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Work of Staff with Disabilities in an
Urban Medical Rehabilitation Hospital

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Abstract

This paper describes the experience of staff with disabilities working in an urban in-patient rehabilitation hospital. Findings are drawn from an NIH funded, 2.5 year ethnographic study. Residential medical rehabilitation programs are essential to recovery when traumatic bodily injury or illness markedly impairs a person's ability to function independently. Physical medicine and rehabilitation teaches patients new ways to use their bodies. Unlike the crisis situation of acute care hospitals where survival is the ultimate question, medical rehabilitation staff help patients to adapt and adjust to new lives. One striking factor emerging from the study is the role of staff with disabilities in medical rehabilitation. Staff with disabilities include former patients working as colleagues, administrators, or supervisors of those who once managed their in-patient care, and who now must educate these colleagues and patients about realities of life with disabilities while also changing their attitudes about the nature of disability.

Introduction

Residential medical rehabilitation programs are essential after life-altering traumatic injury or illness markedly impairs a person's functional ability. During the six to twenty weeks when patients reside in a medical rehabilitation hospital, cultural factors permeate the social universe ultimately affecting staff work and patient care. This paper discusses one such factor uncovered in a two and a half year study of The Body Shop, a Midwestern urban medical rehabilitation hospital.

This paper discusses a brokerage of power and identity playing out in the lived experience of staff with impaired bodies teaching medical rehabilitation patients to learn to adapt to their own newly impaired bodies at the same time as they also

educate colleagues and co-workers without disabilities. This contrasts with customary expectations that in-patients encounter only bodily whole and intact healers and care givers, such as doctors and nurses and therapists, who do not display the same disabilities as their patients. In an ironic contrast, this cultural dilemma links patients and staff in a commonality of impaired bodies rather than separating them in the expected whole versus flawed, healthy versus sick relationship of care provider to patient in which body state contributes to the imbalance of power and dominance that is inherent in this relationship.

Project Overview

Ethnographic field work occurred from 1993 to 1995 in an institute built during the 1950s polio epidemic. Daily census averages 100 patients admitted to one of four specialty units devoted to spinal cord, traumatic brain injury, geriatrics, or orthopedics. Sixty-five per cent of patients with spinal cord or traumatic brain injuries are victims or perpetrators of shootings, beatings, or other violence. According to an Annual Report issued during the field work, The Body Shop annually admits 2,000 in-patients and serves 7,505 outpatients at this and two suburban satellites. It employs a staff of 600 including 15 board-certified physiatrists with a volunteer corps of 250 donating 22,000 hours of service annually.

One striking factor emerging from the study is the experience of staff with disabilities working with a patient population composed solely of people with disabling illness or injuries. Current disability scholars and historians, including Shapiro (1994), demonstrate how the expertise of people with disabilities shapes both disability culture and changing attitudes about disability in general. Shapiro also addresses conflicts between medical rehabilitation consumers and "white coats" or professional rehabilitation providers. Indeed, disability activists argue that aspects of rehabilitation have little to do with, and often are not based on, an understanding of the lived experience of disability. This debate about rehabilitation's merits continues in consumer publications such as *New Mobility* and is heightened by recent cutbacks by insurance and government with authors such as Corbet (1995a, 1995b) arguing that an adequate period of medical rehabilitation extends consumers' lives and is cost efficient in preparing and educating consumers to properly care for their bodies and to negotiate systems to obtain proper care.

Understanding Work and Cultural Change

The importance of staff with disability working in a medical rehabilitation setting lies in the central role of work in structuring societies and cultures. Work related actions and relationships constitute Body Shop staff life. Anthropologists Gamst (1992), writing in *Meanings of Work*, and Applebaum (1992), writing in *The Concept of Work*, hold that through work humans construct significant aspects of culture. Thus, examining Body

Shop staff work provides a unique understanding of Body Shop and disability culture because one task of medical rehabilitation staff work is the enculturation of people with altered bodies in new, socially approved behaviors as they prepare to return to their families and communities. Body Shop staff also counsel and advise families and communities on how to become more accessible to their loved one with a new or worsened disability. Thus, staff with and without disabilities are a potentially powerful facilitators in shaping and changing public attitudes towards disability.

According to Gamst (1995), paid work in the U.S. is a central identifier of the self, replacing kinship in human socialization. Work consumes large chunks of human energy and time, from 40 to 80 hours or more weekly, plus commuting time, as is the case with many Body Shop suburb-dwelling staff. Applebaum further explains the significance of paid work in U.S. society in a way that is especially salient to The Body Shop because medical rehabilitation, by definition, entails teaching patients and families to use culturally approved methods to rebuild and restructure their lives around an altered body. Applebaum says:

Anthropology views work as....the spine which structures the way people live, how they make contact with material and social reality, and how they achieve status and self-esteem. Work is basic to...creation of a human environment, and to the context of human relationships. Work is...sharing of knowledge and skill to create our human-made world.
(Applebaum 1992:ix-xii)

In short, the role of staff with disabilities at The Body Shop and, quite possibly, other rehabilitation institutes and outpatient situations is especially significant and, until recently, its importance has not been recognized. Also, using the Applebaum and Gamst understandings of work, one can argue that Body Shop staff with disabilities engage in a kind of self-identifying work that reinforces and demonstrates Western values while constructing the culture of other staff (interns, residents, student nurses and therapists) as well as of that of new people with disabilities, their families, and their communities.

As it is, conflicts about rehabilitation are played out in the roles of staff with disabilities, in their work and relationships with their consumer-patients as well as in work and relationships with other staff, many of whom, this study found, have little experience of life with disabilities outside of what they learned during their professional training. Unfortunately despite a burgeoning consumer literature and a growing number of ethnographies of disability, few studies examine these places where so much socialization to disability status occurs. The few book length ethnographies that do exist give an overgeneralized view of life in rehabilitation settings. One, Roth and Eddy's *Rehabilitation for the Unwanted* (1967), was done prior to

implementation by the industry of cost-cutting DRGs and HMOs; or like Gubrium and Buckholdt's *Describing Care* (1982), they are limited in scope only focusing on the professions' task-related discourse.

Staff with Disabilities Unique Dilemma

Staff with disabilities are in a puzzling position. Primarily, they are highly trained professionals. Simultaneously, they resemble their patients in that these staff are themselves rehabilitation consumers who survived disabling injury or illness, went on schools or training programs, and now live as professionals with disabilities. In so doing they become unwitting role models, examples, and beacons of hope to patients and families. At times, boundaries separating staff and patient identities blur. Such is the case with two study participants who underwent rehabilitation at the Body Shop where they now work. Olga, a paraplegic Body Shop administrator, is often used as an institutional spokesperson because she is a model, beauty pageant winner, and athlete. Sherry, a spinal-cord injured unit clerk, now is a colleague of the very same nurses and aides who once cared for her during her rehabilitation following an automobile accident.

The Body Shop: Safe Haven from Discrimination

Staff with disabilities hold a representative array of paid positions as physicians, administrators, middle management, department and clerical support persons, and unit supervisors to nurses, aides, and housekeepers. Staff disability parallels patient disabilities: quadriplegia, paraplegia, spinal cord injury, multiple sclerosis, blindness, post-polio syndrome, and chronic illnesses defined as disabilities under the Americans with Disabilities Act.

Because historic, pervasive discrimination left many people with disabilities with few employment alternatives, The Body Shop became for some staff a safe haven in the harsh industrialized Middle Western job market. Former patients abandoned by family and friends found jobs, solace, and a fictive family system here. Informants reported that they saw The Body Shop as a place where one's disability would not be held against one. So, over time, they easily filled clerical, clinical, managerial, and menial positions. Marty, a middle aged male administrator, hired as a patient transporter 15 years ago, explained:

I...couldn't pass a physical anywhere. Insurance wouldn't allow companies to hire me....My father suggested I apply for a job here because physically disabled are here all over the place. How could they turn me down?...They gave me a job. I expected to grow, to advance, to be promoted, to make a living. My expectations were met.

Rehabilitation's Cultural Ethos

Medical rehabilitation's underlying philosophy provides a

cultural ethos for staff lived experience. Primarily, this type of rehabilitation offsets changed bodily functional ability, training patients to use altered bodies in new, different ways often incorporating assistive devices or artificial limbs. Madorsky and Corbet (1995:61) explain that rehabilitation retrains, educates, and empowers the newly disabled to develop expertise in the use and care of their own bodies. Unlike other medical specialties, rehabilitation promises no cures. Instead, patients relearn basic life skills: swallowing, eating, speaking, sitting, toileting, dressing, and walking.

Acute care settings emphasize bodily repair, failing to educate patients and their families on how to live with an irreparable body. In rehabilitation, patients have no choice but to face the reality of psychological and cultural shifts of self perception. Nevertheless, Body Shop staff report that most patients, regardless of disability, believe they will walk out of rehabilitation, fully restored. True, some defy odds. For most patients entering a facility like the Body Shop that specializes in treating those with severe injuries, a good outcome means accepting an altered body.

Rehabilitation then, treats injuries, chronic conditions, and disabilities which Estroff (1993) characterizes as "I am" conditions: highly disruptive of, and involved with, cognition and the perceived self. Rehabilitation is a time when, as Estroff says, patients re-construct their world around the reality of irreplaceable physical losses. Witnessing professional staff with disability competently performing routine tasks could help patients and their families face that reality.

Moral Mandate of Rehabilitation

The idea of rehabilitation resonates with philosophical ideas prevalent in Western culture (Scherer, 1993; Murphy, 1987) such as notions about individual potential for development and change (Stein, 1979); resistance in adversity's face (Stein, 1979); an ethos of individual achievement and mobility (Gritzer and Arluke, 1985; Murphy, 1987; Scheer and Luborsky, 1991; Luborsky and Pawlowski, manuscript); and the concept of body as repairable machine (Hobbes, 1950; Sahlins, 1976, 1996; Scherer, 1993). This moral mandate echoes in attitudes towards work and related activities and in the manner that disabled staff are at once lionized, demonized and stigmatized.

Findings

In this context of rehabilitation's cultural ethos and moral mandate, several patterns emerged during content analysis that indicate that work experience of staff with disabilities illustrates conflicts between rehabilitation's idealized goals and the lived experience of work with illness and disability.

These patterns are:

First, staff with visible disabilities are cast as willing or unwilling examples of a patient's achievement potential to patients and to other staff. For instance, staff see the spinal

cord injured quadriplegic Dr. Charles as an inspirational role model. Dr. Charles has appeared on national nightly TV news and in magazine features but stated that he feels many of his colleagues thought he would fail, that he was less than competent. Toby, a clinical psychologist with a visible disability finally, grudgingly after 25 years, accepted role model status:

My job involves patient advocacy and being...on the spinal cord unit to be a role model for the patients. What I do...is respected. That feels good. I feel confident. ...[but] I didn't want to be a role model for people with disabilities. I wanted to move away from that....I denied [my role model status] for years because that is not what I wanted to do or be.

Second, despite achieved professional status, stigma and negative stereotypes held by their colleagues and coworkers who may have no first hand knowledge of life with disabilities still affect staff work lives and histories. Staff study participants with disabilities reported that they often felt that they had to constantly struggle to prove their competence to their colleagues without disabilities. Dr. Charles angrily described his co-workers' attitudes:

People see me as an exception....I think I've changed people's minds. No body wants to say it to my face, but they didn't think I would make it through my residency. Nobody would have the heart to say anything. But here I am, anyway.

Third, for some staff, Body Shop work is a first contact with disability and an opportunity to learn how people with disabilities live their lives after completing a medical rehabilitation program. Staff recall their initial fear of interacting with unknown others. Charlene, a secretary nearing retirement who has worked at The Body Shop since she was a teenager, says:

when I first came here, I was scared....I didn't know how to talk to them, or approach them, or what to say to them. I think they scared me...because I never came in contact with handicapped people....I was only 17. It was scary. With the help of my mother and people I worked with in the department and physicians and therapists, and just getting to know patients. And joking...And laughing with them.

Fourth, many staff reported that they felt they could not reveal their disabilities either to other staff or to their patients. Some staff with hidden disabilities or chronic illness reported that when they would eventually "come out" to their patients, they felt that they were able to elicit, from those patients, increased cooperation and empathy. Toby, the clinical

psychologist reports:

My disability, my blindness, gives me an edge. Having a cute dog helps a lot. It helps people talk, and I can give them education while we talk. There is a me-patient bond that comes from my having survived a disability...that somehow, I have been through something and survived and that makes a difference....If someone is totally awed, I can use that for education. Then we get into a conversation about their perceptions, and my perceptions of disability and reactions. I use a lot of my experience. With staff, I am not sure. Sometimes my disability is a tool; and sometimes it is a disadvantage....You can't overplay a disability. It'll back fire.

Fifth, some staff with disabilities reported eventually choosing to return to school and enter an allied health or related profession they encountered during their own rehabilitation. Like Percy, former employee and retired pioneer orthotist, these staff see the disability they experienced as the start of a new life. Finding work was their ultimate life goal. Sherry, a paraplegic a unit clerk, says "I measured my life by whether or not I was able to go back to work." Christopher, a nurse on a Spinal Cord Injury Unit reports:

I'm a cardiac patient. Don't stand in my way. It would be easy for me to get disability [benefits]. I could have applied to Vocational Rehabilitation, but they are too defeatist, so I put pedal to the metal and decided to do something with my life and not rely on others. I could die tomorrow, but I have a kinship with the patients.

Finally, staff with disabilities working at lower Body Shop hierarchical levels report, ironically, penalties related to their own disabilities or chronic illness. Nurses or aides taking time off for frequent doctor's appointments or illness are disciplined by being forced to take unpaid time off. Many such individuals are relegated to contingent, or permanent part time status, working with little relief for chronic illness or work related injuries. Unit and department supervisors confirmed that, when this occurs, disciplinary letters are placed in personnel files. Aides so treated are often middle-aged African-American women who are often praised for their unique knowledge and skill in handling patients gained over decades of work on the in-patient units. Allie, a nurse, says:

You get sick time, but if you use it in a certain time, you get wrote up for itThey don't care if you come in sick with a 104 temp or not...as long as you show up for work. I almost lost my job because...I could not walk and I had to take off.....I got wrote up for calling in too much....You would think they would deal with this as a chronic illness

or a disability.

Concluding Discussion

In conclusion, this data shows that even in a setting with an educated, progressive, staff negative attitudes toward disabilities are still evident in institutional policies and practices. If anything, this research shows a need to foster careers of people with disabilities and to investigate if more professionals can be drawn from the ranks of former rehabilitation patients to fill some of the shortages in some rehabilitation fields.

But this report raises as many questions as it answers. It shows a need for further ethnographic research examining staff work in these settings. Additional research is needed to examine interactions between staff with disabilities and patients, and to look at the effect of the presence of staff with disabilities on rehabilitation processes and on the families or groups the patient rejoins after discharge. Staff with disabilities may be a closeted asset whose expertise as disability survivors is not adequately tapped.

Further study also is needed to examine the attitudes of clinical supervisors regarding staff with chronic illness and hidden disabilities. Policies relegating most staff with disabilities to part-time or contingent status while lionizing one or two others, or that penalize nurses and aides for time off for proper health maintenance undermine rehabilitation's holistic aims and give contradictory messages to staff and to patients they serve.

Further research should examine the attitudes of non-disabled staff. Study participants report the need to constantly educate their colleagues and professionals about life with disabilities - a striking contrast between The Body Shop's idealized goals and the lived experience of its staff. Further research must also include an appreciation of the cultural dilemmas and ironies of the disabled staff, those flawed healers playing such a significant role in this important work.

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