

The Relevance of Leisure in an Illness Experience: Realities of Spinal Cord Injury

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Illness is generally experienced as more than merely physical or psychological distress. Depending on its seriousness, illness results in a disruption to one's sense of well being and personal continuity. The stories of people who have experienced spinal cord injuries illustrate not only the impact of illness in disrupting life stories but also the relevance of leisure in the course of this disruption. In this investigation, in-depth interviews with 20 people with spinal cord injuries demonstrated that constraints to previously enjoyed activities contribute to *defining* the experience of illness in three important ways: through loss of abilities, through disruption of relationships, and through dependence on others. Discourse on the phenomenology of the body is utilized to interpret these interviews and to offer a conceptual pathway for examining the relevance of leisure in other illness experiences.

KEYWORDS: *Illness, leisure constraints, spinal cord injury*

In this paper we examine the role of leisure in the illness experience of men and women who have experienced a spinal cord injury (SCI). We first relate illness to contemporary discourse on constraints to leisure, then consider a narrative perspective on illness that is consistent with studies of the phenomenology of the body. Next, we describe a study of the leisure experience of people with SCI. Finally, we relate findings regarding leisure and SCI to our conception of illness.

In the abundance of research on constraints to leisure over the last ten years, constraints have been represented primarily as discrete conditions (such as lack of time, money or self-confidence) that either prevent, curtail or inhibit leisure activity (e.g., Crawford, Jackson & Godbey, 1991; Wade,

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1985). Recent research on the subject has demonstrated that constraints are personally interpreted (e.g., Henderson, Stalnaker & Taylor, 1988; McCormick, 1991) and, through the use of a variety of strategies, are often negotiated to allow some degree of participation (Jackson, Crawford & Godbey, 1993). But to our knowledge no attention has been given to the idea that constraints to leisure activity might be significant in and of themselves as defining characteristics of one's self-conception. When associated with loss of ability or opportunity to do preferred activities constraints to leisure may become especially "problematic" to identity and act as "impediments to the construction and maintenance of desired identity images" (Schlenker, 1987, 274). Such problems, according to Schlenker, "produce a more *intensified examination of information* about self, situation and audience than would ordinarily occur" (p. 274).

The disruption of the ability to engage in preferred activities resulting from negative life events may be particularly distressful when those activities have special relevance to a person's identity. While the general dynamics may apply equally to the loss of a job or the loss of a spouse, among other events, we take as our focus here the case of spinal cord injury (SCI).

Spinal cord injuries are traumatic life events that are enormously disruptive to established patterns of living. The study to be reviewed here demonstrated those effects; but it also revealed that the constriction and loss of leisure activity figures prominently in the experience of illness for people with SCI and in the disruption that inevitably occurs to one's identity and life story. While the reconstruction of a leisure lifestyle, reestablished with varying degrees of continuity and adaptation, becomes important in the rehabilitation process, it is instructive to recognize the significance of leisure in the critical and ongoing experience of illness.

The Illness Experience

"Illness" is the term that applies to lived experience, a person's response to disease or trauma (Kleinman, 1988). Brody (1987) has said that to be "ill" is to experience both an unpleasant sense of disruption to body and a threat to one's personhood. Interest in a "narrative" formulation of illness is growing (e.g., Borkan, Quirk & Sullivan, 1991; Brody, 1987; Churchill & Churchill, 1982; Early, 1982; Kleinman, 1988; Morse & Johnson, 1991; Phillips, 1990; Riessman, 1990; Robinson, 1990; Waitzkin & Britt, 1993). From a narrative perspective, "illness" is conceived as a disruption in a life narrative, where the future-self imagined in the life-narration is made doubtful by some perceived threat to one's health. When a life-narrative is threatened, self-esteem is diminished; self-respect is largely dependent on a rational life-plan (Brody, 1987). Most illness experiences are acute, resulting in an experience of disruption in which the life-narrative is *suspended*. In such cases the threat to health is determined to be transient, permitting a return to the former narration of the life-story. In the case of chronic illness or permanent disa-

bility, the disruption to the narrated life-story is one in which, to one degree or another, the imagined future-self is fundamentally *altered*.

The dynamics of disruption can be understood by considering the nature of the relationship between body and self. Drawing on Spicker's (1970) seminal work on the philosophy of body, Gadow (1982) described a "dialectical progression" in the relationship between body and self. She began with the state she called "primary immediacy," which results from an "overriding unity of the body-self" (p.88). In this state the body is not an instrument with which to act; body and mind act in unison. Leder (1990) argued that the body "disappears" from consciousness when it is functioning in this unproblematic state.

The body is not always in this unproblematic state, however; incapacity of various kinds ruptures this being-in-the-world. The body and self are then experienced as acting upon one another rather than acting as one. In this condition of "disrupted immediacy," the self must struggle with the body as an object. Faced with learning to ride a bike, for example, a child's body/self unity is disrupted by her initial inadequacy. But when disrupted immediacy is merely the result of a developmentally challenging incapacity, a new unity of self and body is more readily imagined and achieved. In achieving this new unity, the self experiences the body as

"... distinct (unlike the experience of primary immediacy) but no longer opposed. They are mutually determining now in the positive sense of mutually enabling. The otherness which self experiences as the (object) body is affirmed as necessary for the full development and articulation of the self..." (Gadow, 1982, p. 91).

In this sense immediacy is "cultivated." For example, the person who seeks to extend the range of her singing voice will struggle with the constraints of the body to achieve a "free and unconstrained use of the new capacity... achieving a new naturalness, one not given but created" (p. 91). That is, once "cultivated," the new immediacy is experienced as primary.

The cultivation of immediacy, of which Gadow speaks, characterizes much of enjoyment-oriented self-expression in the context of leisure (Csikszentmihalyi & Kleiber, 1993). The "flow" model of Csikszentmihalyi (1975) is, in fact, based on the idea that one's consciousness of self disappears as abilities match challenges and action merges with awareness. This is the essence of enjoyment from Csikszentmihalyi's perspective (see also Csikszentmihalyi, 1988).

The illness experience of those who experience a spinal cord injury—an extreme of "disrupted immediacy"—is typified, as is demonstrated in the study to be reviewed, by the loss of the "cultivated immediacy" of leisure activities in which they had engaged before the injury. And as a *radical* disruption, the prospects for cultivating a new body/self unity are likely to seem very remote. For example, one of the informants in this study had a cultivated immediacy associated with hunting prior to his injury. As an experienced hunter he had learned to walk silently in the forest. His spinal cord

injury results in his return to the forest in a wheelchair to hunt, but the experience is clearly different and distressing. Unlike the developmentally challenging incapacity referred to above, with SCI the self and body are radically opposed, making the prospects of a new self/body unity more problematic. This study of the SCI illness experience reveals the role which the loss of self/body unity plays in the disruption of life narratives.

Also central to the experience of illness in most cases is the disruption of relationships. This disruption is often most clearly manifested in the loss of shared activities that had served to shape, strengthen and maintain those relationships. As Charmaz (1991) indicated from her studies of individuals with chronic illness, "Illness experience shrinks their social world. It forces people to pull into their inner circle while pulling away from others" (p. 81). There is, in fact, a substantial literature demonstrating a wide variety of negative effects of disability on friendships, much of it associated with the loss of companionate leisure (Lyons, 1989, 1991).

Leisure activities usually are less important in themselves than the relationships they maintain or enhance (cf. Kelly, 1983). Having relationships disrupted - with friends and family and even with pets, as we will see shortly - also defines one's illness and the alteration taking place in one's personal narrative. Furthermore, the dependence created by disability conflates leisure and illness experience; pursuing familiar social activities that were once a source of intimacy and enjoyment may now bring distress at requiring the assistance of others.

Method

In an attempt to avoid imposing researchers' viewpoints, an "insider's" perspective on the experience of illness was elicited through participant observation and in-depth interviews. The interviews provided the raw data for this report; the "native words" of the informants revealed their "level of emotion, the way in which they have organized their world, their thoughts about what is happening, their experiences, and their basic perceptions" (Patton, 1980, p. 28). While leisure was of particular interest to the researchers, and follow up questions permitted examination of leisure-related issues, the general approach taken was to encourage informants to "tell their stories" wherever that might lead.

Characteristics of Study Site

The study site for this project was a large urban rehabilitation center in the southeast United States dedicated exclusively to the rehabilitation of people with paralyzing spinal disorders. People with paraplegia typically remain at the hospital for seven weeks, while people with quadriplegia remain nine weeks on the average.

Sampling

"Theoretical sampling" (Glaser & Strauss, 1967) was used to identify and recruit appropriate respondents. To initiate this process, four participants were selected who met the following criteria: (a) they had been discharged within the last month; (b) they had participated in therapeutic recreation programs; and (c) they were willing to do the interviews. Selection of these initial participants was done without concern for theoretical relevance since the early stage interviews were used for an exploration of themes. Following analysis of transcripts for these four respondents, sixteen others were selected on the basis of their potential for leading to new insights or for expanding and refining insights already gained (Glaser & Strauss, 1967). It is a "purposeful" sampling procedure based on informants' relevance to the emerging theories (Patton, 1980). Recruitment of informants was suspended when it was determined that data saturation had been reached.

Consideration was given to maximizing the diversity of the sample in terms of severity of injury, age and gender. The only individuals excluded from the study were those who had experienced traumatic brain injury (approximately 23% of patients), since previous research and participant observation indicated that verbal elaboration is often difficult in these cases. Table 1 lists the principle characteristics of twenty informants (identified with pseudonyms). It should be noted that while the group may appear age and gender biased (75% male, mean age = 32.2), the proportions in this sample are consistent with those of the larger population of people with spinal cord injury (Trieschmann, 1988; NSCIA, 1992).

Data Collection Procedures

The interviewer for the project (the third author) had been trained in qualitative research methods while completing a previous interpretive investigation (Lee, 1990; Lee, Dattilo & Howard, 1994). He approached the task by spending four months as a participant observer at the rehabilitation center. During this period he maintained field notes and endeavored to share the lives of SCI patients, in part by spending at least two days per week at the rehabilitation center, much of the time in a wheelchair.

Interviews. Subsequent to this period of participant observation, semi-structured interviews were conducted with informants at two points: (a) pre-discharge, while in the context of treatment and rehabilitation; and (b) post-discharge, from three weeks to five months after informants were discharged. The variation in the post-discharge interview period allowed for some diversity in the sample with respect to distance from injury and in-patient treatment.

Our primary purpose in the interviews was to have informants tell the stories of their experience with spinal cord injury. While we were ultimately interested in the impact of the injury on their leisure behavior and the role of leisure activity and experience in the rehabilitation process, we kept our

TABLE 1
Informants' Personal Profile

Name	Age	Gender	Prev. Job	Injury Level	Date Admitted	Date Disch.	Type of Accident
Adam	18	Male	Student (High Sch.)	T-7 (Para)	7/02/93	10/18/93	Automobile
Wanda	19	Female	Student (College)	C-6 (Quad)	7/07/92	11/07/93	Automobile
Walter	40	Male	Sale Clerk	C-4 (Quad)	9/23/92	2/02/93	Gun shot
Mark	47	Male	Mechanic	T-9 (Para)	9/30/92	12/20/92	Fall from tree
Donald	26	Male	Worked at Carpet Mill	C-5/6 (Quad)	9/08/92	12/20/92	Fall from ladder
Amie	19	Female	Student (College)	C-4/5 (Quad)	6/18/92	1/25/93	Fall from diving
Jason	43	Male	Carpenter	T-11 (Para)	12/10/92	1/15/93	Hit by a big object
Earl	20	Male	Worked at Carpet Mill	C-3/4 (Quad)	9/27/92	1/20/93	Automobile
Mike	24	Male	Student (MBA)	C-6 (Quad)	12/20/92	4/09/93	Automobile
George	18	Male	Student (High School)	T-12 (Para)	12/02/92	1/25/93	Automobile

TABLE 1 (Continued)

Name	Age	Gender	Prev. Job	Injury Level	Date Admitted	Date Disch.	Type of Accident
Martin	42	Male	Driver	C-4 / 5 (Quad)	10 / 07 / 92	5 / 07 / 93	Automobile
Brandon	19	Male	Student (College)	T-4 (Para)	1 / 09 / 93	3 / 26 / 93	Automobile
Neil	45	Male	Janitor	C-4 / 5 (Quad)	9 / 12 / 92	3 / 19 / 93	Automobile
Brian	55	Male	Pastor	C-4 (Quad)	2 / 15 / 93	4 / 10 / 93	Fall from ladder
Tina	17	Female	Student (High Sch.)	T-8 (Para)	2 / 21 / 93	5 / 07 / 93	Natural Disaster
Tony	30	Male	Manager (Health Club)	Lesions to C-2; T-12 (Unclear Diagnosis)	3 / 02 / 93	5 / 02 / 93	Fall
Rachel	28	Female	Waitress	C-4 (Quad)	12 / 17 / 92	4 / 23 / 93	Automobile
Lynn	36	Female	Reporter	C-4 (Quad)	3 / 18 / 93	5 / 07 / 93	Automobile
James	59	Male	Civil Service Worker	T-5 (Quad)	3 / 13 / 93	5 / 21 / 93	Automobile
Daniel	39	Male	Driver	C-6 / 7 (Quad)	10 / 07 / 92	6 / 07 / 93	Automobile

interview process open ended to allow a free flowing discussion of what the injury meant in their lives more generally. If the subject of loss of preferred activities did not arise spontaneously, it was addressed specifically. For all interviews, an "Interview Guide" was developed to address the experience of SCI, previous leisure interests, and continuity and change in leisure experience, but each interview required flexibility with respect to ordering of questions and the ability to examine ideas and experiences unique to that individual. The initial interview guide was changed based on emerging themes and discussions at weekly staff meetings. Questions that were misinterpreted or misunderstood were modified, and new ideas or insights which seemed important to assess for all participants were added.

The length of the interviews ranged from 30 to 90 minutes, reflecting individual differences in informants' willingness and ability to expound. However, in some cases in the pre-discharge interviews, informants allowed only 30 minutes for interviews due to fatigue.

Data Analysis

The "constant comparative method" of data analysis (Strauss, 1987), which analyzes data simultaneously with its collection, was employed in this study. Analysis was facilitated through coding and memoing (see also Charmaz, 1983). Three members of the research team analyzed data, with primary responsibility for interpretation being assumed by the interviewer. Weekly and bi-weekly meetings permitted sharing of the results.

Categories were derived through what Strauss (1987) called the "coding paradigm." This involved *initial* coding, where topics and themes were first identified, and *focused* coding, where topics and themes were reduced to conceptual categories. The constant comparative analytic procedure helped to clarify each category's dimensions and distinguish it from other categories. By comparing newly coded data with categories derived from previous analyses, analytic precision in dealing with ambiguous and experientially mixed categories was enhanced.

Findings

The method just described yielded a collection of quotes organized by substantive categories. While numerous topics and themes were identified, the most prominent general category was the experience of illness. As we examined this category more closely, we were impressed with how regularly leisure activities were identified as aspects of people's lives that were lost or missed, even before leisure was mentioned by the interviewer (i.e., in response to the question, "How did things change for you after the injury?"). This was particularly true with respect to the categories *loss of ability*, *disruption of relationships*, *dependence on others*, and *relapse* to which we turn now.

Loss of Ability

A defining characteristic of the illness experience was the loss of abilities and skills of all kinds; but the informants provided numerous examples of loss of cultivated skills related to leisure participation, i.e., those that had been mastered and taken for granted and that had been a source of considerable enjoyment. In some cases, these losses were translated into a fracturing of one's sense of self and a sense of uncertainty about the future, i.e., into a disruption of one's life story. Rachel, for example, laments the loss of an expressive style that accompanied her passion for dancing. Not only did she feel unable to dance in a motorized chair, she was also uncomfortable with the way she looked. She did not look the way she wanted to look, and it detracted from her experience.

I just never dressed like what I'm dressing like now. I wore jeans and cowboy boots, or I wore dresses and high heels; and this is different for me. I don't like wearing jogging pants and t-shirts and stuff. It's not the way I dress.

For Rachel, the loss of the cultivated immediacy associated with dancing as a physical performance - an activity in which she engaged presumably as an enjoyable expression of self - is compounded by the constraints imposed by SCI on how she can express herself through clothing.

Another informant, Donald, wondered if he was going to be able to hunt again. This condition of uncertainty was associated with most of the descriptions of loss of ability.

Now you sit there and you wonder, "Well, I wonder if I'll see a deer?" And if you don't, you don't, and if you do, you do. But yeah, I still want to see a deer, but I wonder, "Am I going to be able to shoot it like this in this condition or am I going to miss it?"

Tony, for whom sports participation was avocationally as well as vocationally important, was also uncertain about his abilities to do things again in the future.

I've done, you know, no sports whatsoever, no racquetball, no golf, and ... I don't know, it makes me curious. I wonder about, you know, how I'm going to be when I get back, if I'm going to be able to have the agility that I used to have and the coordination to play; and I don't know.

Almost every informant identified things they used to enjoy doing that they could no longer do at all or no longer do nearly as well as before their injuries. Throwing balls (Dan and Tony), playing basketball (Brandon and George), playing pool (Dan), playing ping pong (Daniel), swimming (Brandon), hunting (Donald), and fishing (Mike) were all mentioned as activities in which they could no longer fully engage or needed some modification to do so.

Dan: I can't do the same things now that I used to do before I got injured. ... Me and the guys used to get together, and we'd go shoot pool and, uh, which

I can't do that anymore. So I just get with the wife, and we just go to the park and just take it easy.

Brandon: Playing basketball was my first love, my first hobby. I mean I'm 6:5 and (laughter), I don't know, you know, I miss being able to jump up there and slam that ball through that rim real hard, playing church league basketball.

Mike: As far as recreation, fishing and everything, I just sit down and fish where I stood before. I haven't been out in the boat yet, but the things I used to do... Like my log cabin's being built up there... I used to do all the stuff before, you know, driving nails... I can't do that anymore. I have to let somebody else do that. I was going to do all the plumbing work myself, and I can't do that because I can't crawl under the house like I did. So that's going to be an adjustment, you know.

Mike: I like to hunt a lot; and before, you know, I could hold a rifle like this; but now when I hold it I fall forward because I don't have the balance.

Not all lost abilities were sport-related.

Lynn: Like one thing that I really, really miss is being able to read a book, hold a book and read it, turn pages and.... I've been trying to learn how to do it with a mouthstick, but it's not... I mean a little paperback novel is very difficult to, you know, to be turning it and reading it with a mouthstick. Uh, I don't know really what I'm going to end up doing.

Even as individuals proceeded through rehabilitation and gained a new sense of being able to continue with familiar activities, albeit often in a modified form, there was still a sense of loss. Perceived constraints often served to undermine the full level of satisfaction and enjoyment to be derived from an activity. In the lives of Mike and Donald, activities just were not what they used to be. Mike reported that while it was great to get out fishing, it was not the same experience to him because he could not participate in the entire experience of baiting the hook and other aspects of fishing. In Donald's case, the loss of a fully satisfying hunting experience was particularly problematic because hunting was a "passion" of his.

Mike: It was great to go back fishing again, but at the same time I can't cast as well, you know; probably one out of five times I got the line in the water, and then one out of fifteen times was actually far enough out to fish. And besides, I couldn't bait my own hook, and I can't reel them in. But I mean for me fishing is everything; it's not just catching the fish, it's setting up to catch the fish and cleaning them and hooking them, and that was the only thing that was kind of disappointing to me; I realized how much work I have to do now to be able to do all those things again.

Donald: That's really fun to me to sit there and you have to be real quiet waiting on the deer. It's always enjoyment, but it's not the same. You can't get up and move around, I guess. The enjoyment before was that you could get up and you could move around, or you could change places, because you could walk quietly. But now with this wheelchair you've got to sit in one spot, because a wheelchair makes a lot of noise rolling through the woods.

It would be a misrepresentation to say that the loss of leisure skills was immediately apparent as a problem in the stories of all the informants. To

some leisure seemed irrelevant in the way they initially described their illness experience. They didn't refer to leisure, recreation or free time, nor did they mention enjoyable activities or experiences. In these cases, however, some additional probing was done with the question, "What is leisure like for you now?" Responses to this question were often revealing in a different way:

Lynn: Well, it seems like that's all you have is leisure, you know, because I really can't move too much. It seems like I'm always at leisure almost, except I'm not very comfortable most of the time. I wish I could move around and do something, you know, like play. I wish I could at least move my arms and exercise my arms and do something like that; but in my situation ... I don't know, maybe I'll have my arms working and be able to do a little something one day.

The loss of self-body unity, the loss of the immediacy of being-in-the-world which has resulted from a spinal cord injury, is prominent in these illness narratives. For the majority of these informants, the illustration of this lost immediacy that comes most readily to mind is one involving a former leisure activity. They draw our attention to a lost sense of self-in-action, one which was expressed in the enjoyment of a variety of cultivated immediacies. Even Lynn, whose understanding implicitly distinguishes "leisure" time as those moments of little obligation and responsibility, grieves the loss of pleasurable body expression.

Disruption of Relationships

Another significant sub-category of the illness experience was the disruption of enjoyable interaction with others. The power of the injury to change the lives and relationships of people was often illustrated with reference to leisure activities. While this applied to friends and family, spouses and significant others and even pets, two of the most compelling illustrations came through the voices of two with SCI who were parents:

Dan: With my little boy, I feel like I can't.. He loves baseball, and I feel that part of my life, that I want to give to him, I feel that I can't really just give to him like I want to give to him. You know, like I'd rather swing the bat with my boy or catch a ball with him and I just.... can't throw the football to him or anything. I really miss that, and I feel like that's a part of my life that has just been, been taken away from me.

Donald: And another thing that makes it hard is the fact that I can't run with them [his children]. I can't throw a ball to them. So stuff like that, you know; it's just not the same. But you have to accept it and move on.... After a while my daughter will come around, you know. She's not accepting the fact, I don't think, that I can't walk, completely due to the fact of when I'm in the wheelchair and I have my shoes off and the quadpad under my feet she'll tell me to put on my shoes and I can walk. So, see, that makes it hard on me. It's a major source of stress, yes. Because, you know, they're used to Daddy walking, and all of a sudden Daddy's sitting down and can't do as much with them as he used to. All he can do now is ride them around in the wheelchair.

Friendships and peer groups were at risk as well:

Wanda: Sometimes I feel like my chair is in the way of things like that, so I won't go; or like sometimes my group of friends have gone on hikes in the mountains, and I don't go on that because, of course, I can't hike in the mountains. Things like that I miss out on.

Not being able to relate to others in social situations produced a different kind of pain for Lynn:

I can't participate in a lot of things. I mean like, you know, like this weekend, you know, they kept, you know, like fed everybody the whole weekend, and I couldn't help with that. I mean I couldn't even feed myself, you know. I can't wash dishes. I can't help or fix anything to take, you know. I don't feel like I'm contributing at all.

Some of the disrupted relationships were with pets:

Lynn: What really, really gets me is when I, when I'm around my cats and I can't hold them or pet them or anything like that.

Mark: I used to go in the back yard and play with my dog; and it's hard to play with him now because he'll knock me out of my chair if I'm not careful. He's a big Labrador and he'll knock me out of my chair, and uh it's hard to do.

Clearly, the disruption of relationships parallels, accentuates and may even supersede in importance the loss of primary immediacy that characterizes well-learned involvement in enjoyable activities. And where enjoyable activities were largely shared prior to injury, a *compounded* sense of loss from changes in both activities and relationships is apparently a common experience. (For more on the effect of disability on relationships see Lyons (1991) and Lyons, Sullivan and Ritvo (in press).)

Dependence on Others

Although leisure most commonly involves social interaction (Kelly, 1983), the social aspect for some of these informants was particularly troublesome. In addition to having the relationships themselves disrupted, having to depend on other people was very difficult for some. In addition, this dependence was further complicated because often the needed assistance was unavailable, particularly in post-discharge settings. Adjusting to one's injury appeared to include the need to negotiate being dependent on others. Here again, leisure activities seem to play an important part in the experience of illness.

Martin: If I sit down sideways I have to support by one hand or by a back brace which limits me from digging up the ground to plant flowers. I have to have somebody dig it for me, and I tell them I need this planted there; and, you know how women are, some like it and some don't.

Mike: I mean, when my parents get home we've got other things to take care, and we really just don't have the time because, I mean, by the time they get me taken care of, you know, they want to start relaxing from being at work, you know. I can't blame them for that. I mean there's really... I can't do anything fun by myself; I need somebody to help out.

Mark: Well, sometimes, when I'm at the lake, I have to have somebody help me. I don't like that, but, you know, I'll be on a rough surface (It's not real smooth there; it's kind of hilly and rough), and I have to get someone to help me, you know. I might get stuck or something, you know, get in a bind.

In other cases just the reality of needing assistance was enough to discourage participation in familiar or new activities, as was reflected by Wanda:

I think sometimes I get frustrated about my chair, you know. Like there's this one thing that my friends were going to do. They were going to have a video scavenger hunt which, what they would do is take a video camera and go around and video certain things that were on their list, and I didn't go because I didn't want anyone to have to worry about helping me get in and out of the car, taking my chair apart, things like that. So I didn't go to that.

Relapse

The data previously presented were derived from interviews done both before and after informants had been discharged. The categories derived - loss of abilities, disrupted relationships, and dependency - applied equally well to both situations. But an additional theme - reflecting an extended experience of illness - was unique to post-discharge interviews. It was apparent that some of the transcendence over illness that took place in the supportive environment of the rehabilitation center was reversed in the face of the realities of community life. With the loss of structured activity programming, trained human resources and adaptive equipment, the conditions apparently necessary to the development of cultivated immediacy were largely missing in many cases.

One common reaction to this state of affairs was to become *passive* again. Donald spoke of the initial experience of coming home and doing nothing for a month, despite his family begging him to get out. He watched TV and did nothing else. Lynn aspired to be active but at the time of the second interview was inactive. She indicated that she watched television so as not to face things, but was sick of herself for doing so. Donald's passivity after returning to the community was especially significant because it contrasted with a fairly high level of activity during his time in the center. The contrast itself seems to have the effect of protracting the illness experience for him.

Donald: Yeah. (pause) When I was down at [the center], I was real active due to the fact that there was people around you know. There was more handicaps around that understood how I felt. And then when a person comes home it's a totally different environment. Like at [the center] when you went out, when you went out on an outing, there might be 10 or 12 people with you in wheelchairs. And then when you come home you have to do it by yourself it's hard. And that's what triggered, triggered. That's what triggered me to just shut everybody out, shut myself out. Because when I come home, shoo' [exclamation], it wasn't the same. I didn't get up every morning and go out and see 50 wheelchairs running around. There was just one.

In considering these examples of relapse, it becomes apparent that while rehabilitation may be successful to some extent in the cultivation of new

forms of body-self unity, enabling thereby a degree of transcendence over the illness experience, a supportive, enabling milieu may not always extend beyond the context of initial treatment.

Discussion

The experience of illness associated with SCI is complex and dramatic and extends far beyond the physical pain and loss of functional movement. The illness experience for people with SCI in this investigation was one of dramatic disruption to life stories, including lost abilities, disruption of relationships, dependency and relapse. These themes are similar to the "sources of suffering" identified by Charmaz (1983) which included: leading restricted lives, experiencing social isolation, being discredited and burdening others. In the preceding case material each of these sources of distress is associated at different points with alterations in leisure activity and experience. Disruption of one's physical condition is experienced as a disruption of self. Intrapersonal and interpersonal constraints to leisure activity often define the illness experience in personal ways. Not being able to hunt, to play with one's children and to help with the cooking during social events were among the examples of experiences that seemed to threaten the personal identity of our informants. And at least as important for many of them was the shrinking of their social worlds.¹ In some contrast with Charmaz' findings, which were associated with older people, isolation was less a problem for these individuals with SCI than was the inability to interact effectively within the activity contexts that were previously enjoyed with family and friends.

The loss which concerned most informants at the time of the interview was the loss of *primary immediacy* of the unproblematical body (cf. Gadow, 1982). Frustration with dependency on others to perform the most basic activities of daily living threatened a sense of dignity. For others, however, it was the loss of the *cultivated immediacy* associated with former leisure activities that was most grieved. Activities which were previously engaged in for enjoyment were now problematical. Where the loss of immediacy cultivated to effect the tasks of daily living may be thought of as a threat to dignity, the loss of cultivated immediacy associated with self-expression in leisure activities can be thought of as a threat to personal fulfillment. For those who expressed their illness in terms of lost cultivated leisure capacities, there were those for whom the loss of physical performance was paramount. For others the loss was that of the satisfaction derived from the social camaraderie associated with the former leisure activity.

¹It may be worth reiterating that these two predominant themes should not be seen as mutually exclusive. They are clearly interconnected in many instances. Furthermore, the predominance of young men in this sample, while representative of this disability group more generally, may have led to an under-emphasis on relationship issues relative to those associated with the loss of activity. Studies of other disability experiences might well provide different perspectives on both the relative importance and the interconnectedness of these two themes.

It would be inaccurate, however, to represent the course of illness as consistently negative. Charmaz (1991) noted that among those with chronic illness the "good days" are distinguishable from "bad days," depending largely on "whether the day is consistent with the self they wish to affirm and present to others" (p. 50). Good days are characterized by minimal intrusiveness of the illness, by maximum control over mind, body, and action, and by a greater choice of activities. "On a good day, the earlier and jarring questions about present self, the doubts that erode confidence, and the nagging fears about the future all recede into the past, or may be completely forgotten" (p. 51). The ability to engage in leisure activities contributed to defining the good days; the absence of those abilities contributed to defining the bad. While this paper deals predominantly with those data that demonstrate a sense of loss, it is also clear that the course of recovery, the road to wellness, is shaped through an awareness of what one still can do in making life meaningful and enjoyable.

It is important to register here, however, that the good and the bad days are not simply to be accepted as a matter of good or bad fortune. To return to Gadow's (1982) analysis, the loss of a primary immediacy—where there is an unself-conscious unity of body and self—can be a self-shattering experience. But it is ultimately redressed, whether through one's own resources or the help of intermediaries, with the cultivation of a new immediacy, a new unity of self and body around available capacities. Where this occurs - and how often it occurs is a matter for further research - it is inevitably a dynamic process that happens at different rates and in different ways as a function of a variety of influences. The cultivation of new immediacies may also serve as significant markers, in and of themselves, of psychosocial adjustment. The identification and cultivation of new capacities in the course of rehabilitation is certainly a subject for further research.

Just as leisure activities are implicated in the experience of illness, they can also be associated with recovery, rehabilitation and life narrative reconstruction, or "restorying." The new story one writes for oneself subsequent to traumatic life events and disruptive illness is quite likely to be illustrated with a future self in action in a way that makes life enjoyable and meaningful once again.

Spinal cord injury is, of course, just one of the illness experiences to which the concept of disrupted self-body unity is relevant. Even temporary acute illness frequently results in a disruption of valued leisure activities and companionate relationships. (Consider, for example, the social distance that a contagious cold creates.) But what was dramatically demonstrated with the individuals interviewed for this investigation is the significance that a loss of valued leisure activities had in *defining* the problem of injury and the experience of illness for themselves. To what extent might similar patterns be expected in people with other forms of disability and illness? Given the distinct characteristics of those incurring spinal cord injuries and the experiences that typically follow, it remains for further research to determine whether other forms of serious illness will reveal a similar phenomenology.

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