledge of or not using this social banter provided enough of a barrier to keep unwanted people out of any given business or network. Those individuals who had not come into contact with the accepted business community may not have learned the social codes necessary to successfully negotiate daily interactions.

Although this lack of "customer comes first" mentality seems unusual in the midst of a materialistic culture, it is a subject that is commonly discussed among residents new to the Mid-South. The local newspaper editor commented on the problem of being unwelcome as a newcomer to Jackson, and solicited stories from new arrivals to monitor this ongoing challenge in the community. My perception is that the customer does not come first in this community, unless they are richer in social network, local family history, and/or monetary funds than the proprietor of the business. Positive social relations (or at least the appearance of positive regard) are more important in the culture of the South than other aspects such as economic gain, school, or employment.

Initially, I was employed as a staff occupational therapist working primarily with outpatients, and would be a substitute therapist as needed for inpatients. After 5 months, I accepted the newly vacated position as Acting Supervisor of inpatient occupational therapy, a department with 13 employees. I was considered to have a good working relationship with all departments, as well as having the most experience of any of the occupational therapists.

The Rehabilitation Unit

As I walked down the hall one day toward the physical therapy gym, I was met by cacophonous sounds of therapists speaking encouragingly, loudly, and firmly to patients to “stretch it out a little farther,” “just two more steps,” and “come on, you can do it.” What that must sound like to someone who has never been near a physical rehabilitation unit, much less a hospital! Many patients, especially elderly ones, expressed fear of therapy, assuming that painful torture was a part of the routine. One elderly woman refused to go to the therapy gym on her first day because “those Amazon women will hurt me.” Sensory overstimulation is a significant factor for both patients and staff. The occupational therapy gym was especially cramped, and staff members often spent several minutes per thirty minute treatment session rearranging patients, staff, visitors, and furniture in order to fit everyone in (try fitting 9 patients in wheelchairs, 5 staff members, a mat and 3 tables, 6 large cabinets, and 7 desks against the wall into a room which is roughly 15 ft. x 40 ft.). We were continually promised a new space “sometime next year,” but I had my doubts as to whether it would be adequate considering the general

clamor for space in the hospital building. See Figure 1 for a general lay-out of the rehabilitation unit.

The patients were selected for the rehabilitation unit by the physiatrists, who were consulted in cases where rehabilitation is being considered due to the patient's lack of ability to care for him or herself, or due to the lack of a better placement.⁸ Selection involves deciding whether the patient has the potential to benefit from rehabilitation (they must have the potential to improve their mobility or self care status, or their families must have the potential to learn to provide the appropriate level of care for the patient), or whether the patient is able to tolerate at least 3 hours of therapy per day. The physiatrist, admission nurses, and/or discharge planners talk with the patient and family, advising the patient of the recommendation for admission to the rehabilitation unit, and explain the purpose of rehabilitation. Patients and families are often in a state of shock at what has happened to the patient, and frequently do not remember or comprehend the detailed explanation. When written materials are given, the patient and family are much more likely to come prepared for the rehabilitation experience.

Admission packets include information on what clothing to bring (clothing with allows comfortable and free movement, and which are familiar to patient and relatively easy to put on--no pajamas during the day, as the goal is to get the patient back to a productive and normal role rather than the sick role), what therapies are available, and what other staff members may be available for assistance (social workers, psychologist, patient advocate). A consent for treatment is obtained from the patient (or from the

⁸The patient may be within the hospital itself on another floor, or in another hospital or long term care facility.

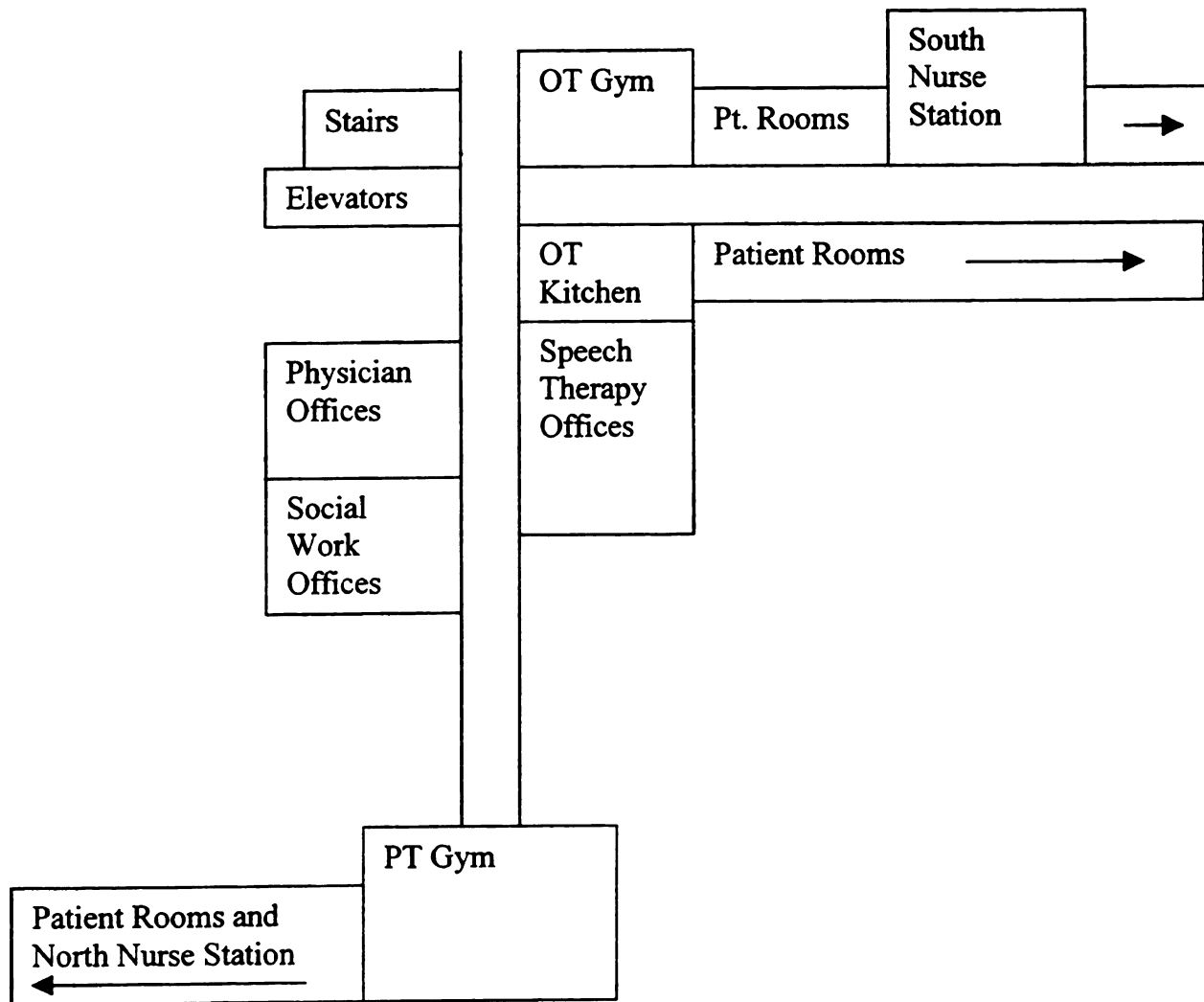


Figure 1. Rehabilitation Unit Layout (diagram not drawn to scale).

family if the patient's competence has been affected). Once the proper insurance precertification has been obtained, the patient is then transported with all belongings to the rehabilitation floor. A nursing and physician assessment are performed first, and a wheelchair is selected for the patient to use. The therapy assessments commence within the first 24 hours. These assessments include evaluations of bed mobility, self care, strength, coordination, visual perception, language abilities (presence or absence of aphasia or dysarthria), cognition, ambulation or wheelchair mobility, transfers, family and social history, and premorbid status of the patient.

The organization of the staff in the 50-bed rehabilitation unit within the 750-bed hospital was typical of rehabilitation units around the U.S. (see Figure 2). The hospital was jointly owned by the city and county, and was a not-for-profit, public system. One point of interest is that the staff members at the bottom of the pyramid, having the least amount of prestige and power, are the ones who spend all of their work day in direct patient contact.

From another perspective, dealing with seriously ill or injured people is a highly stressful job. Escaping this stress is a frequent need of staff members, and some may find solace in moving into supervisory roles, allowing the health care worker to stay within the context of "helping people" without burning out on patient care. As I noted one day in my field notes,

November 21, 1996: I attended a "Guest Excellence Revisited" lecture by a motivational speaker who works for the Disney Corporation. He had a well-polished presentation about being "people who care for people" which was not superficial like so many of these presentations. What I kept coming back to was that this was the way that the institution tries to continue to motivate employees that are more and more stressed. The speaker talked about caring for our patients as if they were our invited

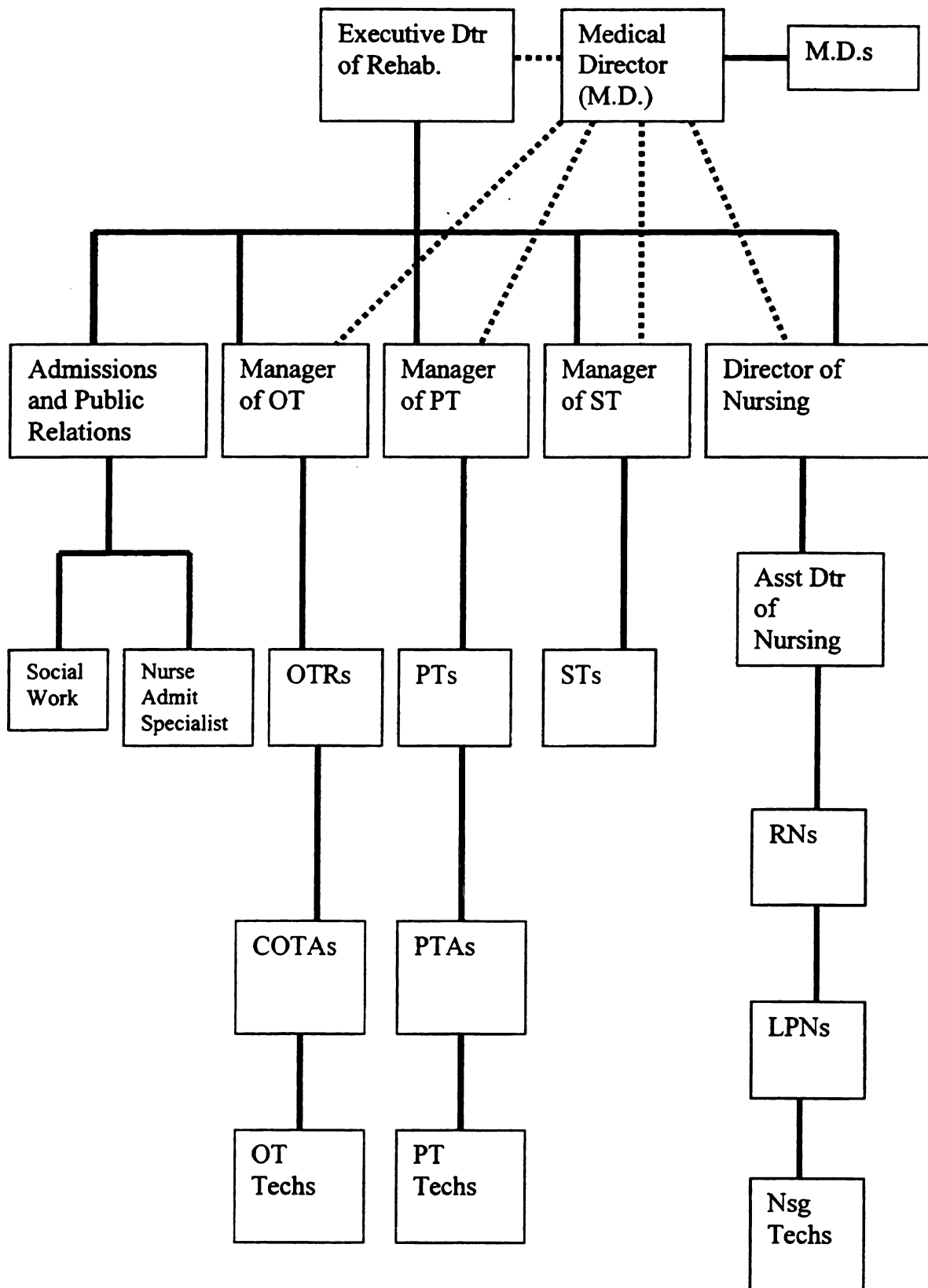


Figure 2. Rehabilitation Department Organizational Chart

guests, and about not complaining about the place in which we work while in ear range of guests. Perhaps I am a jaded old therapist, but I wondered how he (and our administrators) thought we got to the place we are now--tired, complaining, and stressed. We have no private spaces in which to legitimately air grievances or difficulties throughout the day, we have more and more patients, and less time to do everything, and we feel badly when we can't offer the services to our patients and their families that we know they need. Paying an excellent motivational speaker thousands of dollars to speak to all of us hits just the tip of the iceberg. Why can't they see that if people enjoy their work and feel like they are doing a good job, that half of these issues disappear?! With appropriate workloads and the occasional discussion about how we are dealing with the grief all around us, we don't begrudge 5 or 10 minutes per day of helping people out, and we are even able to get to the extras that really make a difference to patients and their families.

This pattern may inform the discussion on why so many misunderstandings take place within the context of the hospital environment, and why more and more patients and family members complain of a less personal environment.

The prestige and power surrounding the medical field became clear with an excerpt from my fieldnotes regarding one informant. He was discussing why he preferred not to hire people with a medical background as his own personal care attendants:

I also spoke to a new volunteer who is a C₄⁹ quadriplegic [paralyzed from the neck down]. He talked freely about his accident 11 years ago when he was in the Army Special Forces, completing anti-terrorist training. He was rappelling down a building, and was to throw a grenade into a window, when the grenade bounced off of something and blew apart his support ropes, causing him to fall 3 stories. His femur was severely fractured, and it severed his femoral artery. He was medi-vaced out, and required nine pints of blood before surgery was even considered. I personally can't believe he lived. Anyway, he is a very talkative fellow, to the point of my not being able to get a word in edge-wise. I finally did get to explaining

⁹A person with this level of spinal cord injury may have the ability to shrug his or her shoulders, but is otherwise paralyzed from the neck down. This particular informant used a joystick near his chin to control his electric wheelchair, and he was able to breathe without the use of a respirator. He lived with his parents, and hired personal attendants to help with his daily care.

my research, and he had some very interesting comments. "I prefer not to hire personal care attendants with health care experience, because they have a 'know-it-all' attitude. They often have trouble letting me be the boss, and attempt to change my routines even when I protest it! I guess they think with their experience, that they know better what I need than I do. People in the health care field are 'corrupted' by being hardened and burnt out, as well as dominating. I don't have the ability to reach over and grab them and make them stop. The only power I have is over who I hire. So I hire people with no hospital or nursing home experience, and train them up myself."

The perception by medical staff members that they know best for any and all patients was a common theme when speaking with staff members on a daily basis. The implied "naturalness" of the staff authority and knowledge over the patient is an indicator of ideology (Taussig, 1980). The unconscious ideology of the staff implied the assumed "rightness" of compliance and "wrongness" of noncompliance.

The administrative organization of the rehabilitation center included an Executive Director who reported to one of nine hospital vice-presidents, who, in turn, reported to the executive vice-president, who reported to the chief executive officer. The structure and administrative functioning of the rehabilitation unit was as follows: all standard nursing functions were part of the "routine" orders, which were automatically performed upon admission (including vital signs, assisting with self care, dispensing of medications). Functions which were not standard, such as placing of restraints, or arranging for special dietary constraints, required a physician's order. Physical and occupational therapy were automatically ordered for all rehabilitation patients, and speech and recreational therapy were added as needed by order of the admitting psychiatrist. Contact between the therapists and physicians consisted of weekly team meetings and chance meetings in the halls. Other than these direct contacts, the therapists generally had

the independence to create and follow the treatment plan within the standards of practice for each field. Each therapist typically spent approximately 75% of his or her day with 4 to 10 patients which had been assigned to this “primary” therapist, but the use of substitute therapists, assistants, or technicians, was common as meetings had to be attended or progress notes written.

Documentation for therapists consisted of weekly SOAP notes (divided into subjective data, objective data, assessment of the patient’s condition, and treatment plan) on each patient (see Appendix C for an example), as well as brief daily notes describing the activities completed and patient’s response. The therapists may also be required to write additional progress updates on particular days for the purpose of the insurance company. Team conference notes and FIM (functional independence measures) forms are also completed by therapists and nurses on a weekly basis on each patient. The physician ultimately decides on the length of stay in the rehabilitation unit, but the therapist has the ability to discharge the patient from a specific therapy. Due to the Medicare rule that patients must have at least three hours of therapy per day in order to justify an inpatient admission in a rehabilitation unit, this discharge from a specific therapy happens only on rare occasions. If a patient is discharged from a particular therapy, the other therapies have difficulty making up for the time lost from the discharged therapy. In most cases, the therapies compromise with each other, stretching a little on the goals so as to continue to prove the “necessity” of each therapy, allowing time for the more necessary therapy service to accomplish the patient goals within the estimated length of stay.

The typical daily schedule of a patient in the rehabilitation unit began with being awakened by nursing aides (called “technicians”) at 6:00 a.m. for toileting, being

weighed, and beginning to get dressed. Showers, which were given every other day, were saved for the evening shift of nurses, as mornings were considered too busy with meals, toileting, therapies, and the dispensing of medications. Some patients would be scheduled to work with an occupational therapist by 6:30 for dressing training, others began breakfast. For patients in physical rehabilitation, self care activities (such as bathing, dressing, personal hygiene, and toileting) often lasted for 2 hours, due to the increased difficulty and length of time required to move paralyzed limbs, transfer from bed to wheelchair, use a non-dominant arm for eating and brushing teeth due to paralysis of the dominant arm, or to get dressed while lying in bed due to the inability to stand. Patients then went to the dining room to eat breakfast with the other patients, with the assistance of nursing technicians. For those identified as having difficulty feeding themselves, an occupational therapist or assistant and a speech pathologist would have these patients grouped at a "feeding group" table.

Therapies would resume in the PT or OT gym or speech pathologists' offices by 8:00 a.m. Most patients attended an hour of occupational therapy (if they had not already worked with one in the early a.m. for dressing), then a half hour of physical therapy, and a half hour of speech therapy by lunch time. Lunch was served in the dining room again, usually at 12:00, then therapies resumed at 1:00 p.m. Most patients were encouraged to stay in their wheelchairs all day if possible, as getting in and out of bed was time consuming for the staff. The patients who were more vocal and assertive about resting received more attention to creating a schedule which allowed for an extended rest period. An hour of physical therapy, perhaps a half hour more of OT and ST, and sometimes a therapeutic recreation activity followed in the afternoon, completed by the 5:30 supper

hour. Showers were begun immediately after supper. Many patients were exhausted by this time of day, and were desperate to get into bed. Patients often complained of exhaustion, which is no surprise if one considers the effects of severe illnesses, surgeries, and bed rest on endurance level. A majority of the patients were over sixty years of age and in poor health before their hospitalization, which contributed to the exhaustion factor. Light sleepers also had problems being able to sleep in a busy hospital, which may explain why many patients were encouraged to take sleeping medications.

Discussion

When comparing experiences with other graduate students and other anthropologists, I had assumed that my experience as a health professional would lend itself to ease of movement within another hospital bureaucracy. The difficulties I experienced resulted from many factors. The hospitals in which I had completed research in the past were teaching hospitals associated with major universities. The Jackson hospital was unaccustomed to research projects, and I suspect the Institutional Review Board had never dealt with research initiated by a non-physician, or with research with a social science emphasis.

Another factor which is of considerable importance in the South is the “Yankee” factor. While I was born and raised mostly south of the Mason-Dixon line (the Ozarks of southwest Missouri), I was not from a “Southern” state, and my Ozarkian accent was somewhat different than the Southern drawl of Tennessee (undetectable distinctions for those who have never lived in or near the South). Being labelled a “Yankee” was a definite negative in Jackson social etiquette, for it was a symbol of the invasion of an

unwanted population. In Jackson, and in the South in general, public criticism of anyone or anything is taboo and lacking in gentility, even if a person is asked to give an opinion. Anyone who publically criticized Jackson or its residents, or its history, was subject to being labelled as a "Yankee," and identified as someone to distrust.

As I became more guarded in my responses and maintained a positive and friendly demeanor (hence the term "Southern hospitality"), I encountered less opposition. Having to seek information or respond to queries in a socially-necessary indirect manner, however, often added considerable time and effort to my data collection.

My young age (31 years old upon moving to Jackson) and my gender may also have contributed to challenges in being considered as a serious researcher by the mostly middle-aged, socially-correct white men in administrative positions. In some communities, higher education degrees are an advantage in social situations. In Jackson, I was regarded as an oddity, if not an over-educated Yankee woman with bad intentions, bringing up subject matters that were "over and done with in the 1960s" or too painful or critical to discuss with anyone, much less an outsider.

Last, I was an anthropologist studying "us," which was met with suspicion by staff and patients alike. Most informants' idea of an anthropologist was of someone who studied old bones or contemporary and exotic "others," not as social scientists seeking to make sense of medical and social matters within our own society. The discomfort and initial suspicion expressed by some informants reflected an informed public who knew the power of information and interpretation, and who did not wish to be under the microscope. I also experienced this discomfort, especially in light of the social taboo against public criticism, and became anxious that a local newspaper would somehow find

this dissertation and use bits and pieces out of context to the detriment of myself and the community.

Due to the assistance of some key people (the Medical Director of Rehabilitation Services who was a native of Grenada, the Supervisor of Occupational Therapy who was a native of New Jersey, and an administrator who was a native of Connecticut), I was able to finally access the patient population and successfully collect data.

Chapter 6

THEORY ON THE GROUND IN JACKSON

Anthropological Theory: Praxis Explored in Jackson

When applied to a small town in the Southeastern United States, the construction of knowledge can be exemplified by the concept of race. Most citizens of Jackson view race as a biological category which is solid and unchanging, and which has a variety of related traits encompassing the physical, moral, emotional, intellectual, and spiritual realms. Anthropologists have revealed that race is a social category, not a biological one. The use of anthropometrics and morphology, which was a common way to categorize races in the recent past, produces no distinct populations which are coherent, measurable, and hereditary in nature (Barrett, 1984; Burgess, 1978; Livingstone, 1964; Sauer, 1992; Smedley, 1993). Despite visible differences among “races” in the U.S., the genetic patterns are not correlated with skin color and other aspects of appearance that are taken as emblematic of race. In other words, there are as many differences within races as there are among races, making “race” non-functional as a morphological or biological category. Race is a social category, not a biological one; therefore, it is socially constructed. Anthropologists are more likely now to use the term “ethnicity,” referring to a categorization which encompasses shared language, institutional forms, material culture, and cultural products (Johnson, 1995).¹

¹For further discussions of ethnicity, anthropology, and symbolism, see Burgess (1978) and Gans (1979).

Socially constructed races are the foundation of two nearly separate communities in Jackson, and have been since the immigration of European settlers and African slaves in the early 1800s (see Chapter 4). Racial conflict is also the foundation of decades of discontent in this area, with African Americans and whites living (with few exceptions) in uneasy sequestration from one another. The discourse between the two communities, or lack thereof, is embodied by every person growing up in the town and surrounding counties, and shapes the explanations of social inequality. How is this embodied, and why would these communities develop such different embodiments?

Acquisition of Embodied Traits

Movement patterns are the result of years of forming neural pathways which are linked according to the function of a particular movement (Quartz and Sejnowski, 1997), that is, contextualized by the goal of the activity, place, position in space, and the cultural or social function of the activity. As a young girl, I spent many summer evenings attending my younger brother's Little League baseball games, and I was fascinated by one of my brother's teammates and his father. This father and nine-year-old son had something in common: they had the exact same walking pattern.² They did have similar builds, but how could a boy consciously learn and imitate his father's posture in just nine years? I would wager that if either of them had been told that they walked just alike, they

²Some researchers in the field of physical medicine suggest that changing postures can actually influence a person's affect. For example, some patients who are depressed exhibit a slumped posture. When cued to use a more upright posture, their demeanor changes, and facial expressions become less sad or dull (Burkhart, 1997; also validated by many personal experiences with depressed patients). This is embodiment and re-embodiment in action.

would have been surprised, and then perhaps self-conscious of this fact, thereby changing the way they walked for a period of time. The genetic similarities between these two people could not explain the postures in isolation from other factors, such as walking posture as a form of communication, the emotional meanings of a given activity such as walking, or the cultural or social context of an event in which walking is an integral part. This exemplifies the habitus of which Bourdieu writes. Taken to its inevitable extreme, this line of reasoning leads one to consider and begin to understand that when groups of people live in isolation from one another, they form different ways of perceiving and approaching life events, and ultimately, different interpretations of history and the present (Hall, 1976). As Ruth Frankenberg described, “. . . experience constructs identity . . . there is a direct relationship between ‘experience’ and ‘world view’ or ‘standpoint’ such that any system of domination can be seen most clearly from the subject positions of those oppressed by it,” (1993, p. 5). Humans create variety across the world through the process, but they also create conflict when differences arise in interpretations, and particular interpretations are favored in the struggle for power and the distribution of resources.

As discussed earlier in this document, the African American community and the white community in Jackson have been isolated from each other since the beginning of the town’s history. African Americans have had fewer places to choose to live, poorer schools leading to poorer literacy levels, lower paying jobs, and less access to daily business opportunities. Those interested and successful in moving to a higher social class learned the “code switching” required in behavior, language, and socialization which would allow upward mobility in the mostly-white business community (Snow 1993;

Stack 1974; Powdermaker, 1966). This code-switching entails speaking less in a variant dialect and more in a standard English dialect, a change from informal to formal behavior, and limiting discussion to benign small talk. Children growing up in the white community remained fairly ignorant that another community existed until exposed to black children and families through school integration, which did not occur in Jackson until the 1980s (and is still questionable in several schools). With no economic or social incentive, and often with negative pressure against it, whites had no reason to cross the color line and learn about African American culture in their own community.

Western Individualism Meets Embodied History

One of the major issues with race relations today is that a part of our population says “Why keep bringing up the past? I have done no wrong--I have had no slaves,” and another part of our society counters with, “This is not over. It will never be over.” The following excerpt was found in the local newspaper after discussion of a presidential apology for slavery had been highlighted in the news media, and was written by a recently hired community commentator, who is a white woman in her sixties:

Are we truly beholden to correct the mistakes, sins if you will, of our predecessors? I am so sick of being told that we must make just retribution for the past! Yes, many Japanese Americans were unjustly incarcerated, but that is what war is all about. And remember, the Japanese attacked us! Yes, slavery was wrong and cruel, but as many black people as white people owned slaves and that was just the way of life at that time in history. To whom do I turn to get retribution for my ancestor, who was unjustly accused as a witch and burned at the stake? To whom do I turn for recompense for the political stupidity which caused the depression and brought such grief and misery to so many? To whom do I turn for justice for the years my children were made to learn new math and missed all that good quality time of learning in the classroom? My taxes paid for that shot of stupidity! Who repays me? Let's stop whining about

the past and get on with today's challenges of living peaceably together ("Readers tackle issues from TennCare to racism", *The Jackson Sun*, March 29, 1998, p. 4F).

The next excerpt is from The Metro Forum, a newspaper targeting the African American community in Jackson, and published by the National Newspaper Publishers Association.

The article is by columnist Shirlene Mercer, a well-respected black community activist³:

There was a list from the . . . [Jackson Sun] newspaper which features the most powerful [people] in Madison County. No African Americans nor women were among those listed. . . . I would like to take the privilege of suggesting several persons who could be matched up with any person of power and influence. . . . So many people are being honored in Jackson, but it is heart breaking to see our community being overlooked. Black organizations should feel compelled to give honors to those within the community who spend time dealing with troubled youth and older citizens. ("Politically Speaking," The Metro Forum, January 13, 1998, p. 4)

The language of anthropological theory is key to explaining this schism in understanding about our history as a nation. How have two groups of people living in the same region of the world--European Americans and African Americans--developed such divergent world views on societal issues surrounding race? Cosmological differences, economic pressures, and continued (and perhaps increasing) separation from each other have contributed to differing understandings of the past and of the necessary future steps for improving relations. Specifically, the ideology of individuality so strongly endemic to

³It should be noted that Shirlene Mercer was also Chair of the Board of Trustees at the hospital in which I was doing my research, but few white people in the institution knew of her column or its contents. Ms. Mercer single-handedly started the community anti-crime marches in Jackson, which were the first of their kind in the nation. Ms. Mercer is also on several state and national hospital organization boards. I would characterize her as the most powerful and compelling black woman in Madison County, if not the state.

European American culture clashes directly with the community-oriented African American culture.

Political Economy: The Bottom Line Masquerades as Necessity

Personal independence in daily activities is central to the goals of occupational, physical, and speech therapy. At times, these goals override and conflict with the intent of the rehabilitation team to guide the patient through purposeful and culturally meaningful therapeutic activities and to include the patient and family as a team members. While working in a small rehabilitation unit within a larger, for-profit hospital in Virginia, my coworkers and I noted that patients needing physical rehabilitation were rare and aggressively sought after due to competition with the larger hospital across town. Frequently, patients were admitted from a nursing home setting, then returned to that setting having made very few changes in physical or functional status: that is, patients were no more independent or strong than when they left the nursing home, and were not significantly more able to care for themselves. Due to the Medicare rule that patients must attend three hours of therapy per day in order to continue to qualify for intensive inpatient rehabilitation, deconditioned and fatigued patients were aggressively “encouraged” to attend therapies, even when they had no desire to attend. Goals such as “Patient will be independent in upper extremity dressing” were frequently noted in the medical chart, when the therapists and nurses knew it probably would not continue when the patient returned to the typically short-staffed nursing homes. Helping the patient to struggle through an hour of independently dressing herself was not something that nurses’ aids would have time to do once the patient was back in the nursing home, and the

patients often expressed the fact that they were not interested in pursuing this goal.

Perhaps a more realistic, meaningful, and patient-centered role for the therapists would have been to work with patients in the nursing home to accomplish small goals of being able to feed themselves a little better, or being able to remember and play with their great-grandchildren. Alas, the hospital needed the income provided by therapy services, and there were no funds or willingness in the nursing homes to provide ongoing therapy, so the pattern of admitting these patients into the rehabilitation ward in the hospital continued. Therapists clung to the sometimes unreachable ideals of physical independence, rather than enhancing the current social or familial roles of the patients.

How do all of these concepts affect people labeled as non-compliant, disabled, or "different" ethnically or according to class? When we examine how institutions are formed, we see that they follow the ideals, policies, and beliefs of the dominant builders of the institution. As Geertz suggests, cultural systems have the capacity to express the nature of the world, and shape the world according to those dimensions (1973). In this society, white, able-bodied, middle- to upper-class males have had the resources necessary to build businesses and institutions, and traditionally have had control over the process of making policies for these organizations. When patients enter a hospital which has been built and managed by the dominant group, and the patient is from a non-dominant group, conflict inevitably arises.

A scenario I observed which exemplifies this difference in cosmology is that of a physician, Dr. John, who labeled a patient, Martha, as noncompliant, thus ridding himself of individual responsibility for the illness. Martha became frustrated that Dr. John would not take seriously her complaints about working conditions at her plant or about the lack

of an affordable pharmacy within reasonable traveling distance. In the field of physical rehabilitation, a more common example is the rehabilitation professional who insists on the therapy goal of independence in dressing and bathing with a patient who knows that his family will be assisting in these tasks. Conflict ultimately arises when the occupational therapist comes into the patient room for dressing training, and the patient has already been dressed and bathed by his daughter. The patient may refuse to repeat these tasks just to placate the therapist (the occupational therapist is required to observe an activity in order to evaluate the patient's performance of the activity of daily living). Upon refusal of this evaluation, the therapist will absolve his or her individual responsibility in improving the independence in dressing and bathing of this patient by labeling him noncompliant. The therapist then recommends discharge sooner than he or she originally intended. This scenario has often been repeated in my twelve years as a practicing occupational therapist in several cities and states.

Other misunderstandings occur when professionals are unaware of the history or cultural practices of a patient's ethnic group. One particular incident involved Mr. McGee, an elderly black man in the hospital after having suffered a stroke. His young, white occupational therapist, Sherrie Hampton, reviewed the OT's role with Mr. McGee, stating that she would be coming to his room in the morning to help him get dressed. The next morning found Mr. McGee already dressed by his family members. When this occurred on several occasions, another staff member learned from the family that Mr. McGee had grown up in the deep South, and had known of black men who had been lynched for being alone with a white woman. Mr. McGee was reluctant to put himself in

the position of being alone with a young white woman, especially when disrobing was required.

Another example of lack of knowledge or comfort between ethnic groups was described by Toni Proctor, an African American rehabilitation technician: "I think a lot of white therapists are afraid of blacks. They have no idea what to do with black patients' hair. Most times they just leave their hair uncombed in the morning, because they don't know how to fix it. They could at least take a comb to it!" Maggie Anderson, a white therapist, relayed another example of ignorance among health care professionals. She recounted the story of a young white therapist working with African American patients for the first time. The therapist, Janice Gunner, saw the bath water that a black patient had used, and commented on how dirty black people were, as evidenced by the dirty bath water. Maggie pointed out to Janice that used bath water has significant amounts of skin cells, and that it is easier to see the darker skin cells of darker people in a light colored bath tub.

The community orientation of the African American culture may be related not only to cultural roots in various African cultures, but also to economic necessity (Stack, 1974). One family with whom I had contact experienced economic upheaval with initial loss of the sole breadwinner. The family abruptly changed from a solidly upwardly mobile, middle class family to a family headed by a single mother raising three children on a quickly diminishing bank account. As finances became more sparse, the values of fierce individualism in maintaining a certain financial lifestyle gave way to an emphasis on sharing resources with another single mother and her children and seeking money and assistance from the extended family, close friends, and former business partners. Hence,

a community network was formed to ensure stability and prevent the family from having to seek governmental assistance or filing for bankruptcy. This example suggests that below a certain critical income level, networking and sharing can become vital strategies for providing for families. Since African Americans are over-represented in the lower socioeconomic categories (as described in earlier chapters), more African Americans are at or below this critical income level. Networking and sharing of resources is common in lower income African American households (Stack, 1974). This process facilitates the development of a community-based rather than an individual-based concept of self in low income African American communities.

The divergent values of individualism and the socially embedded self facilitate the conflict manifested by the newspaper columnists quoted earlier in this chapter. Another factor which continues to widen the divide is racism. For instance, a vast majority of the white Americans with whom I came in contact and who were native to the area believed that interracial marriages were wrong. When questioned further about these beliefs, most espoused feelings of negative regard toward African Americans in general. While in a grocery store one day, a white woman (assuming that I believed as she did) saw a white mother with interracial children and said to me "Isn't that awful? Why would she want to do that?" The meaning of her statement was obvious: the white mother had committed a wrong by having children with a black man. Another white man commented on the difficulties that a rural hospital was having, explaining it by saying "Well, they have a black administrator," indicating that this was the obvious explanation for the struggles the

hospital was experiencing.⁴ Some African Americans also had negative attitudes toward interracial bonds, but these attitudes were more often expressed as resentment towards the black person for abandonment of the race. While it has become chic to equate anti-white prejudice with anti-black prejudice, I have found that they have different origins, as the aforementioned example shows, and they certainly have differing levels of power and influence. When the vast majority of the successful businesses are owned by whites, and the majority of public offices are held by whites, the power differential is unquestionable.

As with the example of Darryl and Jackie in the beginning of this chapter, the two major racial groups in Jackson are operating on different maps of how the world works. With neither party ever communicating deeply with the other, these differing experiences facilitate conflict and misunderstanding. Even those who had prided themselves on having “seen the world” still viewed the world through lenses shaped by years of separation, assumptions, and ignorance of the other.

Reproduction Through Objectivism

One way that objectivism influences therapeutic interventions in health care settings is by the construction of official knowledge. In one pilot project for this study, I studied the experiences of patients within a rehabilitation unit in a hospital in Michigan. The following incident at the facility is an excellent example of the thorough embodiment of official knowledge by staff members. I was helping a new patient learn to get dressed. She had been admitted to rehabilitation for her weakened condition after a fall at home

⁴These examples are a small sample of comments that took place on a daily basis in Jackson when white people were together without minority presence.

and a brief hospital stay. She spoke only Spanish, so I communicated with her in my halting Spanish. She was 86 years old and was able to do most of the tasks, except putting on shoes and socks. I probably could have encouraged her to do more of her morning routine without my help, but I like to get to know the patient before I feel justified in deciding whether the patient just needs a little encouragement. I was not Mrs. Sanchez's primary therapist, and I did not know whether getting dressed independently was her own goal, or just the standard rehabilitation goal.

When I asked her "¿Desayuno?" (Breakfast?), she replied "No" and rubbed her stomach and made a face as if she did not feel well. I then asked "¿Cafe?" (coffee?), to which she also replied no and pointed to the bed. It is a general policy on the unit that once patients are up for the morning, they should stay up in order to build their endurance, which is usually quite poor. Exceptions are sometimes made for especially deconditioned patients, but no exception had been made in this patient's case. The patients are often awakened at 6:00 or 6:30 am, and then breakfast does not arrive until 7:30. The official rhetoric for the schedule of a rehabilitation unit is stated in terms of what is best for patients, but I have often found through countless staff meetings that hospital ward schedules are based on staffing needs, and accomplishing necessary tasks with the fewest staff possible. This conflicts with some patients' needs to maintain a schedule more like home. I had come into her room at 7:30 to help with self-care (washing, hair care, dressing) before she ate breakfast, then she had obviously not wanted breakfast after getting dressed and bathed, but she did want to lie back down (by this time it was a little after 8:00 am). I made the decision to help her get in bed so she could rest until her next therapy at 9:30.

A few minutes later, one of this patient's roommates wanted some orange juice, so I brought the roommate the juice. Mrs. Sanchez then said "¿Naranja? Tambien." (she also wants some orange juice). Another possible conflict arose in my mind--was this patient expecting breakfast in bed? This is a practice that is discouraged on all rehabilitation units, since the idea is to create an atmosphere to encourage independence in self-care and to simulate the home atmosphere. Eating a meal in bed was probably not what she would experience at home (I would naturally check this out with her family, though others would just assume this). I said "What the hell" to myself and brought Mrs. Sanchez the OJ for which she was thankful and seemed quite satisfied.

Twenty minutes later I was confronted by one of the orderlies, whom I will call Tom Beadle. He said, "Did you put Mrs. Sanchez back in bed?" I replied, "Yes." Then Tom said "She needs to eat breakfast." I said "I asked her if she would go to breakfast, and she said no. I even asked her if she would just go down [to the dining room] and have coffee, and she said she didn't want to. She wanted to lie down, so I helped her lie down." In the background, one of the RNs said, "Mrs. Sanchez does not like to get up early!" Tom ignored this and replied to me, "In order for her to go through therapies, she needs energy. So she needs to eat breakfast." I repeated, "She didn't want it." Tom had not inquired whether Mrs. Sanchez normally ate breakfast. I knew Tom was probably the one who had gotten Mrs. Sanchez up early, and I knew his method would have been to wheel her down to the dining room no matter if she said "No!" all the way down the hall--I had seen it done this way. I did not have time to find out if in fact Tom had gotten Mrs. Sanchez out of her bed and made her go to breakfast. I began to dread the meeting I

would probably have with the nursing supervisor or from the manager of the rehab unit, anticipating that I would be reminded that "you can't just do what the patient wants."

I have found this type of incident, in which the patients wishes are placed below the priority of what the staff's "knows to be true," to be frequent. These "truths" often included but were not limited to: 1) eating with a group whenever possible, facilitating "normal" socialization; 2) awakening in time to begin therapy at 8:00am, as this was the "normal" time to start a day; 3) attending therapy despite feeling nauseated or severely fatigued, as this was "the only way to gain endurance and strength back." These official explanations hid other possible explanations, namely that the above guidelines also make staffing easier and more efficient in a hospital ward, cutting down on costs. This indicates the infiltration of objective and official knowledge into the daily action of staff members. My own willingness to ensure that Mrs. Sanchez dressed and bathed herself without finding out if this was actually her own goal was the first level of enforced official knowledge, and was followed by my questioning her decision not to go to the dining room for breakfast due to the "truth" of the belief that eating alone in your room encourages isolation and dependence on people to serve you (which are negative states of being according to official rhetoric).

The orderly enforced the rules which I failed to enforce; this is an example of the concept of "dominated dominators." One of my coworkers harassed me for the first several months of my employment there about how I need to "push" the patients, and I "shouldn't just let them manipulate me like that." After all, our goals were to get the patient to be as independent as possible in self-care so they could be discharged as soon as possible, with the implication that this would decrease the costs for the hospital and

insurance company. This exemplifies the pressure to conform to the official knowledge of the rehabilitation unit, and reveals the relative lack of freedom which the staff members have in acting on their own practical knowledge, or the knowledge of the patient. As Lorna Rhodes (1991) found in her ethnography of an psychiatric unit,

Though the staff sometimes used the vocabularies of institutional and community psychiatry, what they were doing did not fit into either model. They were practicing something else--getting patients out (p. 171).

This discussion is further informed by the concept of the hospital as a *field of power*. According to Bourdieu (1992),

The field of power is a *field of forces* defined by the structure of the existing balance of forces between forms of power, or between different species of capital. It is also simultaneously a *field of struggles for power among the holders of different forms of power* (original italics; p. 76).

The hospital has many holders of different forms of power, each struggling for control of the dominant ideology, dominance over the patient, economic capital, prestige, and cultural capital.

Therapists and other staff members may therefore not only be the dominators, but are also dominated by the field of power within the hospital. The hierarchical nature of the hospital creates varying levels of power, encouraging competition for power over others at lower or equal levels in the hierarchy. This competition was frequently played out during "team conferences," in which the therapists, nurses, and doctors discussed the patient's problems and goals, and in which they competed for dominance in the explanatory models of illness and courses of action. The patient's statement of goals or explanatory models were rarely discussed during these meetings, as the "team's" goals had primary importance, with the "family considerations" given next priority. This

example demonstrates that understanding the political economy of health care settings in the United States is paramount to informed discussions of patient and staff relations in a physical rehabilitation unit.

Political economic forces are powerful variables in health care settings (Morsy, 1990). The majority of patients in most rehabilitation units are elderly and have sustained strokes, and Medicare is a major payer source. Medicare regulations often define how a rehabilitation unit is structured. For instance, in order to qualify for inpatient rehabilitation, the patient must have a “medical necessity”⁵ for at least two of the following: occupational therapy (OT), physical therapy (PT), and speech therapy (ST). While in the rehabilitation unit, the patient must receive a total of at least three hours of these therapies for at least five days per week. Nursing education time, psychological testing or counseling, services from a social worker, time spent with the physician, or therapeutic recreation (all vital services) cannot be used as part of the three hours. This regulation often causes difficulties when patients’ needs are not consistent with Medicare rules. Although skilled nursing beds are intended to be utilized for those patients who cannot tolerate three hours of therapy per day, these gravely ill patients are sometimes admitted to the rehabilitation unit anyway for lack of other beds available, and are quickly scheduled for the difficult therapy regime. The struggle to make the patient conform to therapy and nursing schedules begins with the thought that the patient will ultimately suffer economically when Medicare denies payment, as will the hospital.

⁵“Medical necessity” is a third party payer code phrase for requiring physician consent, prescription, and rationalization.

Charlie Jones, a patient in the rehabilitation unit after a complicated recovery from heart surgery, was exhausted by 11:30am, and had already argued with his occupational therapist about whether he needed to wash more thoroughly when bathing. Then his physical therapist came into his room and said it was time to walk. "I really am too tired. I don't want to do this right now." The PT cajoled and pressured Mr. Jones into participating by reminding him that he needed his strength in order to go home as soon as possible, and that lying down would only make him weaker. As she explained this, she began to push his wheelchair (with him in it) out the door of his room. He did not attempt to stop her, but sighed and seemed to have resigned himself to attending therapy. He refused to walk in his afternoon session. The PT stated that she felt that Charlie should be discharged ASAP because this had happened on three consecutive days, and Medicare was "sure to deny payment on this one."

Physical rehabilitation is situated within the economics of the "bottom line" climate of hospital administration. The term "refusal" is used in discussion and in the medical chart when a person declines to participate in therapy or some procedure. This highlights who has the power of interpretation—obviously, the staff has this power. Any comments that patients make can be used to characterize their attitudes that day, which can be damning in the eyes of an insurance company or in a court of law. For example, if it is recorded that a patient is "uncooperative and refuses therapy," the insurance company may use this to deny payment for the whole stay in the rehabilitation unit.

The general requirement by insurance companies (started by Medicare about 15 years ago) is that patients in rehabilitation units must get 3 hours of therapy a day. If the patient "refuses" and it is recorded as such in the chart, and the patient has not received at

least three hours of therapy, then the insurance company may decide to "refuse" to pay the bill. At least this is what therapists are taught when learning about chart documentation for insurance companies. The patient's reasons for refusal are not always investigated, although I must give credit to the psychologists on the rehab units who frequently did explain why a patient might be refusing. It is interesting that most patients who decline therapy more than once are considered a case for the psychologist by the other rehabilitation team members.

This system reproduces itself with little encouragement from the outside, as therapists rarely if ever receive feedback regarding an insurance company's denial of payment. Most staff members assume that this is the reason for recording "refusals" and attitudes in the chart; however, I have never met a therapist who has had personal experience with lack of payment by an insurance company for an inpatient. (I have personal experience with this for outpatients, but not because the patient refused treatment.) The feedback loop can often take two years for the rehabilitation physicians (called physiatrists) to receive notice by the insurance company; the physiatrists may choose to address the problem themselves (I have heard them discuss cases, but not specifically patient refusal cases), and often the original staff members are no longer employed by the hospital. From past personal experiences and from comments from other therapists, I suspect it is just the possible threat of non-payment by insurance companies that keeps the therapists following the "rules."

I have heard therapists (including myself) justify their actions in enforcing the three hours of therapy rule with a vengeance by stating that if they do not make the patients go to therapy, the patients will just get a bill from the hospital that they will not

be able to pay (the cost of a few weeks, considered a short stay in a rehab unit, can easily total \$50,000). Most of the patients we saw would be quite upset at getting this bill and would not be able to pay it off, even in installments. I recently learned, however, that when Medicare or Medicaid (which cover a large majority of rehab patients) refuses to pay, most hospitals' policy is not to even send a bill to the patient. Of course I was told by the billing department in one facility not to advertise this fact, the implication being that patients would learn of this and take advantage of the system. Rarely will a therapist actually tell the patient of the true consequences for refusing therapy. I have the impression that it is just too much trouble to explain the intricacies of insurance coverage to patients who might have difficulty understanding the reasoning. In fact, I suspect (from personal experience) that the act of explaining these "facts" to patients would illuminate the economization of the health care system by turning the patients into parts of a dehumanized equation.⁶ Could it be that non-payment by insurance companies for the reasons of "patient refused therapy" is relatively rare, and that the system is just using the therapist in this way to stay afloat economically, or to make a profit (since a significantly increased profit can be made from time spent in therapy)? What does this tell us about the role of the patient in this decision making process?

Agency, Resistance, and Consciousness

I have drawn heavily from Bourdieu's theory of praxis in this document, however some significant shortcomings in Bourdieu's theory should be noted. In the following

⁶See Fromm's (1992) translation of Marx for a more detailed account of alienation suffered by those caught in complex, economically-based systems.

section, I augment Bourdieu's theory with more emphasis on individual agency and consciousness, and the various forms of resistance.

Bourdieu suffers from his own habitus, including his background of structuralism. Although he attempts to free himself from the oppositions cherished by the structuralist school, he continues to use oppositions to explain conflict and self-identity throughout his writings (1990). This tendency toward black and white explanations prevents Bourdieu from explaining the gray areas that inevitably occur in human interaction, involving agency, power, and resistance. If African Americans are socialized to wield less power, how does that explain the Shirlene Mercers of the region? Although a group of people may have similar backgrounds in social conditioning, each is still an individual, with unique aspects of family, personality, emotional response, and thought patterns. The habitus guides some along the majority path of nondiscursive normative rules and encourages resistance among others. Predicting exactly who will resist the norm, and in what way, is rather like trying to predict which root of a tree will end up growing in a certain direction--impossible. Major trends, however, can sometimes be foreseen. Such is the case in Jackson, Tennessee.

The example earlier in this chapter of the patient named Charlie is a case in point. Charlie's only path of resistance left available was to choose to do nothing, which probably resulted in a desirable course of events: discharge from the hospital. Some patients resisted therapy through aggression and anger, some through despair and depression. Others used denial to fend off the perception of permanence of a disabling condition, refusing to participate in difficult therapy activities because "I will be able to do it just fine when I get home [and am cured]." Resistance in Jackson tended to be

passive aggressive, as direct confrontation was the ultimate of social sins in this community. One elderly white woman with whom I worked in outpatient therapy requested some more physical therapy in addition to the occupational therapy services I was providing. When the doctor approved and the patient discovered that she would be seeing a Filipino PT, she suddenly asked for a transfer to another facility which was “closer to home and more convenient”—this when she had been coming to see me for three weeks. In the culture of Jackson, and much of the conservative South, telling me that she preferred not to have a minority male work with her would have been considered an unacceptable social faux pas.

Other passive aggressive resistance techniques common to the area were using different levels of congeniality and helpfulness in customer relations. Class, race, and region of origin (and the degree of similarity or lack thereof to the service provider) were the markers used to measure the kind of interaction which would occur.

The heaviest criticism which I must level at Bourdieu and other anthropologists who ignore or devalue the theories of their informants, is the contention that:

Native theories are in fact dangerous not so much because they lead research towards illusory explanations, but rather because they bring quite superfluous reinforcement to the theory of practice that is inherent in the objectivist approach to practices . . . (Bourdieu, 1990, p. 102).

With this statement, Bourdieu has negated all former statements about the importance of the native construct of reality, and in fact denies the theory of praxis. The assertion that native theories are dangerous suggests the supremacy of the objectivity of the observer. He conveniently sidesteps this criticism by postulating that once a person attempts to bring to consciousness the reasons for a practice, that the experience of practice

immediately takes on new dimensions, and that the experience is no longer in its original state. For this reason, he discounts the theories and musings of the native as to why he or she is performing a ritual or practice.

Ruth Frankenberg (1993) put it another way:

there is a link between where one stands and what one perceives . . . the oppressed [*or least advantaged*] can see with the greatest clarity not only their own position but also that of the oppressor/privileged, and indeed the shape of social systems as a whole (*italics mine*; p. 8).

It would seem a shame not to include the voices which might possibly present the clearest view of the system. I propose that the absence of the native voice in ethnographies demonstrates that we as anthropologists have much work to do in order to practice praxis.⁷ Fairclough theorized that ideologies legitimize existing social relationships through the acceptance of "common sense" or shared knowledge about situations and people. Power differentials often go unrecognized in social situations, such as with the example of a physician confronting a medical student with questions about the student's clinical reasoning and resultant actions. The doctor has the power to interrupt, embarrass, and question, while the student generally accepts this use of power without questioning it. Fairclough stated that text was a dialectic between self and other situated in context and social conditions (1989).

Ricoeur was also a post-structuralist who placed the language event at the center of his studies. Ricoeur felt that by concentrating solely on *langue* (the structure of

⁷For similar postulations, the extensive literature on the crisis of representation experienced in American anthropological circles provides stimulating reading: di Leonardo, 1991; Kim, 1990; Lewin, 1992; Ortner, 1984; M. Rodman, 1992; W. Rodman, 1991; and W. Rodman, 1992.

language) rather than the parole, or meaning and context of a speech event, that we actually do violence to linguistic experience. By not examining power and ideology, structuralists actually reify the status quo (1978). Discourse is “a space grown more, not less, prolific in the face of modernity and postmodernity. Caught in a cultural order of things and yet still ex-centric and vulnerable, it depends on the claim that things are not what they seem,” (Stewart, 1996).

Bourdieu and other anthropologists were correct in stating that bringing something to conscious thought immediately changes it, but that does not invalidate it.⁸ For example, if a golfer or tennis player is asked to analyze his or her own swing or backhand, he or she will often suddenly be unable to repeat the movement. In the process of explaining it, they can lose the unconscious or subconscious aspect they had embodied, and can lose the ability to perform it automatically and smoothly. The same can be said for discussions of concepts. The acts of observation and questioning can change behaviors and thought processes in subtle or significant ways, but those thoughts and behaviors are the very streams of ethnographic evidence in which anthropologists try to swim. William Rodman states:

the anthropologist . . . was as much the question as the questioner. . . . and so are all fieldworkers: the people we study us, even in moments when we do not seek to study them. We are not just observers observed; we are interpreters interpreted. To figure out what the devil they think they are up to requires us to try to figure out what they think *we* are up to—our motivation, purposes, and (sometimes) the moral message we bring with us. This is an Other side to reflexivity, one crucial to understanding the dialogics of encounters in field research (1991, p. 433).

⁸Duvignaud (1970) offers an illuminating example of the effect of ethnographic research on the people and events studied, and the profound effect the anthropologists had on the village.

Consciousness on the part of the informant should not negate the theory, but rather should be woven into the ethnographic analysis. The anthropologist cannot know what the native *knows* in the nondiscursive parts of his psyche/body/being. It is my contention, however, that there are those few individuals in each subject group who concentrate on bringing these constructs into conscious consideration, and form theories which have richer meanings than any of those who could come from the outside. To health care workers I would also say: "Listen to your patients. They have much to say with their words and their actions."

Culture is in part defined as common or shared understandings we use to interpret our daily lives. The only way to have shared understandings is with communication, through the medium of language. Language and culture are intimately interwoven, each influencing the other during a human interaction. When we use language during a speech event, we are in essence reproducing our culture. Agency enters into this equation with our own individual interpretations and actions, and the unique ways we may each reproduce the structures and forces prevalent in our lives. Language allows us to bring these understandings outside of ourselves, opening the door for the exchange of ideas and interpretations with others, thus shaping societal change and reproduction.

Embodiment is a central tenet of this study, incorporating a process in which the individualism of the white American biomedical system overrides a more socially embedded concept of self of African American patients. Objectivism and official knowledge are major pillars in the medical disciplines and help to reproduce the system. Political economy must be examined before a full understanding of the construction of policies (both written and unwritten) can be explained. Agency, resistance, and

consciousness are present in the daily actions of patients and health care professionals, as my examination of noncompliance demonstrated.

CHAPTER 7

POWER AND RESISTANCE IN THE REHABILITATION EXPERIENCE

The ideal of the “good,” compliant patient or the “good employee” is revealed in the following pages as an ideology which helps to control the time, economics, and behaviors of those within the institution. Other encounters illuminate the continued struggle for identity and power along the lines of race and professionalism. Echoing the concerns of Rhodes (1991) in her examination of a psychiatric unit, I have attempted to examine many sides of the issues, but have found it problematic to represent all sides simultaneously. I have intentionally represented the patients more often than staff, whose words, especially of the professional level staff, are represented almost exclusively in many other ways, i.e. professional journals, the medical chart, and team meetings. These cases by no means represent a “norm,” but have been selected for the power and resistance inherent in their journeys through the rehabilitation experience.

Of the 1,233 patients which were admitted to the rehabilitation unit while I completed my interviews, ninety percent were white and nearly ten percent were African American. Less than ten individuals were of other ethnicities.¹ This ratio differs markedly from the population of the region in general (estimates of the African American population in Jackson range from forty to forty-five percent). It should be

¹See Table 2 for rehabilitation patient population statistics.

Table 2: Statistics on Rehabilitation Patients in the Unit (1996-1997)
 Total # patients: 1,233

Gender

Female	72%
Male	28%

Race

White	90%
African American	10%

Insurance

Medicare	77%
Private Insurance	9%
TennCare (Tennessee Medicaid)	6%
Other (HMO, CHAMPUS, etc)	4%
Uninsured	4%

Diagnoses

Orthopedic (hip replacement, fractures)	45%
CVA	31%
Debility	10%
Brain Injury	5%
Spinal Cord Injury	4%
Other	5%

noted that the hospital admits patients from a seventeen county region, and many of these counties have percentages of African Americans ranging from twenty to thirty-five percent. The question of why only 10% of rehabilitation patients were African American was first posed to me by a young African American medical resident in Michigan during my pilot study. He noted that African Americans have a significantly higher rate of hypertension and cerebrovascular accidents, or CVAs, (Dressler, 1991a), and that CVAs made up the largest portion of patient diagnoses (forty percent of rehabilitation patients had had a CVA). The roomful of white physical and occupational therapists to whom the resident physician addressed the remark had not considered these statistics before. Some suggested that the rate of survival from CVA was lower due to the probable increased severity of hypertension among African Americans. When it was suggested that African Americans had less access to health care, an uncomfortable and thoughtful silence followed. It has been my experience that most white health care professionals prefer to deny the possibility of institutionalized racism than to consider its existence and its possibly devastating effects.

Team Conferences--Findings

Often, the therapists would initiate discussion with the team regarding a patient who was refusing to participate in an activity, with the intent of encouraging the physician to act on this information. Expectations of action included a variety of suggestions, ranging from talking with the patient, to early discharge from the hospital, or discharge to another setting (such as long term care in a nursing home). Professional level staff members identified noncompliance in thirty-five percent of the patients during my tenure

in the rehabilitation unit.² In half of these cases, I noted significant differences (and implied lack of understanding) between the staff members and the patients. These differences included ethnicity, class, region and culture of origin, and educational level.³ I present the following cases to illustrate the difficulties experienced by patients who do not fit the “ideal patient” category, and explain the details of each case.

Voices

Georgia Nimke was a woman in the rehabilitation unit who had spent several months recuperating in a long term care facility. Georgia had a rare tumor removed from her spinal cord and required therapy in order to regain the strength lost while on bed rest post-operatively. Georgia was a middle-aged white woman who had spent much of her life struggling to be a single mom on a pink-collar salary. She was from the Upper Midwest and was an assertive, no-nonsense woman. Her physical therapist was an inexperienced young white woman from West Tennessee⁴ who complained in team

²This did not encompass the larger category of patients which were considered to have “motivation” difficulties, but included only the patients which were more distinctly identified as noncompliant.

³Gender has not been addressed more specifically in this study, due to a variety of factors. Most of the health care professionals working directly with patients are women, therefore finding examples of gender differences was problematic. Also, a significant majority of patients are women (72%). Gender is beyond the scope of this document, but is a subject worthy of further investigation.

⁴The fact that one woman was from West Tennessee in this interaction is significant in that people in general, but women in particular, from the South are deeply discouraged from being assertive. Negative comments are not aired publicly, but may be communicated to parties other than the person directly involved. Most informants commented that it “was not proper or nice to say something bad,” even if it was constructive in content. Conflicts were therefore not settled face to face, but required a

conference that she was having difficulty getting Georgia to cooperate with the intended endurance and frequency of ambulation goals. The physical therapist wanted the physician to speak to the patient, and to encourage her to participate more fully in her therapy. She also thought the psychologist should get involved in this case.

When I interviewed Georgia, we chose to go outside the building so that Georgia could smoke at will. Georgia spoke of her fatigue and depression, as well as some of the highlights of being a mother and career woman. She was an intelligent woman facing her near future as a partially disabled person, and was having difficulty coping with the devastating events fate had dealt her. She had little support from any source. She was aware that the physical therapist wanted her to do more and do it faster, but her discharge from the hospital was to be only the beginning of another difficult struggle, one that she was not anxious to hasten. She was undertaking what she felt to be a reasonable pace after several months of not walking. She and the physical therapist had discussed her general goals, but they had not discussed the specific goal of walking 200 feet two to three times per day. The specific short term goals are set by the primary therapist, with the long term goal of reaching independence in home activities in the shortest time possible. Perhaps if they had discussed and negotiated this goal, the conflict would have been avoided altogether. The psychologist, attempting to find a compromise between therapist and patient, suggested giving Georgia reasonable choices and encouragement for every step taken. The physical therapist was trying to facilitate the movement of this

number of individuals to circumnavigate the person at issue, with problems and solutions directed at anonymous groups, rather than particular individuals. Persons from the Upper Midwest tend to be direct, which upset those accustomed to a non-confrontational style of communicating.

patient onto the next level of the “critical path”⁵ toward hospital discharge. Georgia was using individual resistance to delay discharge from the hospital to a less than hospitable life, a reasonable goal by many standards, if not by hospital standards. Georgia was eventually discharged from the rehabilitation unit and went to live with her daughter and grandchild. She requested a copy of my dissertation and left her forwarding address.

Georgia’s case was a common example of the rehabilitation team setting goals during team conference without the patient present, and without the patient’s collaboration or agreement. Regulations are in place to ensure patient participation in the goal-setting. However, the only mechanism to ensure that this happens is an occasional (once every three years) visit from an accrediting agency. At the time of the inspection, charts are reviewed for evidence of consultation with the patient or family regarding the goals. If staff members have mentioned in the medical record that the goals were reviewed with the patient, this will usually suffice. Often, therapists may briefly discuss the goals that the therapist has chosen with the patient or family, but the therapists do not allow time for discussion or alteration of these goals. Heavy pressure from administrative directors places therapists in a difficult position: getting the patient through the necessary activities in the quickest amount of time, or be continually counseled, then disciplined regarding the lengthy hospital stays.

⁵A “critical path” is a term commonly used in hospital systems for the ideal treatment plan for a given diagnosis. In the realm of official knowledge, it involves a suggested finite time line, and is used as an evaluation device to suggest a sequence of activities to be accomplished. Unofficially, it is used to present intended time lines to third party payers, and to facilitate the shortest length of stay possible. Many critical paths do not allow or encourage social and psychological adjustment to phases of treatment.

While many patients passively go along with goals that are set by the team, Georgia resisted the pace of the goals set for her. She used what methods she could to slow the process to allow herself more adjustment time and to delay the inevitable. She would be going to her daughter's home, with little support or income, and would need to help care for her granddaughter. Although Georgia was considered to be manipulative by the team members, perhaps her actions were not illogical, but resource-conscious and driven by fear of the future.

"Josephine"

Josephine McGregor was another example of a patient who resisted the suggestions of a therapist. Josephine was an occupational therapist who had undergone knee surgery due to a work related injury. In contrast to Georgia, Josephine had a complete understanding of her own rights and an in-depth knowledge of her alternatives, and she insisted on using a walker instead of crutches due to other health concerns. The physical therapist was taken by surprise by this assertion from a patient and promptly modified her plan without flagging the treatment team to "encourage" this patient. Her higher class standing, greater educational level, and better internal knowledge of hospital policies allowed Josephine to make choices more easily and which fit her circumstances with less conflict than Georgia had experienced. Generally, the patients who had class, educational level, or social background in common with the staff were able to negotiate through the health care system with more ease than those who had less in common with the staff members.

“Grace”

Education was an essential ingredient in determining job potential, as well as a foundation to wield considerable power in a given patient-staff situation. The education level of many Jacksonians and the surrounding region was low. The higher the educational level, the more successful the patients were in wielding the power to make choices during rehabilitation. Grace Simon was an African American woman in her forties who had been involved in a car wreck, and had sustained multiple fractures and contusions. She was a 2nd grade teacher in the local school system, and she was categorized as a “multiple trauma” patient from a car wreck in which she suffered a broken pelvis, a broken leg, and a crushed forearm. She probably also received a mild head injury, but that seemed to have resolved.

She was born and raised in Gary, Indiana, then attended college at Lane University here in Jackson. Her parents were originally from Alabama, but they moved up to Gary in the 1940s when her father had heard there were many jobs available in the steel mills. Her parents had 2 children at the time, then had 7 more after moving to Indiana. Her mother still lives in the same house. Grace considered herself to be from a middle income background. She was married and had 3 children, with the youngest 3 years, then a 12-year-old, and a 15-year-old.

Grace had a serious demeanor, with a hint of steel nerves. She was very forthright in talking about some of her experiences in the hospital, such as the first time she was turned while in traction for her leg and pelvis. “I was in excruciating pain, and I screamed for them to stop [turning me in the bed]. The nurses and orderlies must have been accustomed to this, because they didn’t say much and just kept right on. I don’t

blame them. I know they were doing what they had to do, but I just felt so helpless.”

Otherwise, she was very pleased with the care she got from the staff on the acute floor.

When she began to talk about the staff on rehab, specifically the techs and aids on the nursing unit, she became almost angry, and said she felt they treated people with no respect, and treated them as if they were children. She said that she had to make it clear that she would not be talked down to, and that other patients seemed to fear the techs and aids. One example she gave was at mealtime, when most hospital patients are allowed to choose whether to eat their meals. The rehab patients, however, are cajoled, frightened, and harassed into eating their food, even if it is something they had chosen not to eat. During mealtime, the tone of voice and phrasing of the aids⁶ reminded her of how people speak to the mentally retarded—very patronizing. Grace also described the “pass the buck” syndrome as being very bad on the nursing unit for rehab. An RN may come to the bathroom responding to a call, and when Grace asked for a soapy washcloth, the nurse would say “I will go get a tech to do that.” The amount of time it took to find a tech would probably have been more than getting the soapy washcloth herself. This was very frustrating to Grace. She felt that these kinds of behaviors were common on rehab, but not on the acute floor where she had been.

When I asked Grace if she had experienced any problems which might have been ethnic or racist in flavor, she said that the only thing she experienced was that “some people act like I’m a welfare case [just because I am black].” No one looks their most professional or best when a patient, and Grace dressed in T-shirts with matching

⁶ Most of the aids are black women who have worked in the hospital for many years.

bandanas covering her hair. She felt people were assuming she was low-income and poorly educated because she was black. Beyond this statement, Grace did not seem to wish to go into any more details on the issue of race. She did say that she felt that the problems she had described applied mainly to nursing staff. We did touch on the lack of power a person has when a patient on rehab. She gave the example of when the nurse was orienting her to the therapy schedule the first day. Her breakfast was at 7:30, and her therapies started immediately after. Grace assertively asked, "What if I don't want to get up and go at that time?" The nurse looked blankly at her, then repeated that this was the schedule she was to follow. Grace rephrased her question, and the nurse again seemed to be puzzled and clueless about Grace's hypothetical question. At that point, Grace said she left it at that, and decided to cooperate.

During her hospital stay, Grace initiated two more brief encounters--she seemed anxious to support my work and proud of being asked to participate. One day, Grace caught me in the hallway and told me excitedly that she was being discharged the next day. She had a friend from church and her oldest daughter there. Her daughter was complaining that the youngest sibling, for whom the daughter had cared for the last 3 months, was spoiled. Roberta Simon and her mother argued about whether the young child was spoiled, and discussed her likeness to the grandmother or aunt who was also instrumental in her current care. As Roberta left, Grace called out for her to come back tomorrow, and to dress up (she was in jeans and a t-shirt), to which Roberta replied, "I might."

"You better!" carped Grace down the hall.

When asked what brought on the discharge (over a week ahead of time), Grace responded that God felt that she was needed at home now. (I guess I had expected her to talk about her surprising progress due to her own hard work). “My oldest son [age 15] has been left on his own a lot, and coming in late at night, and I knew that God is sending me home to take care of business.” This was before her daughter had left, and her daughter stared at her (a little skeptically), while the church friend added a few nicely punctuated “Amens” and “Yes, lord.” It made me think of scenes which Maya Angelou described of the “pious” Sunday church lady speaking in tongues, then going back to her usual demeanor and activities the rest of the week. Angelou’s point was that the public demonstration of the religious intention and fervor of the person can be very important socially. In passing, Grace had mentioned her faith in earlier sessions, but chose this time (in front of her church friend) to really glorify God. It was also a joyous time for Grace after having been in the hospital for 3 months, so this may have been her usual way of expressing happiness when things took a turn for the better. The look on her daughter’s face said otherwise, however. Grace also said that God had changed her heart while she was in the hospital, and made her cherish the life she had. In an earlier session, she also said the experience made her appreciate older people (referring to the many elderly on the unit).

Grace asked her daughter if her hospital stay and injuries had affected her, and Roberta replied “It has affected me a lot! I have been trying to take care of my sister, and it is work!” I asked how this had affected them financially, and Grace seemed not as concerned about this issue, as she had the forethought and money to buy disability insurance. “My daddy taught us all the importance of taking care of your loved ones with

insurance. I even purchased cancer insurance due to several relatives on my dad's side having cancer. When I was first injured, I was getting regular sick pay as well as disability insurance checks, then my sick time ran out and my income definitely decreased." The previous session had ended abruptly when she was on the phone (being quite short) with some relative--possibly husband--in trying to locate some bills. Today, however, it seemed to be the last thing on her mind.

Grace gave me her home phone and address, and seemed to look forward to my making a home visit in the future. In talking with Grace, it became more and more clear to me that many of the differences between patients and staff are economic and somewhat educational. Grace denied any kind of major race issue involved in their hospital stays, and she categorized herself as middle class. I have observed a large gap in understanding between very low income patients and the middle class staff who work with them.

Grace was a professional with a bachelor's degree in education, and was an unusually assertive woman for a native of Jackson. She had successfully negotiated a change in therapy schedules by asserting herself in a firm, reasonable manner, and used her status as a professional to gain respect and cooperation from the staff members. She also stated that some health care professionals assumed she was a "welfare case" just because she was black. "I straightened them out quickly on that point, and had no further difficulty with it." Overall, she felt very positive about her experience in the hospital and rehabilitation unit. While most of the African American patients in the rehabilitation unit were of lower economic and education standing, Grace was an exception who used her status and knowledge to gain what she needed from the health care system. Class and

education often transcended other categories such as ethnicity or social standing when the person possessing the “social capital” knew how to use it.

“Monique”

Duvignaud and his colleagues in Change at Shebika: Report from a North African Village (1970), successfully communicated the astonishing effect anthropologists can have on their informants. I experienced this phenomenon in a small and uncomfortable way when I interviewed an OT student. It was so rare that our facility had an African American student that I was eager to talk with Monique Stapleton. A couple of the technicians I had already talked to had stated that they felt the African American students who had been at the hospital had been treated much more harshly than the white students. I wanted to get a sense of whether Monique felt that this was a problem, as she was barely passing her fieldwork.

I waited until I knew she was passing, then asked her for an interview, which she was delighted to grant me. Unfortunately, others saw our weekend meeting take place. (I would rather they had not known). The student was not an exemplary informant, as she had not really given much thought to conflicts among patients and staff, or between herself and the therapists. I asked open-ended questions, without hinting that I suspected problems. We spent most of the interview discussing patients and how they were adjusting to rehab (or not adjusting). While some African American informants in the previous months had held back on the subject matter of race and racism (one actually declined, stating “There’s just some things better left unsaid”), Monique did not seem to have previously considered the questions I asked about race.

When the student left our facility having barely passed her affiliation with us, she wrote on her evaluation of the facility that she felt she had been judged unfairly because she was African American. She mentioned that there were only three people who had treated her fairly: our two physicians, one who is African American, and one who is African Grenadian, and me! I felt very mixed emotions about having been named in her evaluation--glad that she perceived me as unbiased about her ethnicity, but dismayed that all eyes were now upon me about my relationship with African Americans at this facility. In our interview, she had stated that she was being treated fairly, and seemed to have no conscious awareness of the possible race issues which had been mentioned by the technicians. She did mention that she thought it was curious that no African American therapists were employed in a system which was the largest employer of the area. I did not pursue the issue with her during the interview.

To further complicate matters, my picture and brief abstract appeared the same week in OT Week, the national weekly publication from the American Occupational Therapy Association. The minute I walked into work that morning, my department director brought me into her office and was nearly in tears, saying she had been accused of racism, and wasn't that ironic since my abstract about African Americans in rehab had just appeared in OT Week?

My supervisor did not attempt to gain information from me about the interview which she knew had taken place, but another co-worker persistently tried to find out what had been said in the interview. He was a good friend of the supervisor of the student in question and was asking if I had seen any discriminatory type behavior going on in the clinic. He knew I had an interview with the student, and was asking if she had mentioned

any of this to me. I mumbled something about it being a politically and socially charged subject throughout the country, and suddenly had an urgent patient issue to divert my attention. The supervisor of the student, to her credit, never mentioned it to me. However, this incident significantly detracted from the trust between me and the student's supervisor. Later, I was able to formally interview this therapist, and we were able to mend our relationship.

For these very reasons, I had initially been reluctant to do my research at the same facility where I worked. Circumstances were not conducive, however. I learned that the anthropologist should constantly be aware of the effect he or she may have on the informants and their relationships. It also highlights the pitfalls of having multiple roles in one setting. I was able to act on information which I gained as a worker in this department to pinpoint key informants. Perhaps it was poor judgment on my part to interview this student, but I did find out some interesting contrasts between the supervisor and the student. Monique was from a low income family in an urban area in which she rarely had encountered white people, and her college environment was no different. Her obvious discomfort during the first few weeks in the facility may have been in part explained by her attempts to become familiar with unknowns in the environment, coupled with the fact that she was not an exemplary student. Her supervisor, Jean, had in contrast grown up in a middle class white neighborhood, and had been rated near the top of her class. Jean's confidence as a therapist was at times intimidating to those with less experience and knowledge. These factors, along with a general personality clash was enough to complicate and lengthen Monique's affiliation (she was required to spend 2 weeks beyond the standard 12 week rotation in order to pass). According to the

technicians, Monique's experience was strikingly similar to that of the only other African American student in the OT department a few years before Monique. According to the supervisor, neither student had been very academically impressive. These conflicts added validity to my thoughts about noncompliance (or other types of disagreements) being a function of the relationship between people. When staff members have rigid ideas about the "ideal patient" or the "ideal student," these ideals often reflect the ideology of the white middle class staff.

"A.J."

During my fieldwork within the hospital and surrounding community, I struggled with the concept of racism, and how racism is reproduced in this society. The conflicts waged in the media tend to polarize the issues, making clear delineations between racists and non-racists. Consciousness is implied in all interactions, with persons categorized accordingly. Racism was equated by most of my informants with conscious and overt negative behaviors toward people of another race. Many African American patients did not feel that they had experienced racism in the hospital setting, and most whites did not feel that they were racist. The following is an example of an African American patient who felt he knew racism when he saw it, and felt very positive about his hospitalization experience. When asked, most informants defined racism as overt acts or covert attitudes people harbored against those of another race or ethnicity. Very few informants articulated an awareness of institutionalized racism or social trends as forms of control.

A.J. Porter was a quiet, dignified, and articulate man of 55 years who lived in a small nearby town. He was an inpatient in the rehabilitation unit for a week after surgery

to stabilize the stenosis in his cervical spine. I had gotten to know him as I had treated him in the occupational therapy clinic. He had difficulty with sensation in his hands, as well as some motor function, causing him to lose dexterity in both hands. At the time he was reporting his neurological difficulties, the doctors found a spot on his lung (he was a heavy smoker for many years), and he had set a date for a month in the future for exploratory surgery. I was fascinated by Mr. Porter and his wife, as they displayed a certain air of control, as if every request made by a therapist or nurse was being weighed briefly in their minds, then acted on only if it fit with the Porters' ideas of what was appropriate and helpful activity. This was decidedly different from the other African American patients whom I had observed in this setting. I did sense a barrier that I have sensed in other urbanites (the Porters were originally from Chicago), especially in African Americans from the cities. They had a rather stony-faced exterior, and I was unsure if they would even speak to me when I asked them for an interview. After asking them if I could visit them in their home after Mr. Porter was discharged, they took a few minutes to ask how the information would be used and for what purpose, then agreed on the date and time. I called them the day of the interview for directions, and Mr. Porter was happy to oblige.

I traveled to Bells, a town located 20 miles from Jackson, and commenced with following the directions given to me by A.J. Porter. It was a dreary November day, with mud and clouds coloring the leafless landscape. As I drove through the streets of Bells, I came to an area in which the houses were more dilapidated, with obvious poverty as the marker of the neighborhood. I became lost in the confusion of short alleys which someone had named and called streets, so I found a gas station and phoned A.J. After

speaking to both him and his wife, I drove a few more blocks and found the street on which the Porters lived. I approached their single-wide trailer and pulled into the muddy tracks making up the driveway, hoping that the rains had not created a permanent parking place for my car. I walked up the make-shift plywood ramp which had been considerably warped by the moisture of the past few weeks. The Porters apparently had added this ramp just before A.J. had come home from the hospital. He still used a wheelchair, but was beginning to walk with assistance.

I was concerned that the Porters might not be terribly enthusiastic about sharing intimate details of their lives with a near stranger. I became conscious of my middle-class white professional status, and wondered whether the trip to Bells would be worthwhile. They welcomed me warmly, however, and I realized they must have been assessing me and my motivations. I find that this is a common occurrence among urban dwellers as opposed to the friendly and outgoing (if superficial) demeanor of small-town Southerners. The initial lack of eye contact and hesitance to engage in interactions did not necessarily indicate stone hearts, only a stony countenance as a first defense against whatever the world might throw at them. Mr. Porter and I settled down in his scantily furnished living room, while his wife made sweet potato pies for the upcoming Thanksgiving holiday.

A.J. was born in Mississippi, but his family (seven brothers and sisters) soon moved to Indiana, as his father was a poor farmer and had heard of work in the north. When A.J. reached adulthood and sought work, he eventually settled in Chicago, where he met his future wife. Louise was originally from Tennessee, and three years ago they decided to “get away from the rat race and the crime” and moved back to Tennessee. He was not terribly forthcoming in his social history, and I suspect that the area of Chicago in

which they lived must have been poor also. Mr. Porter was on sick leave from his assembly line job at a local metal parts manufacturer. He felt very positive about the company, and found the insurance case manager to be very helpful. I found this perspective to be interesting and very unusual, as this company was known to be one of the most difficult employers in the area. The reputation was that of a hard-nosed and demanding management staff who used people in very difficult jobs, then “let them go” when the inevitable injuries occurred.

Mr. Porter felt very positive about his experience at the hospital, and in the rehab center. He had no complaints, and was not shocked or surprised by any aspect of care as had been expressed by most patients in the rehabilitation unit, as he had multiple injuries in a car wreck in 1989 and was in traction for 90 days. He had some physical therapy after that period. When asked specifically about any racial incidents or discrimination, he said he had no problems. He was an articulate man who spoke precisely and with measured words: “I have been in a lot of places, and I know discrimination when I see it. I have seen plenty [of discrimination], but my hospital stay was free of any problems.” I asked him about the difference between the north and the south regarding racism. “It (racism) exists everywhere, but it is definitely more overt in the south. I know they hire blacks for a lot less wages than whites. That’s why I’ll always be a union man, although there are no unions to speak of in Jackson. When asked, he said he felt that unions would eventually be prominent in Jackson, although it might take a while.”⁷

⁷An incident of significant violence surrounding the attempt to start a union at a plant in Jackson several years ago makes unionization in Jackson even less likely. When asked about unions, most natives of Jackson espoused very negative emotions about unions, citing the incident in which one person was killed. Unions are categorized by

Mr. Porter stated that the industries were hiring illegal and legal Mexicans, and paying them \$2.00 an hour to do work that no American would do for that pay. He also cited a company in Bells as mishandling its food waste (it is a frozen food company), and that sometimes the whole town smelled like rotten food. "Why has this problem not been protested, or brought to the attention of state or federal agencies?" I asked, knowing well what the answer would be in a small, authority-abiding, Southern town. "Because people just want to work and raise their families. They know that if they make trouble, trouble just keeps coming their way."

Mr. Porter was hopeful and optimistic in general about life, despite his run down neighborhood and trailer. He worked hard in therapy, and I suspect he was a very good worker in the plant. He completed high school, then mentioned that he had served in the Army in 1965-67 as a draftee, and spent his overseas duty in Germany. He stated that he really enjoyed Europe, and would very much like to go back some day. He had an awareness about him that suggested that he had seen a lot of places and people and knew that some places were better than others. I had the distinct feeling that no matter how many questions I asked, and how smoothly I presented them within the context of our conversation, that I would never be allowed to see the full depth of his life experiences. He preferred not to discuss the negative aspects of his present and past.

Mr. Porter's siblings live in Mississippi, California, and several other states. He had an unexpected death in his family a few weeks before our interview--his older sister

native Jacksonians as "a Yankee kind of thing", and not something to be sought after.

had died. This brought many of his siblings into the Southeast and he was glad for their visits to him after the funeral. He felt it had really helped him.

Mr. Porter had excellent private insurance, and had so far maintained a working relationship with his employer, with plans of return to work if possible. He seemed realistic about that. He did mention the worries about creditors calling (it sounded as if they had been calling recently), but he was not overly anxious about it. He mentioned that his faith in God was one of the main things which kept up his spirits, and which helped him recover. He said his siblings, wife, and son were very helpful, and they all prayed together, which seemed to him to be fulfilling and meaningful. A.J. Porter and his wife Louise, continued to deal with life's difficulties with positive attitudes and religious faith. Although they did recognize that bad things did happen, attitude was viewed as a self-fulfilling prophecy. In A.J.'s words, when racism confronted him in the past, he said "You have to forgive 'em and forget 'em. Having a bad attitude will get you nowhere but down and out."

A.J. was closer to the "ideal patient" than other informants noted here according to staff members who worked with him. He was articulate, compliant, and somewhat passive during daily therapy. He worked hard, and expressed no unhappiness or disagreement with treatment methods, and generally presented with a cooperative attitude. A.J.'s success at getting the most out of the rehabilitation experience may have been due in part to his recognition that the best way to gain what he needed was to give over active decision making power to the "authorities," keeping opinions to himself. Some patients and staff were more likely to resist the erasure of agency, as the following case demonstrates.

“Toni”

Toni Proctor was in many ways a complete contrast to A.J.’s quiet and unassuming demeanor. Toni, an African American aide from Memphis, had been a technician in the rehabilitation unit for many years, and had been a nurse’s aide before that. She was also unlike most Jacksonians in her outspokenness and willingness to confront and point out problems. She was described to me by one patient as “that big sassy woman.” She was my only informant who willingly admitted that racism, both overt and covert, was alive and well within the hospital. “How many black therapists do we have in this department? None!! How many have we ever had? None!! We have had thirty therapists in this department since it started in the late 1980s, and no black professional level employees. We have had a total of 2 black students, and neither of them has been treated equal to the white students. The one we have now is not passing, and the one we had a few years ago also didn’t pass without a lot of extra time and work.”

Toni was a 43-year-old single mom with 3 kids at home, and a daughter and grandchild who lived nearby. I visited her home one day for an interview which she willingly granted, and I drove into an all-black neighborhood in what was referred to as “East Jackson” consisting of single family rental dwellings and duplexes. As was common in lower income neighborhoods, the landlords had not taken pains to keep up maintenance on the houses. Toni’s children were at school or work, so we were able to talk freely that afternoon. Toni grew up in a low income area of Memphis. “I ain’t no country girl. I grew up in the city, with pavement under my feet. I went to visit a cousin on a farm once, and when I found out that what was bein’ served on the table had recently been out in the field, I couldn’t eat nothin’. I am definitely not country-raised.”

Toni spoke of how young and inexperienced therapists tended to “lord it over us techs”, assuming that her knowledge level about patient care was poor and uninformed. Most of the technicians in the rehabilitation unit were African American. Toni described how she was expected to act as a therapist at times when staffing was low and patient census was high, and how she chose patient treatment activities based on her experience and knowledge of each patient. When therapists were late for a particular patient’s treatment session, she hated to see a patient just wait, so she would often choose something to get started on. Some therapists appreciated this effort, but many did not, confronting Toni or reporting to her supervisor that Toni was usurping the role of the primary therapist with no professional training from which to choose activities. Toni and the other technicians had stopped initiating anything after having been reprimanded every time a new therapist came on board. Many of the therapists in the rehab unit viewed the techs as “lazy”, as they frequently saw them sitting and talking when patients were waiting for their therapist to arrive. Toni felt caught and confused, fighting the authority of the professional level staff but knowing it was a battle that could not be won. Without professional credentials, Toni was not at liberty to make treatment decisions, although at times she was implicitly expected to do so when therapists were absent. There was not so much a misunderstanding of roles, but a disagreement as to whether the roles of therapist and aide being set were appropriate and consistent. Toni felt that these role delineations were erased when it was convenient for the system and for the therapists, but not when it was initiated by the technician. “This is how we’re kept in our place. I don’t really have an interest in being on committees or anything [as we are expected to do], because

anything I say doesn't count anyway. It's always been this way. I was here before these new therapists were, and I will be here a long time after they're gone."

Despite her frustration with the system, Toni worked constantly at trying to better her situation. She continues to go to night school at a local community college to obtain more professional standing, and better pay. She continues to express ideas and opinions in staff meetings, even if they fall on deaf ears.

Toni described how the all-white professional staff sometimes misinterpreted or disregarded African Americans. "I think white therapists are afraid of working with black patients. They are scared of fixing their hair. I saw Mrs. Smith being wheeled into the clinic by her therapist after they had supposedly spent the morning doing self-care activities. Mrs. Smith's nappy hair was sticking straight up! Ain't no comb had touched that hair! Why couldn't the therapist have just combed it? It don't bite! It ain't difficult to just comb some hair. But white therapists, especially the young, new ones, are afraid of black folks' hair. Sometimes you can tell that the therapists are just ignorant of some things. They don't really know what it's like to go without, to not have money, so they recommend this piece of equipment, or that home program, not knowing what the home situation is, or how desperate it may be. It is like pulling teeth to get special adaptive equipment for these families that haven't got the money. Just so they can get their Momma in the tub once a week."

Toni appeared tired, bored, and frustrated with her status as a technician, but she knew change was slow in coming. "One of these days, maybe I will have my degree, and I will be able to do something with my ideas. I would really like to advance." Toni's vantage point was one of crossing the line between the professional staff and the patients.

She had not been indoctrinated as had the professional staff to believe in particular treatment techniques or in maintaining professionalism in the patient-staff relationship. This allowed her the freedom to be blunt with patients or staff in a way that would be discouraged in professional training. She described situations in which some patients just needed to be cajoled into participating for their own good, or in which she lectured to some rebellious young patient who just needed a “good tongue lashing”. Tongue lashing was a special skill of Toni’s, one which will hopefully continue to spice up the lives of patients and coworkers.

At the time of publication of this document, Toni had found herself looking for a job. Her position had been terminated, and after 17 years as a hospital employee, and a less than stellar employee evaluation due to her “verbal disagreements and refusal to follow protocols,” Toni was offered a position in the laundry service, or as a nursing assistant. She felt strongly that these positions were far below her abilities, but she had little choice as a single mother with only a high school diploma. Toni had been an easy target, with her educational vulnerabilities and her blunt nature. These ultimately resulted in further loss of power and position.

Brief Glimpses

Patients’ awareness of race as an issue during their hospital stays waxed and waned, but the staff members who had been there the longest recognized a pattern. This pattern, which can be found at most institutions in the U.S., was echoed in some entries from my field notes, i.e. the lack of awareness whites have of African Americans and vice versa:

One day I was sitting at the cafeteria at work eating lunch alone, when I looked up and took note of my surroundings. All employees were grouped according to race and station. I saw no mixed groups, and no professional level black employees. I know we have a few, so where are they? How do they feel about mealtimes and with whom do they eat? I remember wondering what our student did when she was the only black person of professional level around—I learned that she eventually just went out of the building everyday for lunch. It seems she may have been penalized or ostracized for hanging out with the black techs.

Another day I was sitting at a nurses station writing in a chart, when a patient's call bell rang and rang and rang. I was faced with the daily dilemma--do I try to respond, and use up all of the only paperwork time I have today, or do I try to ask one of the grumpy, overworked RNs to assist? I decided to continue on with my paperwork, knowing that a tech was supposed to be responding. Five minutes later, the tech did come up to the nurses station, looking a little harried from her last patient, and mumbling to herself "Don't everybody get up at once." She was black (as are all but one of the techs at this station), and all of the professional staff sitting around was white. Hmmm....

I was at the Kroger grocery store today waiting in the checkout line while the cashier rang up my groceries. The sacker was a middle-aged black man who seemed to know the business very well, as he was dismayed at how the cashier was passing the groceries down to him. He tried to get her to modify her method but to no avail. So he just kept sacking while he sang "Yes Lord" many times under his breath, shaking his head many times. It was as if to say, "this child is not doin' this job right, and I cain't stand it." The cashier was a young black woman. I rather doubt that he would have given any instruction to a young white woman--African Americans still tend to defer to whites in social and work situations that I have observed. It was a strange experience to stand here in the grocery store in a small Southern town and hear a proud middle-aged black man sing "Yes Lord" as he packed my broccoli. I was thinking this must have happened so many times before in so many different ways.

I observed an argument today between an African American student and a white student. The disagreement began as the white woman, Jan, resisted the hairstyle recommendations of her friend, Sue, an African American woman and fellow student.

Sue: "You need to get the split ends cut off your hair."

Jan: "It took me forever to get it this long. I don't ever want to cut it."

Sue: "It would make it look better. You have such a pretty color [dark blonde] of hair. And those ends just make it look raggedy."

Jan: "I really wish I had black hair like you."

Sue: "My hair is not black. I have sand colored hair." Sue's hair is brown with golden highlights.

Jan: "I have never seen any sand that color. Your hair is way darker than that."

Sue: "My hair is not black, though. Look." She shows her hair more closely to Jan. "I have nieces with black hair and I wish my hair was that color. But it's just this dirty brown."

In the latter example, Jan was acting on a stereotype (that all black people have black hair, or hair of the same color), while Sue resisted this assumption. This was one of the few honest and open interactions in which the agents exchanged concepts in a positive manner, and came away with a new understanding of each other.

The pattern noted here is this: that groups of people who lead separate existences have a lack of knowledge of each other, and they make assumptions about each other. Overt and covert racism and prejudice are still prominent, and can be seen in many daily interactions throughout the community of Jackson. Although the patients may not see the differences during their single one admission to the rehabilitation unit, the staff members at the bottom of the power pyramid who have been there for a long time see the patterns. Institutionalized racism may not be an intentioned effect, but it is real and present in the structure of the system. The labeling of patients as "noncompliant" is one way that lack of knowledge and institutionalized racism is expressed.

Policy and Race

Covert institutionalized racism infiltrates daily policy formation within a hospital through subconscious or unconscious means. A common policy I have encountered in 5 different hospital systems is that concerning absenteeism from scheduled outpatient therapy. The general policy is that if a patient misses 3 scheduled appointments, he or she may be discharged for noncompliance. Most therapists and supervisors believed this to be a very reasonable policy which would not affect most patients. Upon closer

examination and when viewed in the context of economics and ideology, African Americans are proportionately penalized by this policy. As established in Chapter 4 on the history of Jackson, the average economic level of the African American household is significantly lower than the average for white households. The low-income African Americans in “East Jackson” were so underserved that the hospital system built and financially supported a family medicine clinic in the vicinity where it was needed most. This allowed the nearby community to alleviate some of the transportation problems inherent in getting low income patients across town for medical care.

Physical and occupational therapy was not provided by this clinic, however, and patients still had to travel farther to receive such services. The consistency of attendance was directly linked to the patient’s ability to have a network of people who were available to drive and who had a working car on the day of the appointment. If no such transportation could be located, coupled with occasional lack of phone service due to lack of funds to pay the phone bill, communication with and attendance at the therapy clinic became problematic at best. I tended to change the policy as needed for those who did not have their own transportation: I saw them when they came, and I did not see them when they were not there. They were pleased to be seen and were not frustrated by having to wait until I could fit them in. I had both white and African American patients who fell into this category, but it was clear that African Americans were overrepresented in the lower socioeconomic classes, as established in earlier chapters. Most therapists were not tolerant of this scheduling flexibility, as informed by the commoditization of time within Western biomedicine.

The discussion of time becomes more closely linked to this project when considering the discussion I had with a white woman in her fifties. We were discussing how racism is more covert, and she began relating sayings which were common knowledge a few decades ago. The phrase “CP time”, or colored people’s time, was frequently used among whites to describe African Americans’ use or attention to time. “Whenever a black person was late for something, we would always say they were on ‘CP time,’ and we all knew what each other meant: that Negroes did not pay attention to appointment times, or did not seem to be concerned if they were late.” This negative perception of some whites regarding African Americans’ use of time may continue to influence policies through more unconscious channels.

Another policy implication is that of nepotism, or what I call the pseudo-nepotism of the good ol’ boy network which was so prevalent in the hospital system. This particular hospital system was especially resistant to the ideology of written records in policy development. The other hospital systems in which I had worked were steeped in written policies and standards of practice, while the Jackson facility had relatively few written policies and standards. The oral tradition was quite prevalent in this cultural region, and the literacy rate was poor compared to most states as established in Chapter 4. This would seem to have influenced the learning of hospital standards by word of mouth. I discovered another possible reason for the resistance of putting policies in written form: it would set a standard which would need to be followed, and this would seriously undercut the ability of the staff to trade political favors in order to accomplish a desired end. The case of a student becoming an administrator is an excellent example of nepotism and pseudo-nepotism at work.

A student asked to be placed in my department from a remotely located university, as he had family who lived within an hour of Jackson. Before I learned of this student, I was told by an administrator that I needed to hire Jim Smith. I told the administrator that I had not heard of a Jim Smith, but that I would be glad to consider him along with other candidates. Later when Jim was introduced to staff members, he made it known that his brother was a physician, and that he was personally acquainted with the chief executive officer of the hospital. This white student had no significant or lengthy work history. By the time he finished his internship, he had met with the CEO on several occasions, had offered his own clinical supervisor a job working for him, and had an agreement that he would be a manager of a new service in the town in which his brother worked as a physician (this job had formerly been promised to a woman who had worked in the hospital system for several years). By being a brother of a physician and being acquainted with the CEO, this student's opportunities were far greater than most students or long term employees. If a written policy existed which prevented hiring employees based on nepotism or pseudo-nepotism alone, then other qualified candidates might have had a chance; those who were not in the loop of personal acquaintance with key players were not considered. By the same process, African Americans and women often had fewer opportunities to advance in the hospital system, as their connections with the decision makers was often tenuous at best.

Patient choices were not the only facet of hospital life shaped by education, class, and culture. Employment in the system was also greatly affected by these structures. Approximately eighty-five percent of the African Americans employed within the hospital system were employed in environmental and food services. Only ten percent of

professional or administrative jobs were held by African Americans, although African Americans made up forty percent of the population in Jackson. Trudy Smith was an African American nursing technician in her fifties employed in the rehabilitation unit. When asked why she thought that so many black people were hired into low end jobs in environmental services, and so few in some other departments, she had this to say, “I reckon folks are just used to hiring blacks in domestic jobs. Around here they are just used to being waited on by black people.” John Watson, a younger African American technician, commented on the process of being hired, “you just got to know somebody to get in. And sometimes they just don’t want to hire blacks.” John also expressed frustration that his opinions about patient care were not taken into account, due to his non-professional status in the rehabilitation unit. He stated that he and the other technicians actually spent more time with the patients, yet the nurses and therapists often did not consult him regarding patient behaviors or suggestions which he felt would work more effectively.

These life histories and notable interactions exemplify how a system reproduces itself, and how this reproduction reflects the ideology of those in power. Georgia was a patient who was not accomplishing her therapist-generated goals quickly enough to meet the standard which the system had set, and she was unwilling to give up her power to decide when and how much she should walk. Josephine used her knowledge of the therapy world to smooth her own transition to home and daily activities. Trudy and John recognized the pattern of reproducing the status quo in practices of hiring more African Americans into “domestic” jobs. Grace fought against racial stereotypes among some staff members, and resisted the domination of the institution’s schedule over her own

needs. Monique became more conscious of racial issues during her tenure at the institution, but was unable to articulate possible links with her own situation. A.J. fit the institution's ideal of the cooperative, quiet patient, and he benefitted from this positive regard among the staff. Toni continued to struggle against the patterns she recognized as institutional racism, but was frustrated with her lack of power to effect a change. Institutional policies, whether official or unofficial, continued the reproduction of the system in its own image.

Noncompliance

Noncompliance is a phenomenon which is situated within the context of patient-staff relations, the power structure of the institution, and the political economy of the health care field. Most cases in which noncompliance was reported in this study involved major ethnic, class, cultural, or educational differences between the patient and the staff member reporting the problem. These differences were largely unnoticed by most staff members, or were framed in terms of "value" or "moral" differences. Those patients or staff judged to have lesser morals or values were more often African Americans of low socioeconomic standing, continuing the cycle of institutional reproduction, and maintaining the power of the white middle class.

CHAPTER 8

DISCUSSION AND CONCLUSION

Noncompliance is not a simple phenomenon which befalls certain uncooperative patients, nor is it an "irrationally motivated" nonadherence, as suggested by the American Psychiatric Association (Meichenbaum and Turk, 1987). "Noncompliance" as a legitimate term should therefore be limited to those few cases in which purposeful and dishonest manipulation take place. In the inpatient rehabilitation unit, this type of behavior is so rare (in comparison to its occurrence in other types of settings, such as outpatient treatment of Worker's Compensation cases) that I cannot actually say that I have seen it among the thousands of patients with whom I have worked. More often, it is a function of the relationship between patient and staff who differ in ideology, explanatory models, education, class, or ethnicity, or a combination of the above factors. This lack of agreement between patients and staff can be a result of resistance in action, depression, or disagreement with a system which has become increasingly standardized for some ideal patient in a fantasy world. It may also be a lack of knowledge of the system on the part of the patient and therefore of the types and timing of choices that can be made more easily. The grief which people experience during the initial phase of disability often goes unrecognized or at least unaddressed as a legitimate factor in rehabilitation, and can lead staff members to assume inappropriate conclusions about a patient's motivations.

In a recent television documentary, a young woman sat talking about adjustment to her disability (both her legs had been amputated above the knee due to severe injuries sustained when she was hit by a speeding van one evening). She talked of how shocking it was to look in the mirror and see her stumps, or to just sit and contemplate the fact that she would never again be able to thoughtlessly get up from a chair and stride across the floor. She lamented the loss of habit and routine, of unconscious movement and body ritual that walking with her own legs had given her, and that she had not been aware of until it was suddenly taken away. These losses are so rarely brought into the open and verbally expressed by people with new disabilities that I felt it pertinent to comment on this young woman. Most people going through physical rehabilitation express this loss in other ways--through anger, denial, resistance to therapy, and depression, as with the patient, Jim Rochel.

Jim was an active white man of 56 years when a severe stroke left him with one side of his body paralyzed, and unable to walk or use his left arm. His occupational therapist asked Jim what he would like to be able to accomplish through therapy. With an incredulous look on his face, Jim answered angrily, "Well, I want to walk and use my arm, of course!"

"What activities or tasks would you then be able to do that you can't do now?" asked the therapist, attempting to get more specific goals for which "objective" progress could be measured.

"I would live, instead of rotting in this wheelchair, instead of rotting in this hospital bed. I don't want to go to a nursing home--they just leave you there to starve and die!" Jim's recovery was punctuated by angry interchanges with therapists and nurses

who wanted Jim to continue to do more for himself. Jim resisted attempts to learn new methods of accomplishing his tasks, which would have allowed him to go home sooner in the care of his wife.

When I interviewed Jim in his home three weeks after his discharge from the rehabilitation center, he was bitter about some of his experiences there. "One of the worst things was not being able to decide anything for myself. If they wanted me to get up at 5:30 am to get weighed, that's what I had to do. I just wished they would have listened once in a while, instead of telling me what to do constantly." When speaking with Jim's therapists and nurses, most expressed frustration at Jim: "Jim was so abrasive that he was hard to be near," or "He was so noncompliant with everything I suggested. I don't think he really wanted to get better." One therapist managed to create a working rapport with Jim, and at least understood that his personal history had everything to do with his behavior in the rehab center: "Jim had a horribly abusive background. He described things that had been done to him as a child that no one should have to endure. I think Jim didn't trust anyone, and was so afraid of losing what little control he had of his life, and afraid that his wife would leave him, that he was sabotaging efforts to help him get back to a semblance of normalcy." My interpretation was that Jim was expressing his loss of control, and loss of familiarity of bodily ritual. Most of Jim's rehab team members were unable to recognize or uninterested in pursuing Jim's reasons for his "noncompliant" behavior. With little enough time in the day to care for 6 or 7 more patients dealing with disabilities that were just as severe as his, most staff members avoided interacting with Jim, and were relieved to see him leave. The therapist who had been able to develop a rapport with Jim received a poor evaluation for "spending too

much time talking with patients and staff, and being continually behind on documentation.” Perhaps if more tolerance of emotional repercussions of disability had been built into the system of rehabilitation, and more therapists were rewarded rather than penalized for spending time with patients, the rehabilitation experience would have been more successful for Jim. The pressures against Jim were largely economic pressures (decreased time available for staff to spend listening to patients, and rigid rules about reimbursement based on accomplishing certain “essential tasks” in the shortest length of stay possible). Other pressures include the emphasis on the purely physical, and less emphasis given to the psychological and emotional factors faced by patients negotiating a life-changing illness or injury.

Many people have difficulty adjusting to having paralyzed limbs, and not being able to feel it or move it as in the past. One woman with whom I worked in a rehab center, Moira Elswood, was an active person in her sixties when she was paralyzed from the chest down in a freak tram accident. We were working towards being able to use adaptive equipment to hold a spoon in her hand so that she could eat independently. We had spent many sessions, and “Moira” had difficulty conceptualizing that there were alternative ways of accomplishing daily tasks. “I can’t move my fingers. How do you expect me to be able to feed myself?” She had finally had the “Aha!” experience when she had been able to fork a piece of bread and get it to her mouth using the universal cuff device. My student and I were thrilled along with her at this triumph, and we hoped she would begin to accept and understand that life could approach normalcy in some ways, and that all was not lost. Her mood had been considerably brighter that day, until she had surprise visitors—old friends with whom she socialized weekly before her accident. Her

friends were obviously shocked at the sight of so many people in wheelchairs and seemed apprehensive about visiting Moira. Moira's mood immediately sobered, and her first statement to her friends was "Look, Madge, I am paralyzed. I can't move anything!" as she waved her immovable fingers in the air.

I felt Moira had suffered a setback in her adjustment and that we needed to provide more successes in therapy in order to help her acknowledge that she was able to do some daily tasks independently. Moira struggled through therapy and apprehensively returned to her lakeside condo (which had been modified slightly for her electric wheelchair) with the help of home attendants and a supportive man whom she had been dating. I learned two weeks later that Moira had decided she could not live independently and had admitted herself to a local nursing home.

I often think of Moira and her struggle with her own disability. I have come to the conclusion that Moira did not have difficulty understanding the possibilities so much as she could not get past her loss of bodily control and function in the allotted 12 weeks of rehab immediately after her accident. If rehabilitation could have taken a slower pace for Moira, giving her time each day to emotionally process the days accomplishments and failures with trained staff and family members, perhaps she could have more successfully entered independent community life, and found meaning once again.

How does economic status influence self-identity? Not only does income level directly shape choices in services and material goods, but class values have a tremendous effect on how a newly disabled person views the future. Joe Sonoco was a young black man with a high school education who had been trying to extricate himself from drug dealing in his neighborhood. One night he was stabbed in the back at a party over a drug-

related conflict, with permanent paralysis from the waist down being the result. His options upon discharge from rehabilitation were to live in transitional housing (Section 8 Federal Housing for those without income or home) or to move in with his brother and his family in a small, wheelchair-inaccessible house (his girlfriend with whom he had lived had left him while he was hospitalized). His concept of himself as someone who had been working at making himself better was shattered, mirrored by the expression on his face as we watched the roaches crawl across the floor on an outing to visit transitional housing.

Joe's story is completely different from John Pillsbury, who had experienced a similar injury from a cycling accident. John had a doctoral degree in public health and was a top executive in the state health department. His girlfriend, who became engaged to him during rehabilitation, came to visit him every day to learn his exercise program and daily routine. My most memorable outing with him was a trip to the state health department building to evaluate it for wheelchair accessibility. John was able to place orders for all new office and conference room furniture to allow for wheelchairs, as well as having the bathrooms and water fountains rebuilt for easier access. Automatic doors were also installed at the building entrances. While John's future was certainly affected by his paraplegia, his personal narrative was much less interrupted than Joe's. John was able to return to work, maintain his personal relationships, return to participation in sports, and become an advocate in the state government for people with disabilities. His educational background and personal power also helped him to obtain an accessible apartment at no extra expense. His ontological security was quickly re-established.

Noncompliance: Fault Line Over Deep Rumbblings

This project has supported the concept of noncompliance as a function of the relationship between patient and health care professional: the embodiment and expression of resistance, grief, depression, action, and power. The relationship in which this fundamental lack of communication and comprehension exists is complicated by lack of time, trust, and attention to the heart of the issue. The ability to live a fulfilling and meaningful life is at stake. The same could be said about the relationship between the races: the rhetoric of blame surrounding “the noncompliant” is suspiciously similar to the current explanations of racial inequities in this society. Statements such as “They just don’t want to improve themselves” or “they are lacking in personal responsibility” are easy ways of framing a world in which the speaker sheds the necessity for effort to make things better.

This project has contributed to the anthropological literature by operationalizing how institutionalized racism and continuing economic pressures in the health care sector directly effect patient care. The study also establishes the continued importance of personal, community, and political history as the foundation of current trends in social and political life. Without understanding the ideological implications of a current “level playing field” as a denial of history and habitus, we will not be able to respond to those who would continue the reproduction of institutionalized racism, whether intentional or unintentional. Although the discourse has changed from overt racism to learned helplessness or fiscal irresponsibility, the discourse and official knowledge continue to conceal the nondiscursive intentions of socially constructed ethnic identity.

In Chapter One, I introduce the reader to the major concepts of noncompliance, race, and disability. Chapter Two reviews the literature, including a discussion of disability and identity, informed by anthropological theory of praxis. Chapter Three outlines and explains my methods in this study. In Chapter Four, I developed an historical perspective on race, with evidence to show that racism persists, although it may have changed forms in the past thirty years. As racist statements and behavior have become socially unacceptable, a new classist tendency has renewed the separation of races, veiling the inequities of the races in more appealing concepts of “economic instability” or “fiscal irresponsibility.” Differing definitions of racism abound, with many white people being totally unaware of the privilege that whiteness brings.

Ultimately, race is one path institutions take to limiting access to economical and political power. As discussed in Chapter Four, from the beginning of the European colonization of this land to the present day institutional reproduction of culture and power relations, race has been used as a way to support one ideology over another, creating a structure invisible to most individuals.

Chapter Five describes the structure of the rehabilitation unit, and begins the presentation of findings of this project. At times, the examples in this study show that race was not a conscious issue with many patients or staff, but the habitus was a silent and ever-present shadow brought to occasional consciousness by a racist statement or action, or by the recognition of the reproduction of the institution. Toni and the other technicians had a unique vantage point: partly in the professional world of health care workers, and partly in the patients’ world, blurring the lines between subject and object, and professional and patient. In Chapter Six, I revisit the theoretical foundation of

embodiment, political economy, and power, and how these concepts are exemplified in my findings. Chapter Seven further develops my findings and relates them to institutional policy and reproduction. The concluding chapter redefines noncompliance, and calls for a recognition of the complexity of rehabilitation as it relates to access, agency, and resistance in medical institutions.

The events and interactions recorded and analyzed in this document focus the anthropological lens on the physical rehabilitation unit as a microcosm of society in which the elements of change, loss, and conflict are forced upon people in a constriction of space and time. This country has successfully built an underclass in which African Americans are overrepresented, as reflected in access to goods and services, and in the perceived noncompliance of patients in a physical rehabilitation unit. The physical rehabilitation unit is a space filled with struggles for ontological security, personal empowerment, and a meaningful life, in the context of sudden change and new beginnings.

A clear responsibility exists within the field which facilitated the beginning of race rhetoric, and then was paramount in discovering the flawed logic of a biologically based racial definition. The rhetoric of "difference" which has been so liberally applied to a variety of situations and events undercuts our abilities as humans to prosper as a species. Anthropology as a discipline has the potential for analyzing the root of racism and classism, for explaining the perceived and actual differences between people, and for suggesting changes which may improve the status of patients, families, and communities.

Anthropology has begun the task of taking on this responsibility¹, but we need to move more quickly before other more damaging explanations take hold. Many in the scientific community recognize that race is not a biological classification system (although many questions remain as to whether the medical community has embraced this idea), but rather a social classification system with very real consequences for those in each category. Anthropologists now need to convince the public in the U.S. of this fact and take a more active role in providing data to support this reality.

Jackson, and other towns like it, need more Shirlene Mercers--native Jacksonians, or at least those who know how to best present information to other Jacksonians. They need to hear from more people who know both sides of the issue, and who care enough to do something positive about it. Bright spots of hope exist in Jackson, with the advent of Diversity Luncheons sponsored by the mayor, interdenominational and interracial church activities, and the courting of minority businesses in the region. In an effort to improve quality and availability of health care to all people, this project's results will be shared with the hospital, the community, and with rehabilitation professionals in a responsible and constructive manner.

Anthropology can be a unique and powerful tool with which many aspects of culture are analyzed and challenged, including the anthropologist's own lens upon the world. It is my hope that this project will contribute meaningful cultural interpretation of the challenges presented to society in understanding race, and how the continual social

¹See Anthropology Newsletters from 1997 to present for continued commentary on the subject.

construction of race is reflected in the official and unofficial knowledge acted upon through institutional policies and structures.

GLOSSARY

ambulation: technical rehabilitation term for walking.

aphasia: partial or total loss of the ability to comprehend or recognize language; may or may not affect the ability to write or recognize written language. Receptive aphasia may result in the person's lack of ability to understand language, but words are produced without difficulty (Wernicke's aphasia). Expressive aphasia does not effect the ability to understand, but only to produce language (Broca's aphasia).

bed mobility: the ability to roll, move, and get up and down from the bed. Assessed by PT and OT.

CVA: cerebrovascular accident, or stroke.

dysarthria: the loss of the function of the oral structures in speech production; language comprehension is not affected.

femur: the long bone of the thigh

femoral artery: the major artery of the thigh

FIM: functional independence measurements; most commonly used nationwide system for rating the patient's ability to complete essential tasks including ambulation, self care, swallowing, cognition, and social interaction. The rating scale is from 0 to 7, with 0 indicating unable to do any of this activity, to 7 indicating that the patient is completely independent and needs no adaptive equipment or extra time to complete the task.

hemiplegia: paralysis of one side of the body, as with a stroke or some brain injuries.

hypertension: high blood pressure.

multiple sclerosis: a chronic degenerative disease of the central nervous system in which gradual destruction of myelin in patches throughout the brain and/or spinal cord interferes with the nerve pathways and causes muscular weakness, loss of coordination, and speech, cognitive, and visual disturbances.

MVA: motor vehicle accident.

neglect: medical term for the lack of the brain's ability to process sensory input from one side of the body (usually the left) as a result of brain insult. Not related to the capabilities of the eyes or the sensory organs of skin and ears--these may function perfectly, yet the patient is still unable to process information from these organs, and is essentially blind and insensate on that side of the body. Patients are most often unaware that they have a deficit, as the brain tends to fill in the "blind spot." This creates a special safety risk, as patients who have neglect run into walls which they are unable to perceive, or they attempt to use a paralyzed limb and fall frequently.

not-for-profit hospital: hospital which utilizes any profit to reinvest in the institution; for-profit institutions give profit to the owners or investors. The hospital in this study was a not-for-profit institution, but has historically given a significant portion of its year-end profits to the city and county (these gifts have ranged from \$300,000 to \$1,000,000).

nursing technician: non-professional level nursing assistant having on-the-job training, or a CNA (certified nursing assistant) background; responsible for toileting patients, dressing, feeding, and transportation to and from therapies; similar to orderlies in some systems; referred to as a "tech."

occupational therapy: a health related profession focusing on purposeful, meaningful, and culturally-appropriate activities to improve independence or enhance role performance in work, leisure, and self care tasks for people who have physical or emotional dysfunction. A registered occupational therapist has at least a bachelor's degree in occupational therapy from an accredited college, and a certified occupational therapy assistant has an associate's degree, and both have passed a national board exam to receive the designation "OTR" (occupational therapist registered) or "COTA" (certified occupational therapy assistant).

OT: occupational therapist.

physiatrist: physician specializing in physical medicine, dealing with the treatment, prevention, and diagnosis of disease by essentially physical means, including manipulation and exercise.

physical therapy: a health related profession focusing on the physical parameters of regaining function--strength, balance, coordination--through the application of therapeutic exercise and modalities. A physical therapist has at least a bachelor's degree in physical therapy from an accredited college and passed a national board exam to receive the designation "RPT" (registered physical therapist), and a physical therapy assistant has an associate's degree and has passed a state board exam to receive the designation "PTA" (physical therapy assistant).

professional staff: clinical licensed staff members having at least a bachelor's degree in their discipline; registered nurses, occupational therapists, speech pathologists, physical therapists, physicians.

PT: physical therapist.

public hospital: hospital which accepts all patients. Private hospitals reserve the right to turn away patients who are indigent.

quadriplegic: a person who had sustained a spinal cord injury in the cervical spine; usually results in at least partial paralysis of the upper limbs, and full paralysis from the chest down.

SOAP note: standard documentation of patient progress for therapies; consisted of subjective (patient's statements or reports), objective (quantifiable or observable findings of evaluation), assessment (the professional interpretation of the subjective and objective), and plan (treatment plan and measurable goals).

speech language pathology: the study and treatment of speech and language disorders especially through the use of exercises and audio-visual aids. Speech language pathologists have at least a master's degree from an accredited university, and has passed a national board exam.

ST: speech therapist or speech language pathologist.

synergy pattern: pattern of movement which is characterized by decreased voluntary use of smooth muscle contraction, involuntary movement of the flexor muscles of the upper extremity, and extensor muscles of the lower extremity; occurs as a result of brain damage to the motor cortex.

therapeutic recreation: leisure activities used by a therapeutic recreation specialist in order to improve a patient's mobility, self care, emotional, social, or cognitive skills toward improved quality of life. The therapeutic recreation specialist has a bachelor's degree in therapeutic recreation from an accredited college, and has passed a national examination to receive the designation "TRS."

therapy technician: non-professional level assistant having on-the-job training, or a CNA (certified nursing assistant) background; responsible for transporting, toileting, dressing, and feeding patients, and assisting the therapists and therapy assistants; considered a step up from nursing technician as it requires more training and less physical labor; referred to as a "tech."

TR: therapeutic recreation.

transfers: transitional movements from one position to another, such as moving from bed to wheelchair, or wheelchair to floor.

universal cuff: an elasticized or velcro-fastened band worn on the hand of a person who has no active finger movement but has active wrist, elbow, and shoulder movement; the band has a pocket attached within which can be placed a variety of utensils.

APPENDICES

APPENDIX A

APPENDIX A

Semi-Structured Interview Guide

The following questions were used as a basis for interviews and discussions with patients or former patients and their family members. Interviews were 45 minutes to three hours in length, with some patients being followed briefly, others for several months to a year, depending upon my access to them. Interviews were flexible and semi-structured, allowing the participants to say whatever they wanted, and to lead the discussion with what they felt was important. When the information given was minimal, more detailed follow-up questions were asked to help develop the topic. Straight-forward questions about problems encountered were avoided in most cases, as most participants declined to offer criticism or complaint in this manner. When the participant was allowed to bring up conflicts without particular prompting, the information given was detailed and genuine.

1. How old are you? Are you married, single, divorced? Do you have children?
How many? Where are they?
2. Where is your family from? Where did you grow up? Tell me about your childhood.
3. How much schooling have you completed?
4. Are you employed? If so, what kind of work do you do? If not, retired? From what? Homemaker? Unemployed?

5. Where are your parents from?
6. What kind of work have they been involved in?
7. Has rehab been what you expected it to be? Tell me about your experiences here.
What is your typical day like? Tell me about occupational, physical, or speech therapy. How did night-time differ from day-time in the rehab unit?
8. What surprises has rehab brought you? Was it what you expected? Had you ever known anyone who went through rehab?
9. What is the most difficult part of going through rehabilitation? If you knew someone who was about to begin rehabilitation, what would you tell them?

APPENDIX B

APPENDIX B

Biographical Profiles: Alphabetical by Last Name

Bob Burkeen : 33-year-old single white man who was an occupational therapist from Canada. He was from a middle income family. He frequently spent extra time getting to know his patients, and was often penalized for not getting his paperwork done.

Arthur Deaton : 48-year-old married African American man who had suffered a spinal cord injury due to a poor surgical outcome. He spent 6 weeks in the rehabilitation unit, then returned home to the care of his wife. He was unable to return to work in a local manufacturing plant. He initially had private insurance, then switched to Medicare when he was officially retired from his job and rated for permanent disability. He was considered compliant during his inpatient and outpatient therapy. He was from a middle income family.

Moiria Elswood: 72-year-old widowed white woman who was a retired homemaker. She had sustained a spinal cord injury in a freak tram accident in the resort town where she lived. She was paralyzed from the chest down with partial use of her arms and no active finger movement. She spent 12 weeks in the rehabilitation center, then was discharged to home with the use of an electric wheelchair, personal care attendants, and a good friend. Soon after her discharge, I learned that she had admitted herself to a nursing home after an especially difficult weekend with unreliable personal attendants.

Jean Forbes: 25-year-old single white woman who was an occupational therapist in the rehabilitation unit in Jackson. This was her first job as an OT, and she was originally from the Midwest. She was from a middle income family.

Sherrie Hampton: 23-year-old single white woman who was an occupational therapist in the rehabilitation unit in Michigan. She was from an upper income family, and had been raised in a suburb of a large Midwestern city.

Jackie Hatfield: 49-year-old divorced white woman who was born and raised in the Upper Midwest. She had worked the field of occupational therapy for 4 years, and was from a low income family.

Charlie Jones: 74-year-old married white man who was in rehab for deconditioning following heart surgery (Michigan pilot study). He was originally from Michigan, and

had retired from automobile manufacturing. He was considered noncompliant, and was in the rehabilitation unit for 10 days before discharging to a nursing home, as his wife was unable to give him as much assistance as he would need. His insurance was Medicare. He was from a middle income family.

Darryl Kincaid: 23-year-old single African American man who was attending outpatient therapy after paralysis due to a spinal cord injury acquired when he crashed a stolen truck. Darryl had a sporadic work history, and was living with a girlfriend in an apartment that was not accessible to his wheelchair. His family had declined further contact with him. He attended outpatient therapy 2 times out of the 12 visits prescribed. I later learned that Darryl was living in a nearby nursing home. At the time of his inpatient admission to the rehabilitation floor, he was considered extremely noncompliant and stayed for 4 weeks. He was from a low income family.

Ronald McGee: (Michigan pilot study) 76-year-old married African American man who was in the rehabilitation unit for 15 days after having a mild stroke. He was born and raised in Mississippi and had been a farmer and handyman. He had moved to Michigan looking for work in the 1960s. He was considered mostly compliant, with the incident about dressing as an exception. His insurance was Medicare. He was from a low income family.

Josephine McGregor: 48-year-old married white woman receiving physical therapy in acute section of hospital. Josephine was a health care worker who had had knee surgery. She is from the Northeastern United States, but has lived in the Southeastern U.S. for twenty years. Before she became a health care worker 6 years prior to this event, she had worked in a variety of industries and businesses. She was considered mostly compliant, having an instance or two of noncompliance. She had private insurance, and she returned to home within the week. She returned to work the following week. She was from a middle income family.

Shirlene Mercer: A married African American woman in her fifties, and a local activist. At the time that my data was gathered, she was the Chairwoman of the Board at the hospital. She was retired from teaching in the public schools, and was a political activist for a local politician.

Georgia Nimke: 46-year-old divorced white woman from Ohio, was in the rehabilitation unit after having surgery to remove a spinal cord tumor, then spending several months in a nursing home. She had been a medical office secretary in the past, but was unable to return to work due to her level of disability. She discharged from the hospital after 27 days, and moved into her daughter's home to help with the grandchild and to get what assistance she needed. She still used the wheelchair about 50% of the time at the time of her discharge. Her insurance coverage was TennCare (Tennessee's equivalent of Medicaid), and she was considered to have significant problems with compliance by her therapists and nurses. She was from a low income family.

A.J. and Louise Porter: 55-year-old African American man and his 53-year-old wife, entered rehabilitation unit after surgery to stabilize his spinal stenosis. Born in Mississippi, then moved to Indiana as a child, eventually settling in Chicago where A.J. met Louise. Louise was originally from the Jackson area. A.J. had private insurance, and was regarded as a compliant patient. He was in the rehabilitation unit for 14 days, and was interviewed in his home after his discharge from the hospital. A.J. was an assembly-line worker in a local manufacturing plant. He was not able to return to work. A.J. was well on his way to graduating from the wheelchair completely when I interviewed him. He was from a low income family.

Toni Proctor: 43-year-old separated African American woman originally from Memphis who was employed as a therapy technician. She had worked as a nurse's aid before becoming a technician. She was from a low income family.

Jim Rochel: 56-year-old married white man who had lost his manufacturing job due to his illness and subsequent disability. He had spent 3 weeks in the rehabilitation unit after a stroke had caused paralysis in his left side, and had been home in the care of his wife for 3 weeks at the time I interviewed him. Jim used a wheelchair for mobility, and was making slow gains in his ability to walk. He was considered to be noncompliant and unpleasant in his interactions with staff. His insurance was TennCare, and he was from a low income family.

Maria Sanchez: (Michigan pilot study) 86-year-old widowed Hispanic woman originally from Mexico, currently living with her daughter in Michigan. She was in rehabilitation for 12 days after a fall at home and brief admission to a general medical floor in the hospital. She had Medicare as her insurance, and was considered noncompliant. She spoke only Spanish, and was provided with an interpreter on brief occasions. She returned to her daughter's home after her discharge. She was from a middle income family.

Grace Simon, and daughter Roberta: 45-year-old married African American woman in rehabilitation after a motor vehicle accident. Categorized as multiple trauma (fractured leg, fractured arm, concussion/mild brain injury, internal injuries). She was born and raised in Gary, Indiana, though her parents were from Alabama. Grace attended Lane College in Jackson, and met her husband here. She was in the rehabilitation unit for 22 days. She was considered largely compliant, with occasional instances of resistance noted by the nursing and therapy staff. Grace was a school teacher in the public schools. She had private insurance, and was from a middle income family. She went home after discharge with the help of some family members, then eventually returned to work as a school teacher.

Trudy Smith: 55-year-old married African American woman who had worked for the hospital for twenty-five years. She was born and raised in Jackson, and was from a low income family.

Monique Stapleton: 22-year-old single African American woman who was a student intern at the hospital. She had a family member who lived in a nearby town, but she had been raised in a metropolitan Midwestern city. She was from a low income family.

John Watson: 32-year-old single African American man employed as a nursing technician. He had transferred from the housekeeping department 2 years before this interview. He was born and raised in Jackson, and was from a family with a low income.

APPENDIX C

Sample SOAP Note

O: Patient is a 57 yr old black male, attended initial occupational therapy evaluation in standard w/c [wheelchair], unable to propel. Med. hx. [history]—s/p [status post; “after”] right CVA [cerebrovascular accident, or stroke], left hemiplegia with onset on 10/12/97; hx of HTN [hypertension], insulin-dependent diabetes mellitus. Was employed premorbidly as a plumber; married. Wife in good health. Patient oriented x 3 [able to identify himself, his location, and the time/date].

Pinch: right	lateral: 20 psi	left	2 psi
	3 point: 15 psi		unable
	tip pinch: 12 psi		unable

Nine hole peg test: right 22 seconds left unable to grasp pegs

Visual Perception: Severe left neglect noted with House-Clock-Flower drawing test.

Cognition: Slow processing noted. Poor short term memory. Remote memory intact.

ADLs [activities of daily living]: Max assist [maximum assistance, requiring assistance with 75% of task] with UE dressing and bathing, dependent [unable to do any part of task] for LE [lower extremity] dressing and bathing. Moderate assist [able to complete 50% of task] for feeding. Max assist x 2 [with two people helping] for transfers [transitional movements from chair to bed, sit to stand, etc.].

Assessment: Patient has deficits in left UE strength, ROM [range of motion], sensation, coordination, visual perception, and cognition. Severe left neglect noted.

Plan: OT 2x/day, 6 days/wk for 4 weeks with the following goals:

1. UE dressing at min assist
2. LE dsg [dressing] at mod assist
3. Patient will be able to use left UE as a nondominant assist in manipulating objects.
4. Patient will be able to identify objects in left visual field with min cues.

Recommended LOS [length of stay]--4 weeks. Will need 24 hour care, at least mod assist for some self care by discharge. [This estimate is usually given by all therapists and nurses involved with a particular patient. This statement projects that this patient will need constant supervision and moderate assistance for self-care activities after discharge, due to the severity of the deficits listed in the objective and assessment sections of the note.]

Carrie K. Alexander, MA, OTR/L

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