Socialization to the Culture of a Rehabilitation Hospital: An Ethnographic Study

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Objectives. Most previous research on rehabilitation of patients after spinal cord injuries has dealt with the attainment of outcomes valued by staff members or with the prediction of successful outcomes based on sociodemographic characteristics of patients. This study examined the rehabilitation process from the insider's perspective of an individual patient to determine his view of important adaptive problems and to examine how these problems were addressed.

Methods. Ethnographic methods were used for fine-grained documentation of the experiences of one 30-year-old man with spinal cord injury. Daily interviews were conducted with this patient during his 116 days of inpatient rehabilitation. An interdisciplinary research team analyzed the data with the constant comparative method to identify a number of recurring themes.

Results. Findings indicate that in addition to learning how to function in the local world of the rehabilitation hospital, the patient also learned a new identity as a person with a long-term disability.

Discussion. A central theme was the patient's ongoing attempt to figure out how his future was related to his life before the injury and how he could use previous competencies in adapting to disability. Staff members seemed so intent on teaching the patient new skills that they often discounted the significance of his past experience and failed to engage in helping the patient connect his future life story to his past.

This article is an account of one aspect of an interdisciplinary ethnographic study of the day-to-day changes that occur during rehabilitation of a person with spinal cord injury. Our aim was to view these changes from the perspective of the individual patient, rather than from the perspective of the rehabilitation hospital or its staff members. This aim was shaped by reflection on the body of existing research on spinal cord injury, which is heavily weighted toward outcomes valued by staff members and toward sociodemographic characteristics of patients used to predict certain outcomes. As Trieschmann (1988) stated in her extensive review of the literature on rehabilitation after spinal cord injury, "from past research we know quite a bit about who will adapt to spinal cord injury, but we know very little about how they adapt" (p. 110). The goal of this study was to identify in depth how an individual patient adapted over time. Ethnographic research methods were chosen because of their ability to capture an insider's perspective and a holistic view of what insiders consider relevant and important (Krefting, 1989).

The primary purpose of this article is to discuss one of the major interpretive themes that emerged from the study: socialization to the culture of a rehabilitation hospital. An additional purpose is to convey the research.
process through which this theme was derived and interpreted. An important characteristic of ethnographic research involves interpreting findings from the perspectives of both insiders (patients and staff members) in the action and outsiders (the researchers), whose past knowledge and theories allow them to compare their findings with the findings from other research (Geertz, 1973, 1983; Kleinman, 1992). Findings will thus be presented in a way that reflects two levels of analysis. The first level, which describes literal aspects of how the patient learned the local world of the rehabilitation hospital, uses the concept of culture as a way to think about local worlds. The second, more abstract level of analysis, in which the patient learned a new identity as a person with a disability, uses the concept of narrative as a way to think about patients’ life stories.

Planning the Project

Development of the study was a collaborative effort that involved a faculty member and graduate students in an academic program in occupational therapy, as well as an interdisciplinary group of researchers and clinicians from a nearby rehabilitation hospital. Initial planning meetings were attended by research staff members and research fellows from various disciplines, as well as research personnel from several clinical departments of the hospital. Some of these persons remained with the project as part of the core research team, and others became members of a group of consultants called peer debriefers, whose role was to reflect on methods and findings of the study as they evolved.

In ethnographic studies, general research questions that guide the initial collection of data are identified. The nature of these questions typically evolves as the study progresses and as new issues emerge. The original set of research questions for this study included identification of the patient’s previous adaptive patterns; adaptive problems faced after the onset of injury, including their sequence and relative importance; strategies used to solve problems or cope with issues; affective responses to adaptive problems and solutions; long-term expectations about the future; perceptions about the rehabilitation process and how these differed from or were similar to the perceptions of staff members; and sources of support used in dealing with adaptive issues. Socialization to the culture of a rehabilitation hospital, a major interpretive theme that emerged from the data through a process of grounded theory development, incorporates aspects of many of the original research questions.

The study was intended as a methodological demonstration to evaluate ethnography as a way to study adaptation to disability. It thus involved a single respondent. In selecting a respondent while he or she was in acute care before rehabilitation, we sought an English-speaking person 18 years of age or older who had experienced a recent traumatic spinal cord injury that involved some upper extremity disability but that did not involve dependence on a respirator. The last two criteria were intended to identify a person who was likely to need some physical assistance after discharge from rehabilitation but who would not have the special long-term support problems common to persons who are respiratory dependent. Gender, ethnic background, and socioeconomic status were not used as selection criteria. It was important, given the nature of the study methods, to select a respondent with the capacity for abstract reflection on his or her experience and the willingness and ability to articulate these reflections verbally.

Implementing the Study

The respondent who was chosen was a 30-year-old white man who had sustained a T-12 incomplete spinal cord injury due to a fall from a scaffold while working at his job setting up lighting for a concert. In this article he is called Russell, a pseudonym that he chose himself. Although his spinal cord injury did not involve upper extremity impairment, Russell had fractured his left arm in four places during his fall. Immobilization of this arm meant that Russell had only his right arm for functional use during rehabilitation. He had been injured 25 days before his admission to the rehabilitation hospital and had spent this time in an acute care setting. We obtained Russell’s informed consent to participate in the study before his admission to the rehabilitation hospital so that data collection could begin on his first day.

Russell reported that he had been suspended from school in the ninth grade, after which he took a welding course and worked in construction jobs. About a year before his accident he moved to a city several hundred miles from his original home to take a job as a roadie setting up for concerts. Russell had married in his late teens, had a son, and was divorced when the child was 2 or 3 years old. The son had lived with Russell’s ex-wife until about 6 months before Russell’s spinal cord injury. At that time he came to live with Russell. After the accident the son moved in with Russell’s brother and his family, who lived nearby.

The major source of data for the study was daily interviews with Russell in an unstructured format that allowed him to identify what had happened that day and his thoughts and feelings about these events. Four research team members conducted the interviews on a rotating schedule. These interviews, which ranged in length from 10 to 50 min, were audiotaped and later transcribed into written text for analysis. Russell had the right to decline an interview whenever he chose. He remained in the hospital for 116 days but gave his last interview on day 99, stating that he had too much on his mind from that point on. During the 99 days he participated, Russell was interviewed 71 times. Weekend interviews were conduct-
Analysis and coding were maintained with a system grounded in the data and reflected available theories and on a designated set of interview transcripts. This system was excluded considerably after analysis of these forms of data collection to continue throughout his stay, even though he terminated his own interviews on the 99th day of his hospitalization. After his discharge, a few follow-up interviews were conducted with Russell when he came for outpatient physical therapy. All transcribed interviews were checked for accuracy before analysis, usually by the person who had conducted the interview.

A process for data analysis was developed jointly by the primary interdisciplinary research team, which included an occupational therapist, rehabilitation counselor, social psychologist, and an occupational therapy graduate student. This process began as each team member identified what seemed to be important themes from the study as a whole before looking at actual data texts. Thus, a system of interpretive categories was initiated. This system was expanded considerably as analysis of texts proceeded sequentially from day 1 through Russell’s hospitalization. Interviews were coded and analyzed through close, sentence-by-sentence examination of the text, a process referred to as microcoding (Patton, 1980; Strauss, 1987). Analysis was based on the constant comparative method, in which interpretive themes that emerge from the data are continually examined and revised as new data are analyzed (Glaser & Strauss, 1967). Because of a commitment to an interactive process of analysis and interpretation as a research team, records of data analysis and coding were maintained with a system of notecards placed on bulletin boards rather than with a computerized coding system. Connections between specific pieces of data and interpretive themes were established by the research team and recorded both in a filing system and on a designated set of interview transcripts.

About one third of the way through the analysis, the research team members met with an interdisciplinary group of project consultants designated as peer debriefers. The function of the peer debriefers was to examine and critique both the process and the content of emerging interpretations to ensure that they were grounded in the data and reflected available theory and knowledge relevant to issues that emerged. After the research team had incorporated recommendations of peer debriefers into the analysis system and were confident that each group member had a common understanding of the coding and interpretive process, a more efficient analysis system was adopted in which interviews were individually coded by primary research team members.

Weekly group meetings were no longer devoted to microcoding, but rather were spent discussing new or potentially controversial interpretive issues that had been identified by individual group members.

Methods to ensure trustworthiness of data included careful checking of the accuracy of interview transcription and triangulation of data from several sources including the key respondent, individual staff members, and clinical team rounds. Trustworthiness of the analysis process was addressed through ongoing review and revision of alternative emerging interpretations by an interdisciplinary group of primary researchers and through reviews of data analysis and interpretation by an outside group of peer debriefers.

Reporting of results in ethnographic research differs in some respects from the usually more straightforward reporting used in quantitative studies. Kleinman (1992) referred to ethnographic writing as “a dialectic between social theory and empirical findings” (p. 133). Thus, in this report, major interpretive ideas from relevant literature are discussed in conjunction with findings from this study. An insider’s perspective is conveyed through verbatim statements from interviews with the key respondent and with clinical staff members. These interviews have been edited only through addition of parenthetical terms that provide clarification. In addition to the present work, other major findings from the overall study are addressed in separate articles on adaptation to wheelchair use (Bates, Spencer, Young, & Rintala, 1993) and significance of family support (Rintala, Young, Spencer, & Bates, in press). Other articles are currently being developed on coping strategies and on evaluating the research methods as a way of studying adaptation to disability.

Learning the Local World of the Rehabilitation Hospital

In recent years, recognition of important differences between the specialized world of health care and the daily life contexts of patients has been growing. These differences have important implications for how illness and care are experienced, as illustrated by the illness narratives of Arthur Kleinman (1988), who has advocated use of ethnographic methods from the discipline of anthropology to develop “focused miniethnographies” of the local worlds of patients and of care providers (Kleinman, 1992, p. 130). The concept of culture, referring to the shared way of life of a group of persons, is a way to conceptualize these local worlds and the interrelated body of practices and beliefs that shape how things are done and what they mean to members of the group.

Thinking about health care institutions as local worlds with their own cultures is not a new idea. During the 19th and early 20th centuries, the moral treatment era...
in psychiatry was based on the notion that providing what was considered a normal social environment and round of meaningful daily activities would improve the functioning of persons with psychiatric disabilities—a notion that proved successful in treating a substantial number of patients (Meyer, 1922). In the 1950s, this notion appeared as the concept of the therapeutic community (Jones, 1953). Formal research on the nature and effects of treatment environments was influenced by a now classic study conducted by anthropologist William Caudill (1958) on the psychiatric hospital as a small society. Sociologist Erving Goffman (1961) included mental health settings as well as prisons in developing his concept of "total institutions" that encompassed all aspects of life for their residents. Psychologist Rudolf Moos (1974) conducted extensive research that examined the effects of differences in the social climates of psychiatric institutions on patient outcomes. Studies have also been conducted on the local worlds of nursing homes, as exemplified by the research of Miller and Gwynne in England (1972) and Moos in the United States (1984).

To date, the tradition of research on the cultures of health care institutions has not addressed rehabilitation settings. Although Treschmann (1988) reviewed several behaviorally oriented studies that addressed specific aspects of rehabilitation hospital environments, the behavioral approach purposely avoids consideration of meanings and interpretations that are fundamental in studying culture in the ethnographic tradition (Geertz, 1973, 1983). Thus, this study extends research on hospital cultures to a rehabilitation setting and to individual experience after traumatic disability rather than experience with chronic illness as found in mental health or nursing home settings.

When interview data on Russell's socialization to the local world of the rehabilitation hospital were examined, five subthemes related to aspects of the hospital's culture emerged. These included the physical surroundings, the system for providing care, the scheduled round of activities, the staff members, and the fellow patients.

**Physical Surroundings**

Russell's earliest impressions of the local world of the hospital were focused on its physical surroundings. When Russell was first transferred to the rehabilitation setting, he was disconcerted by the difficulty of fitting his belongings into his living space and by the lack of cues for helping him get oriented. Moving to a new room the second day had a profound effect on him.

**Day 1:** They told me that there'd be a room for me to put the plants, all this stuff. All that's going to have to go. At the other hospital I had a clock I could look at. That was nice. Here I feel totally lost.

**Day 2:** I can look out the window now and I got someone to talk to in here. I got a room full of plants so it don't seem so gloomy.

As Russell's mobility increased, he began to use more spaces both inside and outside the building.

**Day 12:** When I get a wheelchair I can work with one arm. I can go down to [physical therapy] and work out on my own all the time.

**Day 49:** We go up there across the street in the parking garage. They had a nice cool breeze up there. You can go up and look around.

Russell learned relatively early to get some of his desires met by arranging for things to be brought to him from outside the hospital.

**Day 4:** We ordered out for pizza. To heck with the food here.

**Day 51:** I tried to get 'em [my cousins] to bring me beer today. I can go up in the parking garage and drink it.

**System for Providing Care**

Another important aspect of the local world of the hospital was its system for providing care. During his first few days Russell was frustrated by what he considered a lack of attentiveness to his physical needs, including his meals, catheterization schedule, and pain medications. His words reflected his recognition of the differences between the care system in the acute hospital and that in the rehabilitation hospital.

**Day 1:** When I was in pain, they were there to help me [in acute care]. And I can see I'm not going to get that help here.

He spoke about his discomfort with asking for help.

**Day 12:** You know, you go to ask somebody to help and everything. Around here there aren't too many people I want to ask. For nothing. I'd rather just sit for an hour and go to bed. Just ask 'em for what I need.

From the beginning Russell was expected to assume some responsibility for his care. He agreed to these responsibilities in areas such as skin care, although he joked about the mirror he was given to check the skin on his buttocks.

**Day 1:** They gave me a new toy to check myself. I told 'em I'm gonna stick it on the bottom of my wheelchair to walk behind people wearing dresses.

Russell also joked about the special language used in the hospital for ordinary things.

**Day 5:** I said, "Man, I gotta take a shit." And the lady started laughing and said, "It's called a bowel movement." But it's still the same thing.

Staff members sought to get Russell to become attentive to his body and urged him to interpret pain as a positive sign of returning sensation rather than as a debilitating problem.

**Day 31:** They say it's good, you know, if you can feel the pain or something, you're supposed to, you're feeling something. They said it's good. I said hell.

**Day 35:** Something's been going on with my legs, my feet these last 2 days. I think they're trying to come back.

Russell learned some aspects of his care such as...
catheterization quite readily, but he refused to assume responsibility for his bowel program in spite of staff members’ efforts.

Day 35: Well, like I told her, man, we’ve already had it [catheterization] done to us a hundred times. You know, if we couldn’t figure out how it works we’re in bad shape. Or pretty darn.

Day 99: I just wish my bowels would come back. That’s the main thing that bothers me the most. They do all the work here. They try to get me to do it. Just keeping telling ’em no. That’s something I can’t and won’t get used to.

Scheduled Round of Activities

Another important aspect of the culture of the rehabilitation hospital was its scheduled round of activities. Russell’s initial impression was that these routines were not organized in a sensible way, and he made attempts to change them for the first week or so.

Day 3: The doctors came to visit him [Russell’s roommate]. I’ve been here a day before him and they haven’t talked to me yet. Then they came over and said, “We’ll be back at 11 o’clock for you.” I said, “Well, you’re here, why don’t you just evaluate it now?” I just sat around and waited until 11.

Day 5: They’ll send one in to do catheterize me and 10 minutes later they’ll send another one to do him. I said, “Well why can’t they do it?” It don’t make no sense.

Later Russell made compliance with expected routines into a game with staff members. He developed strategies for working around the system.

Day 5: I’m supposed to be up now. You can’t get nobody to do nothing on a shift change around here so I was up in the chair until about 4. So I stayed an hour longer which makes up for the hour I’m supposed to be in there. That ain’t how you’re supposed to do it, but I figure if that’s the way they want to play I can play the game too.

Day 33: [Referring to posted sitting schedule] That’s old. I don’t even go for that anymore. I just go for that when I don’t want to get up.

Russell continued to make decisions about which aspects of the expected round of activities he considered worthwhile.

Day 31: I gotta start classes next week. Supposed to give you an idea how to take care of yourself and [expletive] like that. I guess that’s where I’ll be asking all my questions.

Day 55: Played hookey from classes. Had a headache, came down here, got something for the pain and by down and went to sleep for about an hour.

In some areas Russell decided to go along with things as they were routinely done, although he did not necessarily view them as they were viewed by staff members.

Day 31: They don’t need us [in weekly rounds]. They can talk among themselves and do everything. They don’t really need us there. It gives us a chance to put our two cents in. You get ‘em all there at once, you can get it all out at once. But it probably don’t do no good. You can complain and complain, and it ain’t gonna do no good. I just keep my mouth shut.

In responding to the established routines of the hospital, Russell spoke repeatedly about his discomfort with the pace of activity. Initially it seemed much too slow to him and later, seemed much too quick.

Day 3: The way they get me up, I feel useless worthless. And it’s driving me crazy just sitting here. Kicking gates and mosquitoes. Once in a while you get a mosquito. That’s the fun of the day.

Day 94: Time goes by so fast when you need it. When you don’t need it, it goes by so slow.

Staff Members

Forming social alliances with staff members within the rehabilitation setting seemed to be an important aspect of adapting to its culture. Russell’s initial impression of staff members was that there were a great many of them who looked alike and whose functions were confusing.

Day 3: They’re introducing us to all these different people. I don’t remember any of the names or anything. They’ll remember me easier than I’ll remember them.

In addition to learning formal roles of the players, Russell quickly developed personal relationships with staff members, including those he particularly valued as well as those he mistrusted.

Day 9: My [physical therapist] doesn’t let me get away with much [expletive]. She’s the one that gets the most out of me too.

Day 24: I don’t have too much trust in these doctors here. But I’m here until I get on my feet, or I’m ready to leave, one or the other.

Russell formed his closest alliance with his physical therapist. Beyond reaching him specific skills, she played a major role in helping him deal with his losses and think about his future. The importance of this therapist’s opinion about his future was illustrated by their interaction concerning Russell’s hope of walking, a goal that had great symbolic significance to him.

Day “My left leg is still lame, but it’s getting stronger. I told the therapist lady as long as I can eventually be able to walk. She still won’t say I’ll walk. I said, “I’m gonna make you say it one of these times, you know.” She goes, “I can’t.” Well, there’s all kinds of different ways of walking. You know, there’s walking with crutches. I said that’d be great. She goes, “Yeah, you’re never gonna give up are you?” I said, “Nah.”

Fellow Patients

Relationships with fellow patients also played a major role in the processes of socialization and adaptation to a rehabilitation hospital. Throughout his stay, Russell used social comparison with other patients as a way of gauging his new identity as a person with a disability.

Day 5: I’m so lurch compared to what I’ve seen here. It’s kinda depressing. The first day they brought me here they put me in a
room with three other guys, and oh my God, I dreaded this place. Cause all around me they were in so bad a shape. They were on breathing machines, and none of them could eat. These guys couldn’t even talk for themselves.

Although Russell found the situations of some fellow patients to be depressing, he viewed other fellow patients more positively.

Day 5: I saw a guy in therapy the other day. I guess he had both of his legs amputated. I watched him doing burn-outs in his wheelchair.

Russell formed a particularly close relationship with one patient whom he perceived to be similar in many respects. They supported one another in various ways.

Day 5: One thing we gotta be thankful for. We got each other for roommates. It makes life a little bit easier.

Russell and Harvey (roommate’s pseudonym) developed a style of joking behavior that allowed them to use humor as a way of dealing with the frustrations of their daily experiences. Much of this humor was directed at staff members.

Russell also related serious conversations with Harvey about issues of dealing with a disability and its effects on family members.

Day 53: I explained it to him one night. I said, “You know, for one thing, she [Harvey’s wife] is going through a lot of changes with you being in a wheelchair, and for two, you know, she’s pregnant. So you gotta take it easy on her and help her out.” He goes, “I didn’t think of that.” I said, “Well you better think of it cause you’re not the only one that’s losing from all this [expletive], you know.”

It is noteworthy that Russell seemed to recognize the rehabilitation hospital not only as a place but as a way of life.

Day 1: They say some of these guys are here ‘cause they want to be. Why in the hell would anybody want to be here? I got an idea why. ‘Cause they’re afraid to face the world outside.

After his first week Russell spoke of his sense of confinement in this local world.

Day 9: It’s just like a jail. The food’s terrible. You can’t do nothing. You can’t go nowhere.

As Russell neared his discharge date, his views about this local world suggested his socialization to its way of life in ways that echoed his perceptions of other patients on the first day of his rehabilitation experience.

Day 59: Supposed to be getting out on the 21st. Three weeks. It’s kinda scary. They’re just not prepared for wheelchairs to be all over the place. Here [in the rehabilitation hospital] they are.

Learning a New Identity as a Person With a Disability

In addition to the literal account provided above of Russell’s adaptation to a new and largely foreign world of the rehabilitation hospital, it is important in the ethnographic tradition to examine the broader meaning of his experience (Geertz, 1973, 1983). As the process of analysis and interpretation of findings progressed over time, we began to interpret Russell’s rehabilitation experience as a way by which he developed a new identity as a person with a long-term disability. This development involved Russell’s anticipation of what life would be like when he returned to his local world outside the hospital, reflections on the kind of person he might become, and examination of how his future was related to his past.

The concept of narrative has been used to examine how major illness is incorporated into persons’ life stories (Kleinman, 1988). This use of narrative is exemplified in Murphy’s book, The Body Silent (1990), in which he provides an account of his own progressive disability. Murphy clearly used his past experience as an anthropologist as a way of thinking about his future life story.

This book was conceived in the realization that my long illness with a disease of the spinal cord has been a kind of extended anthropological field trip, for through it I have sojourned in a social world no less strange to me at first than those of the Amazon forests. And since it is the duty of all anthropologists to report on their travels, whether to Earth’s antipodes or to equally remote recesses of human experience, this is my accounting. (Murphy, 1990, p. xx)

Bruner, a cognitive psychologist, has studied narratives or life stories as ways persons make sense of their experiences in light of agreed-upon cultural interpretations of human intention and action (1990). Bruner wrote:

I have introduced the concept of narrative in deference to the obvious fact that, in understanding cultural phenomena, people do not deal with the world event by event or with text sentence by sentence. They frame events and sentences in larger structures which provide an interpretive context for the components they encompass. (p. 64)

We suggest that the specific events of Russell’s rehabilitation experience be interpreted as a chapter in his life story in which he is transformed from an able-bodied person to a person with a disability.

Several subthemes emerged from the interview data as we interpreted how Russell learned a new identity as a person with a disability. These subthemes included views of his future life and how it related to his past in terms of mobility, living arrangements and household management, work and financial status, and relationships.

Mobility

When Russell entered the rehabilitation hospital, his first priority was to regain the ability to walk. This priority seemed to reflect his fears of being a “cripple” and the life that disability would create.
Day 7: If I walk out of here, maybe not out of here, but I'll walk again. I've gotta walk. That's all there is to it. I gotta walk. Wouldn't be fair to my son, having a cripple for an old man.

Russell could not maneuver his wheelchair effectively because of his arm fractures; this affected his first impressions of what it meant to be in a wheelchair.

Day 10: I don't like getting up in that wheelchair, not being able to go nowhere, do nothing. They might as well stick me in a damn closet. All you can do is sit there and think of how helpless you are.

On this same date, however, he spoke about the possibility of being a long-term wheelchair user.

Day 11: You know, I wonder if I'm gonna get a wheelchair to go home with me even if I learn to walk because it's not guaranteed how long I'll be able to walk.

Russell's views about the importance of mobility also surfaced when the possibility of driving was brought up in rounds.

Day 31: That's when the doctor turned around and asked about the driving class. I said, "Hey man, I've been driving since I was 15 years old. What do you mean, I need a new driving class? Driving ain't no problem." He goes, "Well you're gonna have to drive with one arm." I says, "As long as it ain't a standard, I'm all right." Now if I was trying to ride a motorcycle, I'd understand. But I'm not. (Expletive), I always drove with one arm.

Day 35: I might try for a day pass this weekend. That way, I can find out what's going on with my truck. It's parked at the apartments. I should bring my truck down here and park it in the parking lot. That way, when I want to go home, I can take that. I can take off. If I want to run and go get some food, I can take off. The bad thing about that truck is, I'd have to leave my wheelchair wherever I got in the truck. I could get Harvey to watch the wheelchair while I go to the store.

Living Arrangements and Household Management

Russell recognized that decisions he would have to make about where to live would be quite different after the injury.

Day 9: Before I got in here I was planning to get a house. Shot them plans to hell.

He now had to consider kinds of help he would need in thinking about where to live.

Day 51: See, if you leave here, unless you got somebody to work with, you're screwed. Unless you got somebody to take care of you or something. Who's gonna turn us when we're at home? Who's gonna help us put our clothes on and stuff? I'm thinking I'm probably gonna stay with my brother for a while. But you know, I started thinking, well, should I just go and move back in my apartment? And get one on the ground floor. But you know, I sit there, I can't do that. It looks like I'm gonna have to stay here until I'm able to do everything on my own.

Staff members interviews confirmed Russell's continuing struggle with how he could manage living in the community. On Day 51, Russell's occupational therapist commented:

The only thing that worried me yesterday was that Russell appeared to be depressed towards the end of our session, and he even became tearful when I said, "Why is this talk to Social Security so important?" He said, "Because it'll make the difference whether I stay with my brother or whether I can go back and have my own apartment, and I want to be as independent as I was in the past. I've never had to worry about where money is coming from, I've always been an independent person, I've been active on my job, and I know I will not be able to do my job again, so financially I am concerned." That's when he became tearful.

It is noteworthy that Russell did believe that some of his past experience living on his own would be useful.

Day 23: I like doing woodwork, you know. If I ever get a chance and start doing it again, I can make pretty much all the furniture I'll need.

Day 55: Made enchiladas in [occupational therapy] today. I didn't taste 'em. It's not the way I usually make enchiladas. They say that you got to prepare a meal, you got to cook at least once before you get out of here. I want to make enchiladas tomorrow the way I usually make 'em.

Work and Financial Status

One of the major areas in which Russell's views about his future changed during rehabilitation was in thinking about work. His initial thoughts about this issue reflected attempts to use his past experience.

Day 3: As soon as I get out of here I can go back to work again, I won't be able to do the same kind of work I did up in the air. But I can go and run the show. My boss says that I've got a job.

Day 29: I've been thinking about what am I gonna do for a living. You know how people make T-shirts. I went to a seminar about that with my brother last summer. It be something I could do at home.

Soon Russell's thinking began to reflect the view that his past experience would not be useful.

Day 27: I won't be able to do anything I used to. I'm an iron worker. A welder. No construction work or concerts. No, I won't be able to do any of that stuff. My whole life in the past has all come to a stop. I know I'll never get my legs back like they were. That company will probably get me another job, but I'm not sure I want to bother with that anymore. The reason why he is giving me a job is sympathy. A year, two years, I can get one of these jobs where you sit down, like a cashier. But I've never done anything like that.

At this point Russell was encouraged to apply for benefits that would provide support during the time he would be unable to work.

Day 26: I called Social Security today. Cause I'm not going to be able to work for over a year. Here this one guy, he collects workman's comp and Social Security. He makes $1,500 a month being in that chair. Then Social Security pays his parents $300 and something dollars to take care of him. If I get it (Social Security), I got sun and I'm gonna live alone. I don't want to live with my brother.

Russell's view about his future increasingly reflected a constrained view of what would be possible for him and doubts about the soundness of his ideas about the future.

Day 56: Had a bit of a long talk with the occupational therapist. Have to learn something to do, keep on living, cause everything I knew before went down the tube when I took that fall. My whole life and everything went down the tube. Feels like just, give me an apartment and stay there all the time. Only time I need to get out of there is to go to the green store. Maybe if I can get something.
Relationships

One area of his future life that Russell did seem to view positively was his potential to be a good parent to his son. He believed that his spinal cord injury did not alter his son's view of him as a father, nor did it diminish his ability to fulfill the responsibilities of fatherhood, which he believed he would handle somewhat differently from the way his brother had handled things.

Day 33: My son, it just seems like, it didn't look like it [Russell's injury] bothered him at all.

On day 113, Russell's physical therapist said:

His son is really excited about having his come home. Russell talks a lot about how his brother disciplines his boys and Russell's son, and how he and his brother are a little bit different. I think Russell is excited to get his son back underneath his wings.

During the rehabilitation process, Russell also began to think in somewhat different terms about relationships in his life generally. He described himself as being largely a loner in the past with most of his time spent working or in leisure activities that are essentially solitary, such as woodworking. When Russell was encouraged to think about sexuality and intimate relationships as part of the patient education program, he stated that it was not important to him at that time.

Day 51: I fell asleep during class. Some of it's good and everything, but like that sexual idea, I'm in a wheelchair right now, the main thing is getting out of the wheelchair. Later on, fine, I'll start to worry about it then. Now it's the last thing on my mind.

On the same day as this experience in class, staff members reported that Russell talked about his views of himself as a husband. On day 51, Russell's occupational therapist reported:

"He said, 'I'm glad I was divorced prior to my accident, because I would not have blamed my wife, because she probably would have left me. If you know, after the accident, being paralyzed and not being as functional, I wouldn't have blamed her. But I'm glad I was divorced. I don't know what I would do if my wife would have gotten paralyzed, and I would have to deal with her.'"

However, staff members interviews indicated that Russell was thinking about future relationships. On day 51, Russell's occupational therapist noted that:

He also was concerned about when he was going to meet people, especially girls, and they were going to be interested in him because he's paralyzed, and I told him, 'Well, Russell, there's other people out there. That's why I encourage you to go out on [community] outings. I've made a recommendation for him to go Thursday night, the baseball game, and he refused, and I've been encouraging him to go out with other patients, so that he'd be able to adapt and reorient back into the community. I said, 'You need to do this while you're in the hospital; it won't be a shock once you get out there.' And he said, 'Well, in the past I always worked and I didn't have time to go out.' I did mention to him that 'I'm out there and also single, and at the clubs I've seen guys and girls in wheelchairs, and having a good time if you just stay home, like you used to in the past, you're not gonna meet people.'"

Near the time of his discharge, staff members reported that Russell was reflective about the kinds of relationships he had formed with persons in the rehabilitation hospital and how they were different from past relationships. On day 113, Russell's physical therapist said:

"He has commented, 'I know, I'm not gonna miss this place, but I'm gonna really miss the people and the environment, and being around.' He's really enjoyed the interaction at the level that he's had here, different from the interaction he has, say, on the job, with construction workers where they tell dirty jokes. He's had some really more intellectual conversations and I think he's developed a way of talking. He's nervous about being removed from that and then where he's gonna find those sources once he gets out."

As Russell came to think of himself as a person who would be using a wheelchair rather than walking, he reflected on what being a person with a disability is like in the larger society. He recognized that the local world of the community would be different in some important respects from the local world of the hospital.

Day 33: You really think about it, you get to some of these places in a wheelchair and find out how many places are not set up for wheelchairs. They figure if you're in a wheelchair, that you should stay home.

Day 50: After a while you get tired of arguing about something and give up all the time [referring to Social Security Administration]. When you're in a chair, you learn to give up.

Reflections

The process of socialization to the culture of the rehabilitation hospital appeared to be relatively successful at the literal level of teaching Russell how he could manage basic self-care and household activities when he returned to the community. Many of the concerns he voiced about these aspects of his future were addressed. Arrangements were made for Russell to have an apartment with his son near his brother's home, and an attendant would...
provision of ambulation training as an outpatient, as well as for drivers' training. Follow-up appointments were also planned, at which time Russell would be evaluated to determine when his body jacket could be discarded and when his fractured arm would be ready for more extensive therapy.

At the level of socializing Russell to a new identity as a person with a disability who could lead an active and fulfilling life, the process was less successful. Russell left the hospital with the expectation that he would leave home only for outpatient therapy and grocery shopping. He seemed to have little belief in the value of the future vocational evaluation that staff members had mentioned to him frequently. He thought instead about the possibilities of setting up a business he could run from home. Russell did believe in his ability to function well as a father to his son, and had at least explored the possibility of other kinds of social relationships, although initiating new relationships seemed to frighten him.

One theme that occurred again and again throughout the process of socialization was the difference between Russell’s view of the sequence and pace of the process and the staff members’ view. A standardized view of what the process is like for typical patients with spinal cord injury appeared to be embedded in the local world of the rehabilitation hospital. This standardized view seemed to be invoked to determine Russell’s readiness for sequential steps in the process, as illustrated by the consistent opinion among staff members that addressing work issues was premature until some point in the future (1 to 2 years was the time frame usually cited) when Russell would be considered ready for a formal vocational evaluation. This plan seemed incongruent with the great value Russell attached to work and his sense of urgency about being able to see himself as a working person in the future.

Another striking theme that occurred repeatedly during the process of socialization was Russell’s continuing efforts to connect his future life story to his past. Evidence suggested that staff members might have been so intent on teaching Russell new skills that they failed to engage in helping him connect his past competencies and experience to an image of the person he might become in the future. Staff members had clearly been reluctant to explore with Russell the potential application of his past work experience to thinking about future work possibilities. The lack of connection appeared in other areas as well. For example, although Russell insisted that he had cooked for years, staff members asked that before leaving the hospital, Russell cook with their methods to demonstrate his competence. His response was revealing. He stated that he did not even taste the enchiladas made with the staff members’ methods and indicated that he wanted to make enchiladas his way the next day. A similar situation occurred when drivers’ training was mentioned to Russell. Rather than acknowledging his assertion that he had driven for years and engaging him in thinking about what might be different now that he would have a wheelchair to manage, staff members conveyed the message that he would have to take the standard drivers’ training, implicitly suggesting to Russell that his past experience was irrelevant.

The process of learning new skills and a new identity through socialization to the culture of the rehabilitation hospital could be made more meaningful to patients if staff members collaborated with them more directly in applying standardized services and treatment goals to each person’s particular life circumstances. Individualizing clinical interventions to make them more meaningful can be based in part on careful listening to what patients say about their daily rehabilitation experiences and on careful analysis of the communication inherent in what persons do (Fidler & Fidler, 1963). For example, exploration of Russell’s insistence on making enchiladas his own way might have revealed the personal significance of his competence in cooking as verification of his ability to continue to live on his own or his ability to continue to be a good parent to his son. Nelson (1988) articulated the fundamental relationship between past meaning and future purpose. Understanding the meaning ascribed to past experiences by patients can help health care providers direct work toward purposes that patients feel strongly about.

Narrative is a way of interpreting meaning beyond the level of isolated events. Narrative analysis provides a view of particular experiences as part of a coherent personal history that each person reconfigures on an ongoing basis. Polkinghorne (1988) spoke of the process of revising one’s life story in response to major life events.

In this study, Russell struggled with great ambivalence about his future, on the one hand feeling that his life as he knew it before his injury was “down the tube,” and on the other hand defending his belief in the competencies he acquired before his injury. One of the major lessons of the study may be the importance of health care providers’ collaboration with patients in exploring the value of the patients’ past experience and in helping them see continuity as well as change as they anticipate who they might become.

Ways in which a narrative perspective can be incorporated into therapy were identified by Mattingly (1991) in an ethnographic study of the clinical reasoning of ex-
experienced occupational therapists. Mattingly referred to a process of "employment" in which "actions take their meaning by belonging and contributing to the story as a whole" (p. 1002). This requires that the therapist

(a) see possibilities for creating important experiences in which the patient will be staked, (b) make moves to act on those possibilities, (c) respond to moves the patient makes in return, and (d) build on the experience by showing the patient a future in which this therapeutic experience becomes one building block. The therapist tells the story not in words but in actions. (Mattingly, 1991, p. 1002)

Mattingly contrasted this form of individualization of therapy with standard ways of conceptualizing treatment goals. "Narratively, individualization involves the construction of a particular story of the treatment process rather than reliance on a generic line of action that strings together standard goals and activities" (p. 1003).

As a form of research, the ethnographic methodology used in this study to capture an insider's perspective on health care experience has both weaknesses and strengths as a way of understanding adaptation to disability. Data collection and analysis are complex, time-consuming, and challenging activities, and inherent in this approach is the need to develop the methodology as the study unfolds. As is typical in the qualitative research tradition, the applicability of findings about Russell to other persons with spinal cord injuries must be investigated in future studies rather than assumed on the basis of sample characteristics.

The strengths of the ethnographic approach include its ability to help therapists understand the process of rehabilitation from a patient's perspective and thus to see ourselves as others see us. Interpretive ethnography prompts us to examine the larger significance of mundane daily activities. As Murphy (1990) reminded us, becoming a person with a disability is not an abstract change in social status but a process that occurs through encounters with persons and events in daily life. The richness of narrative data from ethnography can provide important insights into issues of meaning and open the possibility for a clinical practice that is more firmly grounded in the social ecological approach.

Finally, in addition to prompting questions about current theories that underlie rehabilitation practice, this study also broadens the understanding of the culture of institutional settings and ways in which our assumptions, beliefs, and practices influence both health care providers and patients.

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