Exploring the Meaning of Continuity of Recreation Activity in the Early Stages of Adjustment for People with Spinal Cord Injury

YOUNGKIHILL LEE
School of Recreation and Sport Sciences
Ohio University
Athens, Ohio, USA

JOHN DATTOLO
DOUGLAS A. KLEIBER
Department of Recreation and Leisure Studies
University of Georgia
Athens, Georgia, USA

LINDA CALDWELL
School of Hotel
Restaurant and Recreation Management
Pennsylvania State University
University Park, Pennsylvania, USA

This study was undertaken to gain insight into how people with spinal cord injury (15 men and 5 women; age range = 17–59, M = 30.2) perceive their return to previously enjoyable activities. An "insider's" perspective (Conrad, 1987) was generated through participant observation and in-depth interviews, and the data were analyzed with Strauss's (1987) constant comparative method. Participants reported actively seeking previous activities and negotiating the meaning of the activities to continue their participation. The subthemes that define the meaning of continuity were (a) seeking continuity as an aspiration of adjustment for future actions, (b) establishing a sense of continuity through approximations to preinjury activities, and (c) accommodating for continuity for the purpose of establishing a sense of continuity. Exploring the nature and importance of continuity in this population suggests a broader discourse and extension to other disruptive life events.

Keywords spinal cord injury, continuity, adjustment to disability

Among many types of traumatic injuries and disabilities, spinal cord injury (SCI) constitutes one of the most devastating conditions in life. It is estimated that there are more than

Received 1 May 1995; accepted 7 September 1995.
The research reported here was partially supported by a grant from the American Association of Spinal Cord Injury Psychologists and Social Workers. We express our gratitude to those who participated in and facilitated the study.
Address correspondence to Youngkill Lee, School of Recreation and Sport Sciences, Grover Center, Ohio University, Athens, OH 45701, USA.

209

Copyright © 1996 Taylor & Francis
0149-0400/96 $12.00 + .00
250,000 people with SCI in the United States and that 8,000 additional people sustain SCI each year (Trieschmann, 1988). Unlike other types of disabilities, SCI occurs in a moment but requires long-term changes in personal life in the days, months, and years that follow. SCI brings major changes in roles, activities, and lifestyles, thus leading to a process of continual adjustment (Trieschmann, 1988).

The experience of SCI can be discussed from the perspective of body failure. Using Strauss’s (1991) sociological meaning of disability, SCI presents a “failure of the body: failure of part, body system, external body appearance, or any combination of those” (p. 385). Body failure creates many types of constraints in daily life that demand negotiation. Even familiar activities have to be approached anew.

However, the experience of SCI is more than a failure of the body. If body failure is salient to the continuity of everyday life and in a larger sense to an individual’s life story, then the meanings given to life through those actions or performances are also lost, resulting in “discontinuity between selves of the past, present, and future” (Strauss, 1991, p. 362). Therefore, SCI is more than a loss of physical mobility. What is more significant in physical disability is the disruption of continuity in the person’s “life story,” where the imagined future self becomes doubtful (Brody, 1987; Kleiber, Brock, Lee, Dattilo, & Caldwell, 1995).

In their qualitative study, Kleiber et al. (1995) described the illness experience for people with SCI as a sense of lost abilities, disruption of relationships, dependency, and psychological frustration from these experiences. What was notable in that study was that leisure was implicated in each of those categories. Illness is the disruption to one’s sense of self, and leisure interests and abilities were often central to that disruption. Often, the recreation participation of the past is no longer possible in the present for people who have been seriously injured, because of the practical realities that a “failed” body imposes.

**Continuity and Health for People with SCI**

The traditional medical definition of health indicates that to be healthy is to be free from illness and infirmity (Price, Gali, & Slenker, 1985). Thus, one who is experiencing illness cannot be considered to be healthy by this definition because the state of health is viewed as the opposite of illness. This narrow medical view of health has been challenged by the World Health Organization (WHO). Health is more than an absence of illness or disease, according to WHO; it is complete physical, mental, and social well-being (WHO, 1981). In contrast to the medical perspective, WHO’s definition of health clearly encompasses the role of wellness in daily life.

However, both medical and holistic perspectives are criticized by some researchers (e.g., Kagawa-Singer, 1993; Locker, 1983; Radley & Green, 1987; Scheer & Groce, 1988), in that the definitions explicitly exclude individuals with disabilities who persevere and succeed in spite of their disabilities. In the case of SCI, people who are coping well with their disabilities cannot possibly return to preinjury conditions. However, they are still able to perform their social roles in spite of constraints. Kagawa-Singer (1993) argued that “these individuals have no socially sanctioned position on the health-illness continuum, for they are neither sick nor well” (p. 296). Borrowing the concept of liminality from Murphy and his colleagues (1988), Kagawa-Singer further argued that being neither sick nor well, the chronically ill or disabled are socially in a state of limbo. They must create socially valued positions for themselves by re-establishing the fact that they are still the same individuals even though they
Kagawa-Singer also suggested considering self-integrity within a social context when judging the state of health for people who cope well with their disabilities. She defined self-integrity as a sense of coherence in one’s self in spite of physical changes (i.e., I am the same person as I was before). Viewing self-integrity within a social context indicates that self is influenced by other people and thus socially constructed. What is important in this concept is that people’s sense of health may largely depend on the degree to which they are able to sense the continuity in self that is socially based. Further, from a broad perspective of illness, being ill is more than body failure in a medical sense. As previously mentioned, an equally important matter in illness experience is the significance of discontinuity in life story. Although unable to return to a preinjury status, those who cope well with long-term disabilities can find the subjective perception of regaining continuity of self an important part of their definition of health, and, thus, this may be more relevant in defining health for them.

Using the concept of self-integrity, Kagawa-Singer (1993) studied people living with terminal illness and proposed the conceptual model of health on the basis of her empirical observations. Figure 1 represents her model of health, in which two dimensions are important: physical status and social function. Physical status (horizontal axis) indicates the predominant biomedical dimension often used to measure status of health, in which one end signifies sickness and the other end, wellness. The model signifies physical status as an objective reality where health can be judged by others. Social function is a dimension that social scientists frequently use to assess health, where one end of the line indicates ableness and the other end, unablesness. The vertical axis emphasizes the subjective assessment of health by an individual, not by outside observers. According to the figure, Quadrant I indicates well physical status and able to perform social functions, and
would be considered to be healthy. Quadrant II shows well physical status and unable to perform social functions, where people may not feel healthy owing to the loss of social role and identity. Quadrant III indicates both sick physical function and unable to perform social functions, where one cannot consider him/herself as healthy. Quadrant IV represents sick physical function and able to perform social functions, where one can be healthy in spite of physical sickness.

Although Kagawa-Singer (1993) described the relevance of Quadrant IV to people with cancer whom she studied, we believe that the same quadrant is relevant to people with SCI as well. After being medically stabilized, some people with SCI can perform a variety of social activities, while simultaneously not feeling physically well. The sense of possibility expressed through social action may provide a sense of self-worth and coherence in life. Therefore, what gives one a feeling of health is the degree to which one is able to be satisfactorily engaged in social activities in spite of physical limitations (Kagawa-Singer, 1993). In other words, the perceptions of continuity in social action serve as an important vehicle in defining the health status of people with long-term disabilities.

As important as it is to social integration, leisure may also be useful as a context for self-expression and the affirmation of competence (Kelly, 1983). Leisure-related identities express and affirm individuals' talents and capabilities (Shamir, 1992). Haggard and Williams (1992) posited that leisure plays an important role in maintaining self-consistency and positive regard. Using Schlenker's (1984) identity theory, Haggard and Williams discussed the term self-affirmation as "a process whereby individuals strive to affirm or validate cognitive self-images that they deem to be desirable, that is images consistent with those embodied by their ideal self" (p. 2). They theorized that freely chosen activities such as leisure can be "particularly potent in the self-affirmation process" (p. 3), and they demonstrated empirically that leisure activities facilitate the self-affirmation process. What should be noted here is that self-affirmation is not an end product; rather, it is "an ongoing process of continued self-definition, validation, maintenance and enhancement" (p. 2). For those who cope well with SCI, trying to affirm one's self and gaining a sense of capability through leisure, in spite of SCI, should be seen as wellness experience that is thus consistent with the experience of health.

**Problem Statement and Purpose of the Study**

Development of the capacity to continue satisfying and rewarding activities to regain a sense of well-being may be an important health-providing strategy. Despite the presumed significance of activity continuity to people with disabilities, little is known about how people with SCI interpret their engagement in activities they enjoyed previously. No single study exists that explores the meaning of continuity in the context of leisure for people with SCI. Although many researchers have conceptualized and investigated the concept of continuity for older adults who are retired (e.g., Kelly, 1993), the underlying idea of continuity is inherently problematic for people who have experienced a sudden injury without preparation for the dramatic changes that follow.

We undertook this study, which was part of a larger investigation of the leisure of individuals with SCI, to gain insight into how people with SCI perceive their return to previously enjoyable activities. Our focus was the meaning of continuity of leisure activities in the context of SCI in the early stages of adjustment where individuals first come to terms with their conditions. We delimited our analysis to the early stages of adjustment because all participants were observed and interviewed within a year of their injuries.
Method

In an attempt to avoid imposing our viewpoints, we sought an "insider's" perspective (Conrad, 1987) through participant observation and in-depth interviews. These qualitative methods permit investigators to conduct detailed examinations of experiences associated with events under study. Researchers using qualitative methods attempt to capture what informants say in their own words. The "native words" gained from the informants reveal 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). Lofland (1974) suggested that a researcher "must find out about those terms rather than impose upon them a preconceived or outsider's scheme of what they are about" (p. 4). We used qualitative methods in this study to examine the nature of disability as lived experience (cf. Matza, 1969), that is, from the perspective of an "insider" who is an "expert" on what it means and how it feels to have a SCI. This insider's perspective is the essence of qualitative methods. Although leisure was of particular interest to us, the general approach taken was to encourage informants to tell their stories, wherever that might lead.

Study Site

The study site for this project was a large urban rehabilitation center in the southeastern United States, dedicated exclusively to the rehabilitation of people with paralyzing spinal disorders. The facility has earned federal designation as a Model Spinal Cord Injury Center. The ages of individuals receiving services at this center range from 18 to 35 years. More than 30% of the patients have been injured in automobile accidents, and approximately 75% of them are male. People with paraplegia typically remain at the hospital for 7 weeks, and people with quadriplegia on the average remain 9 weeks.

Gaining Access to the Setting and Population

After obtaining human subject approval, Youngkhill Lee observed various therapeutic activities and read medical records and other relevant documents to gain insights into the people with SCI. Therapeutic recreation staff "sponsored" most activities associated with the fieldwork in this study. "Sponsoring" included allowing Lee to observe at the agency and in the community, locating participants, and informing him of various upcoming relevant activities. As a participant observer, Lee always introduced himself to others and explained his role as a researcher. He also verbally ensured the confidentiality of all information obtained from observations and interviews. As a person without SCI, he also participated in various recreation activities in a wheelchair. Doing so helped him to develop a rapport with participants and allowed him to hear conversations as they occurred naturally while being involved in various activities. After 4 months of observation, Lee approached some people to request interviews, describing the procedure and the general content, while also assuring them of confidentiality. On agreement, participants were asked to sign informed consent forms, and interviews were arranged.

Sampling

We used theoretical sampling (Glaser & Strauss, 1967) to identify and recruit appropriate respondents. To initiate this process, 4 participants were selected who (a) had participated
in the therapeutic recreation program, (b) were close to discharge (approximately 1–2 weeks prior), and (c) were willing to participate in the interviews. These selection criteria were considered without concern for theoretical relevance as the early stage of interviewing was used as an exploration of themes. After analysis of interview transcripts from these participants, we recruited other participants on the basis of their potential for providing new insights or for expanding and refining insights already gained. In this process, consideration was given to maximizing diversity in level of injury, age, and gender. The only individuals excluded systematically from the study were those who had experienced traumatic brain injury because previous research and participant observations indicated that verbal elaboration is often difficult for these individuals. Recruitment of participants was suspended when we determined that data saturation had occurred, that is, when the data coding process did not yield any significant new information or themes. At this point, we felt that, for the purpose of this study, further interviews would not lead to new insights.

Participants
A total of 20 people (15 men and 5 women) who ranged in age from 17 to 59 years (M = 30.2 years) participated in this study (Table 1). Participants reported either being employed (n = 13) or being a student (n = 7) before their injuries. The most common causes of injury were automobile accidents (n = 12), followed by falls (n = 4). Seven of the participants had paraplegia, and the remaining 13 had quadriplegia. Although the group may appear age and gender biased, the proportions in this sample are consistent with those of the population of people with SCI (National Spinal Cord Injury Association [NSCIA], 1992; Trieschmann, 1988).

Data Collection Procedures
We used two qualitative data collection techniques: participant observations and semistructured interviews. Participant observation was used in the first stage of data collection to identify the themes and in the second stage, interview process, for follow-up. We conducted semistructured interviews in the second stage of data collection to further explore the themes generated through participant observation. In this interview stage, the interactive process of data collection and analysis occurred simultaneously.

Participant Observation: Youngkhill Lee spent 4 months as a participant observer at the rehabilitation center. As described earlier, he observed people participating in therapeutic recreation activities and hanging out after daily rehabilitation. Observations of various events were made while Lee was in a wheelchair participating in activities. Events, actions, and discussions that contributed to the development of categories were recorded in field notes. Although some field notes were made in participants’ presence, others were recorded immediately after Lee departed the center. Although participant observation was important in becoming acquainted with the situation, its primary purpose was to set up the interview phase of the project by identifying some preliminary questions.

Semistructured Interviews: Subsequent to participant observations, semistructured interviews were conducted with selected participants before they were discharged from the rehabilitation center. For all interviews, an “interview guide” was developed to help Youngkhill Lee obtain insights into the experience of SCI, participants’ previous leisure interests, and continuity and change in the leisure experience. Because each interview
### Table 1
Participants' personal profile

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Previous job</th>
<th>Injury level</th>
<th>Date injured</th>
<th>Date admitted</th>
<th>Date discharged</th>
<th>Date of accident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>18</td>
<td>Male</td>
<td>Student (high school)</td>
<td>T-7 (Para)</td>
<td>7/01/92</td>
<td>7/02/92</td>
<td>10/18/92</td>
<td>Automobile</td>
</tr>
<tr>
<td>Wanda</td>
<td>19</td>
<td>Female</td>
<td>Student (college)</td>
<td>C-6 (Quad)</td>
<td>6/16/92</td>
<td>7/07/92</td>
<td>11/07/92</td>
<td>Automobile</td>
</tr>
<tr>
<td>Walter</td>
<td>40</td>
<td>Male</td>
<td>Sales clerk</td>
<td>C-4 (Quad)</td>
<td>8/29/92</td>
<td>9/23/92</td>
<td>2/02/93</td>
<td>Gunshot</td>
</tr>
<tr>
<td>Mark</td>
<td>47</td>
<td>Male</td>
<td>Mechanic</td>
<td>T-9 (Para)</td>
<td>9/13/92</td>
<td>9/30/92</td>
<td>12/20/92</td>
<td>Fall from tree</td>
</tr>
<tr>
<td>Donald</td>
<td>26</td>
<td>Male</td>
<td>Worked at carpet mill</td>
<td>C-5/6 (Quad)</td>
<td>9/08/92</td>
<td>9/08/92</td>
<td>12/20/92</td>
<td>Fall from ladder</td>
</tr>
<tr>
<td>Amie</td>
<td>19</td>
<td>Female</td>
<td>Student (college)</td>
<td>C-4/5 (Quad)</td>
<td>6/10/92</td>
<td>6/18/92</td>
<td>1/25/93</td>
<td>Fall from diving</td>
</tr>
<tr>
<td>Jason</td>
<td>43</td>
<td>Male</td>
<td>Carpenter</td>
<td>T-11 (Para)</td>
<td>10/08/92</td>
<td>12/10/92</td>
<td>1/15/93</td>
<td>Hit by a big object</td>
</tr>
<tr>
<td>Earl</td>
<td>20</td>
<td>Male</td>
<td>Worked at carpet mill</td>
<td>C-3/4 (Quad)</td>
<td>2/04/92</td>
<td>9/27/92</td>
<td>1/20/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Mike</td>
<td>24</td>
<td>Male</td>
<td>Student (MBA)</td>
<td>C-6 (Quad)</td>
<td>12/07/92</td>
<td>12/20/92</td>
<td>4/09/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>George</td>
<td>18</td>
<td>Male</td>
<td>Student (high school)</td>
<td>T-12 (Para)</td>
<td>12/02/92</td>
<td>12/02/92</td>
<td>1/25/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Martin</td>
<td>42</td>
<td>Male</td>
<td>Driver</td>
<td>C-4/5 (Quad)</td>
<td>8/10/92</td>
<td>10/07/92</td>
<td>5/07/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Brandon</td>
<td>19</td>
<td>Male</td>
<td>Student (college)</td>
<td>T-4 (Para)</td>
<td>1/09/93</td>
<td>1/09/93</td>
<td>3/26/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Neil</td>
<td>45</td>
<td>Male</td>
<td>Janitor</td>
<td>C-4/5 (Quad)</td>
<td>8/08/92</td>
<td>9/12/92</td>
<td>3/19/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Brian</td>
<td>55</td>
<td>Male</td>
<td>Pastor</td>
<td>C-4 (Quad)</td>
<td>6/05/92</td>
<td>2/15/93</td>
<td>4/10/93</td>
<td>Fall from ladder</td>
</tr>
<tr>
<td>Tina</td>
<td>17</td>
<td>Female</td>
<td>Student (high school)</td>
<td>T-8 (Para)</td>
<td>2/21/93</td>
<td>2/21/93</td>
<td>5/7/93</td>
<td>Natural disaster</td>
</tr>
<tr>
<td>Tony</td>
<td>30</td>
<td>Male</td>
<td>Manager (health club)</td>
<td>Lesions to C-2; T-12 (unclear diagnosis)</td>
<td>3/02/93</td>
<td>3/02/93</td>
<td>5/02/93</td>
<td>Fall</td>
</tr>
<tr>
<td>Rachel</td>
<td>28</td>
<td>Female</td>
<td>Waitress</td>
<td>C-4 (Quad)</td>
<td>12/17/92</td>
<td>12/17/92</td>
<td>4/23/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Lynn</td>
<td>36</td>
<td>Female</td>
<td>Reporter</td>
<td>C-4 (Quad)</td>
<td>2/21/92</td>
<td>3/18/93</td>
<td>5/07/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>James</td>
<td>59</td>
<td>Male</td>
<td>Civil Service worker</td>
<td>T-5 (Quad)</td>
<td>3/13/93</td>
<td>3/13/93</td>
<td>5/21/93</td>
<td>Automobile</td>
</tr>
<tr>
<td>Daniel</td>
<td>39</td>
<td>Male</td>
<td>Driver</td>
<td>C-6/7 (Quad)</td>
<td>10/07/92</td>
<td>10/07/92</td>
<td>6/07/93</td>
<td>Automobile</td>
</tr>
</tbody>
</table>

*Note. C = cervical; T = thoracic; Para = paraplegia; Quad = quadriplegia.*

required flexibility, the ordering of questions and the ability to examine ideas and experiences unique to that individual was dependent on each participant. The initial interview guide was changed on the basis of emerging themes and discussions at weekly staff meetings. Questions were continuously modified and added as new insights warranted further exploration. The length of the interviews ranged from 30 to 90 min, reflecting individual differences in participants' willingness to continue, ability to expand, and fatigue. With permission, interviews were tape recorded and transcribed into verbatim
accounts for data analysis. The primary purpose of the interviews was to have participants tell of their experiences with SCI.

Data Analysis

We used the constant comparative method (Strauss, 1987), which analyzes data simultaneously with its collection. Analysis was facilitated through coding and memoing. We analyzed data, with primary responsibility for interpretation being assumed by Youngkhil Lee. Weekly or biweekly meetings permitted sharing of insights. The coding process was used to identify categories of ideas. We regarded a category, therefore, as a theme that emerged from data directly rather than being preformulated. A category emerged from various incidents that held similar ideas. Coding in this project involved initial coding and focused coding.

Initial Coding: We used collaborative interpretation approach (Guba & Lincoln, 1981) to minimize the potential biases of each of us. The first step required Youngkhil Lee to make initial codes in the margins of all participants' transcripts. Next, John Dattilo and Douglas A. Kleiber examined coded transcripts of some participants to generate additional insights. These coding sessions served to clarify, extend, and revise Lee's initial codes. In addition to this procedure, Dattilo and Kleiber read each other's comments on Lee's initial coding, thus ensuring thorough communication between all of us. Lee then reviewed the codes and comments in the margins and brought questions and concerns to the team meeting.

Beyond these steps, John Dattilo and Douglas A. Kleiber completed the initial coding on two transcripts each. The coded transcripts were then returned to Lee for his review to provide additional insights. Four uncoded transcripts were sent to an external consultant for his review, coding, and interpretation. The consultant's marginal codes and comments, along with a written report of his overall interpretation, were returned to us.

Focused Coding: In this stage, coding became selective and conceptual. We applied a limited set of codes developed in the initial coding process to large amounts of data. This process enabled categories to be developed rather than simply labeling topics or themes. This selective procedure resulted in a set of conceptual categories (e.g., illness experience, wellness experience, perceptions of therapeutic recreation, etc.). The codes raised the sorting of data to an analytic level, rather than merely a description of large amounts of data. The primary purpose of focused coding was to build and clarify a conceptual category by examining all the data for correspondence with that category. As we examined and reexamined data, we checked associations with newly developed categories. Subcategories (e.g., meaning of continuity) were sought to explicate and exhaust the more general categories. Further, we generated properties (e.g., seeking continuity, establishing a sense of continuity, accommodating for continuity) to explain each subcategory in detail. The constant comparative analytic procedure helped to clarify each category's dimensions and distinguish it from other categories. This process enhanced analytic precision in dealing with ambiguous and experientially mixed categories.

Findings

Although there are a number of themes that emerged from the study, the meaning of continuity was a salient theme or category when people with SCI were asked to describe their experiences with familiar activities they enjoyed before injury. Although the com-
The Meaning of Continuity

monsensical meaning of continuity implies “remaining the same, being homogeneous, and unchanging” (Webster’s New World Dictionary, 1988), the meaning of continuity from the data goes beyond the sameness of the contents, styles, and situations of activities. The properties or subcategories that define the meaning of continuity are (a) seeking continuity as an aspiration for familiar future actions, (b) establishing a sense of continuity through approximations to preinjury activities, and (c) accommodating for continuity by negotiating through various constraints.

Seeking Continuity

Having a traumatic injury does not mean that individuals must relinquish previous leisure interests. Participants repeatedly reported seeking activities that they enjoyed before their injuries. For these participants, seeking previously enjoyed activities is an expression of motivation. For some, seeking continuity apparently began at the onset of the injury, as illustrated by the following comment from Mark: “From the day that I was hurt, I knew that I was going to go back to doing what I did before.” Seeking continuity in recreation activities was also captured during participant observations. During several leisure assessments conducted by therapeutic recreation specialists (TRs) at the point of medical stabilization, Younghill Lee often heard patients expressing interest in doing specific activities again. They frequently spoke of their previous leisure interests to the TRs and reported continuing interest despite their injuries. There was similar evidence in the progress notes written by a TRS: “I definitely want to swim again” (Progress Note on “Brenda,” 10/6/92).

The interview data provided additional insights into participants’ desires for continuity. Although the current disabling situation did not make returning to a previous activity easy, the prospect of returning to a preferred activity appeared to be a basis for action during rehabilitation. The following statements reflected the seeking of continuity:

I was in [rehab. center] and did my rehab and learned all about the sports I could still do, you know, like tennis and basketball, that I could still be playing, and I’m looking forward to doing that again. [Adam]

Well, I would just go deer hunting, and you usually get two a year or something like that, . . . and I stayed in the woods a lot. I liked the woods and scouted out a lot and that was just a very important part. Like a weekend, I couldn’t wait for a weekend to come around and go hunting. I still want to do that. I just have to roll in there now instead of walk. [Mark]

I guess scuba diving starts next month or the month after training, and I’m going to get put on the list there because I want to learn how to scuba dive. We’re going to go down and try it all over again. And teach her and take my daughter again, and, uh, we’re going to enjoy life again which will be a different experience for everybody all over. [Martin]

As seen from these quotes, these participants expected to adjust to facilitate doing previous activities. The following quote further illustrates this point: “A lot of stuff that I do that I used to do back then; it’s just done in a different way. I won’t give it up.” What was interesting to us was that participants recognized the need to modify and negotiate situations and opportunities to seek continuity. In other words, they not only described the
desire to go back to familiar activities, but also expressed an awareness of the potential changes associated with doing so.

The desire for continuity is a personal goal for rehabilitation and adjustment. The goal of returning to familiar activities emerged as an important priority in the course of rehabilitation. Because SCI directly affects the ability to carry out everyday life tasks, current experiences are likely to be incongruous with past involvement, and the current skill level may not match the demands of the activities. Seeking continuity appeared to be an ongoing quest for mastery over incongruity and inadequacy. The following descriptions illustrate this point:

I would not knowingly opt or choose to have the injury, whether it be a later stage or earlier stage. I’m not going to let it dictate the way I live. It might make some changes, and I might be on a lower level or less visible level, but basically I’m going to do what I did all along. [James]

I’m going to do it again. It’s just going to take me a little bit longer, and I hate that it’s happened. I don’t have a problem with going out there and doing it again, doing the same things I did before. [Mark]

As these quotes indicate, seeking continuity further represents the intended plans and subsequent actions aimed at achieving a sense of control over incongruous life situations, despite the illness and the changes it brings. For many participants, continuity as a goal was not just something to consider, it was something that “must” be achieved:

Well, it’s just another obstacle that you’ve got to overcome, I guess, is the way I feel about it. Whether I was standing, which would have been a lot easier, but I’m sitting now, and I’ve just got to take that into consideration and go on. I don’t have any negative thoughts about it or anything. I just know that I’ve got to do it sitting down now. I’ve got to overcome. [Donald]

I’ve got to be still trying to do things that I used to do but in a different way. To be a painter, artist, I’ve got to find a new way to either paint with my mouth... but I know I’m going to do something. Be able to go on. I’m not giving up, not going to quit. [Brian]

For some, continuity was regarded as new hope in their lives. Use of the word hope might be interpreted as that which a person desires yet currently cannot achieve but might possibly in the future. Hope, in this sense, appears to reflect a willingness for future action, as illustrated in the following quote:

Well, I was just hoping I’ll be doing all the same things I learned how to do at rehab. Go fishing, get out and go pushing somewhere, like maybe do a little road race or fun race, and get out and practice doing those. I mean I really don’t have the musculature to do it, I really don’t have the triceps, like getting up hills is a really hard proposition for me, but I’m hoping that eventually I can go out and do some leisure things and they won’t tire me out. Because now I know if I do them I get tired out real easy. So I’m just hoping eventually I can just go out and do those things like I did before. So I’m hoping leisure will still become more a part of my life like it was before. [Mike]
For some participants, seeking continuity was expressed as part of a plan: "My plan is to go back to doing as much as possible that I did before." During rehabilitation, participants may not have experienced every activity they did before their injuries, but they reported that they visualized returning to familiar activities in the future. The following description provides such evidence: "I play the piano now, and I plan to get back into that. I haven't really started yet, because I don't have my piano with me anymore, [but] I plan to get back into that."

Establishing a Sense of Continuity

Although participants often showed their desire for continuity, they also described their exposure to some previously enjoyed activities during rehabilitation. A phrase that seemed to capture the experience of adapted activities was that they were "a little different but the same." Many individuals interviewed reported that some activities they enjoyed previously were clearly different but still afforded them the opportunity for similar positive experiences. Because of the experiences of previous activities in new ways, the phenomenon of "different but the same" was interpreted as a sense of continuity. The term sense suggests that feelings are incomplete, still evolving, and yet to be fully incorporated into the previous lifestyle. Experiences of near likeness, an awareness of possibility, and experience of fun and enjoyment define the sense of continuity.

For most informants, the sense of continuity is not the feeling of exact sameness between past and current involvement. That is, informants did describe the sense of continuity as a near likeness to previous involvement. They mentioned that what they are experiencing now is "it is about the same," "a little different," and "not much changed." The sense of continuity in this context means that although they experienced some degree of difference, their experience during participation was similar to previous involvement. The following interchange between Younghill Lee (R) and a participant (Adam) illustrates this point:

Adam: I'm just getting back used to playing the games. They're all about the same, really."
R: No difference?
Adam: Yeah, it's a little different. It's a little different but not much has changed. I can still play, you know. It's the same thing. I mean, you can get frustrated with it because you can't get up and run around like everybody else does, but other than that it's about the same.

Although previous activities are not experienced in exactly the same way, a sense of continuity is perceived when an awareness of the possibility of replicating previous experience occurs. The sense of being able to participate in previous activities appeared to connect participants' past, present, and future lives. An awareness of the possibility is a very different reaction from the perceived loss of ability and despair, which is a defining characteristic of the illness experience of someone with SCI (Kleiber et al., 1995). A sense of continuity appears to allow participants to move beyond the illness experience and provides a feeling of possibility in spite of limitations and constraints.

Because I'm in a chair doesn't mean I'm not allowed to play basketball. Shooting is not as good but I can still shoot a basketball. It's still the same... Uhmm, I don't think there's a difference. [Brandon]
Going to the malls, I’m in a chair and in traffic and it’s just a little more difficult to get around in the stores, but I can still shop, I can still spend money. [Annie]

I can still sit up at the shop and cut and polish stones. I can still go in and saw wood and put furniture together and, and do those kind of things. Anything that I can handle with my hands, you know, working with heavy lumber, I won’t have the strength to deal a lot with it, but if it’s not extremely large. Hey, I’ll do whatever I want to do! [James]

Participants also reported experiences of similar emotions when participating in activities in which they engaged before their injury. Although the manner in which they participated may have been different, their experience was at least somewhat consistent with what they remembered feeling when involved in a particular activity. Being unable to use one’s four extremities would necessarily make fishing a different activity, but one participant found a sense of continuity from an experiential perspective: "Yeah, just relaxing out in the fresh air, yeah, . . . . It was basically just to relax because that’s what I always used fishing for was just for relaxing, to relax me." Having fun with activities further contributed to establishing a sense of continuity for the participants, as exemplified by the quote "You can still have just as much fun." The experience of enjoyment was related to hunting for one: "I went on a hunting outing with them. It was different hunting in a wheelchair but it was still enjoyable." The following quotes illustrate the importance of experiencing similar emotions in establishing a sense of continuity:

I can’t cast out as far but I can still cast . . . . Basically there’s no change. I still enjoy it. Like when I went on the fishing camp back in January; I enjoyed fishing then probably even more than I used to enjoy it before. [Mike]

Still just as fun. I didn’t do any better or worse either [laughter]. Actually, I might have done a little bit better after my accident than I did before. I love bowling still; oh, it’s so much fun. Sometimes I think I have more fun now than I did before. [Wanda]

**Accommodating for Continuity**

The ability to participate in previously engaged-in activities that may have been taken for granted is challenged by numerous physical and environmental incongruities imposed by the failed body. Scott (1991) maintained that constraints that inhibit or block leisure expression may not necessarily mean discontinuation of participation. He argued that "people may, instead, modify their behavior [italics added] to maintain a pattern of sustained involvement" (p. 323). Accommodation for continuity is defined here as negotiation to modify activities, behaviors, and circumstances to achieve continuity. Whereas the previous property of establishing continuity was described in an experiential way (i.e., near likeness, awareness of the possibility, and similar emotion), accommodation for continuity is expressed in behavioral terms, wherein participants tried to do something to establish the continuity. The common statement "I just have to do things differently" illustrates accommodation for continuity. This accommodation requires elimination of some aspects of performance and finding different ways of performing through the use of other people and adaptive equipment. Accommodation for continuity occurred
in two distinct ways: accommodating to partial loss and accommodating with the use of
adaptive resources.

Accommodating to partial loss: Maintaining and seeking continuity involves experienc-
ing functional incapacities while focusing on functional capacities to approximate previ-
ous participation patterns. Not all previous actions can be experienced in the same way
owing to body failure. Therefore, accommodation to partial loss includes an accommo-
dation to body failure. Going to a movie theater serves as a good example. Although the
most popular seating may be the middle rows of the theater, people with SCI are not
afforded spaces near those popular seats but rather spaces located in the back. However,
compensation for such discontinuity occurs by focusing on aspects of the experience that
are continuous: “I still watch the movie the same, still buy popcorn, still get a Coke to
drink.” Additional evidence has suggested another accommodation to partial loss:

> I’ll have to drop part of the woodwork, but I enjoy getting in and doing
woodwork. I enjoy going in and building things, implements and things, you
know, welding and cutting steel and all that stuff. [James]

Another example can be directly drawn from field notes taken during a dancing
session:

> Bill [a volunteer with quadriplegia] was giving us specific directions to move
and change our wheelchairs in certain ways. He kept saying “one, two,
three, four, and back two, three, four” as he demonstrated his movement to
make dance steps. One push, whether backward or forward, means one step,
which is an equivalent step for the able-bodied. They make steps with hands
and wheelchairs. Changing directions seems to have the same meaning. We
used short left and right changes of direction as our movement. Participants
with quadriplegia found different ways to dance. They could sing and smile;
they rocked their trunk[s] up and down on wheelchairs; they moved around on
stage with their motorized chairs. (Field Note 6; September 3, 1992)

Also frequently noticed during the participant observation period were participants with
quadriplegia using their mouths to control ‘‘sip-and-puff’’ tubes instead of using their
hands and fingers. Although a number of activities were continued through accommoda-
tion to partially failed bodies, this was not possible with all activities.

Accommodating with the use of adaptive resources: Accommodation to partially failed
bodies may be extremely difficult for people with SCI without adaptive resources such as
equipment or supportive people. A wheelchair itself is an adaptive device. For one par-
ticipant with quadriplegia who tried photography as a hobby, the loss of hand dexterity
required other people to assist him:

> I won’t be able to use the darkroom as well as I did before. I’m going to have
to put someone else into that. I could roll my own film where now I have to
have somebody, I have to either train somebody to roll it or have somebody
else [who] knows about photography to roll the film before we can develop it.
[Martin]
Many participants with quadriplegia required other people to transport them.

I can cast now. I haven’t practiced in a while but I could cast when I was leaving rehab. I’ve got a special grasping cup to hold the fishing pole and as long as the fish isn’t too big I can reel it in. I just need somebody there to either bait my hook or put on a lure or something and take the fish off; but that way at least I get out of cleaning fish. [Mike]

Although use of human assistance is instrumental for maintaining and seeking continuity, adaptive equipment is also a valuable resource for making accommodations. During the participant observation period, Youngkhill Lee often observed occasions when participants attempted to negotiate their functional limitations by using adaptive equipment. Examples of adaptive equipment are too many to list here. However, an important function of adaptive equipment is that its use facilitates accommodation. In doing so, the equipment enables the performance of old activities in different ways, thus ensuring some degree of continuity. The following quote describing the use of flotation devices during swimming speaks directly to the role of adaptive equipment in affording continuity:

It’s not really different. The only thing that’s different is that I don’t, I can’t keep myself floating as easily, and I always have to have a life vest on when I’m in the water. But otherwise there’s nothing any different about it. [Martin]

It appears that regardless of a partial loss of functioning and the use of adaptive resources, perceived similarities between previous and current experiences, styles, and contexts may be essential in creating a sense of continuity. Accommodation is a process of connecting past recreational skills to current functional levels imposed by disabling condition using adaptive resources.

Discussion

Having SCI does not mean that the person needs to relinquish all former leisure interests. Instead, participants reported actively seeking previous activities and negotiating the meaning of the activities to continue their participation. The theme of continuity of recreation activities for people with SCI has at least three subthemes. First, continuity involves the desire to return to familiar activities enjoyed before the injury. Seeking continuity was reflected in (a) the motivational state to establish a sense of continuity, (b) a goal of continuity that “must” be accomplished, (c) the hope for continuity, and (d) planning for future participation. Second, the postinjury experience of preinjury activities is expressed as “different-but-the-same.” Therefore, the sense of continuity does not represent a precise return; rather, the experience of previous activities was expressed as an approximation to the previous experience, through an awareness of possibilities and the experience of previously felt emotions. Third, continuity involves an accommodation to a partial loss of physical functioning through the use of the adaptive resources.

Nevertheless, it is important to qualify these findings as reflecting only the early stages of adjustment. Just as leisure activities are implicated in the experience of illness (Kleiber et al., 1995) and initial wellness in this study, they may also be associated with the life narrative reconstruction, or “restorying” (cf. Brock & Kleiber, 1994; Brody, 1987; Kleiber et al., 1995; Lee, Brock, Dattilo, & Kleiber, 1993) that becomes more important as one comes to terms with permanent disability. The new story one writes for
The Meaning of Continuity

oneself subsequent to traumatic life events may be illustrated with a future self in action, whether that action involves a continuity with former activities or a discontinuity associated with adoption of entirely new activities. Initially, however, it is clear that a sense of continuity in leisure was important to those studied in this investigation whose selves were disrupted by SCI. It appears from the current data that the road to health and initial wellness for people with SCI is likely to first pass through a period of reconnecting with a past self.

Although there is no clear definition of health for people with SCI, individuals who expressed continuity in their stories may be considered healthy when the concept of health proposed by Kagawa-Singer (1993) is applied. Although participants in this study may not be physically well, they are able to perform leisure activities and saw continuity in engaging in these activities. Quadrant IV (sick physical function and able to perform social function) in Kagawa-Singer’s conceptual model is relevant to the participants in this study. In other words, the stories presented in this study demonstrated the preservation or restoration of continuity that enables participants to view their lives as having some consistency in the wake of disruption. Reclaiming former activities, albeit with some modification, is arguably a good reflection of health for people with SCI. Consistent with Kagawa-Singer’s notion, Triebmann (1988) also claimed that the ability to establish a sense of self-worth and to experience satisfaction with current activities in spite of traumatic SCI is a key factor in coping and well-being.

Establishing continuity can also be viewed as an adaptive strategy for seeking a positive health status. Atchley (1971, 1989) described continuity as a healthy adaptive strategy that links to personal well-being for older adults. He found that continuity of interests is particularly important in establishing and reinforcing integrity and a sense of well-being (Atchley, 1971). Although he mentioned the concept of continuity in relation to older adults, the same idea may be applied to other groups, including people with SCI. One salient aspect of the illness experience is uncertainty about the future (Kleinberg et al., 1995; Weiner, 1975). Seeking and establishing continuity may mitigate the impact of the disruption caused by SCI. Further, as this study well demonstrated, the prospect of continuity of leisure activities was both a source of encouragement and a buffer against the dramatic change experienced by the participants in this study.

When interpreting the results of this study, it may be useful to consider individual differences. Not all people would experience the same sense of continuity in all situations. What may be disruptive or dislocating for one person may not be so for another. In addition to differences between individuals, there may also be intrapersonal variability, resulting in the perception of more disruption at one time and a stronger sense of continuity at another time.

Perhaps Yoshida’s (1993) pendulum model of the self-reconstruction process of people with SCI applies to such variations. Yoshida used the pendulum as a metaphor to depict the nonlinear pattern of the identity-rebuilding process for people with SCI whereby five primary selves swing back and forth in everyday life: (a) the former self, (b) the supernormal identity, (c) the disabled identity as a total self, (d) the disabled identity as an aspect of the total self, and (e) the middle self as an identity between disabled and nondisabled. According to Yoshida, the dynamic shifting of different identity views occurs from moment to moment, situation to situation, and day to day. The fluidity of identity construction is "a continuous, evolving, dual-directional process and the assumption that people 'adjust' to their disability once and for all is also challenged" (p. 241). Similar observations were also made by Charmaz (1991), who reported that the experiences of loss and transcendence are inherent aspects of the experience of chronic illness.
She reported that “loss and transcendence are not static, for one individual may experience both; . . . loss and transcendence are grounded in time—in moments, in good days and bad days” (p. 258). The sense of continuity of recreation activities thus may be influenced by different views of self emerging at different times and in difficult situations.

It would be misleading to suggest that participants in this study immediately sought and experienced continuity. The illness experience is salient throughout the course of adjustment, but especially in the early stages. Indeed, we found that psychological distress and frustration due to the inability to participate in leisure activities a significant part of the illness experience for people with SCI (see Kleiber et al., 1995, for details). More specifically, using Charmaz’s (1991) metaphor of good days and bad days in the experience of chronic illness, Kleiber et al. stated that “the ability to engage in leisure activities contributed to defining the good days; the absence of those abilities contributed to defining the bad” (p. 297). Although this study highlighted the stories associated with good days, it is also evident that stories of the illness experience color the overall adjustment process for the people with SCI.

Nevertheless, it appears that the meaning of continuity resembles the concept of “coming back” (Strauss, 1991). According to Strauss,

to come back means not dwelling on performance impossibilities but on performance abilities. To come back means to reconnect the body and the person of the past with the body and the person of the present through possible performances, while accepting that certain performances may no longer be possible and that other performances have a changed nature. (p. 363)

From this perspective, the meaning of continuity may be viewed as a part of the process of coming back or recovering from the illness experience.

Exploring the nature and importance of continuity in this population suggests a broader discourse and extension to other disruptive life events. From a conceptual perspective, clarification of the nature of continuity of leisure activities in the process of “restorying” offers insights into the dynamic nature of identity reconstruction, as reflected in Yoshida’s (1993) and Charmaz’s (1991) studies. Although activities identified by participants in this study were mostly physical, it is likely that a wide variety of leisure activities can contribute to both continuity and restorying. As a context for self-expression and self-invention, leisure may be particularly significant in both processes. Finally, because this study only reflects the “early” stages of adjustment to a negative life event, studying life disruptions over a longer period should be still more revealing of the meanings of continuity and change.

References


The Meaning of Continuity

(Eds.), Research in the sociology of health care: The experience and management of chronic illness (pp. 1–32). Greenwich, CT: JAI Press.


