The Experience of Head Injury on the Impairment of Gender Identity and Gender Role

Sharon A. Gutman, Jeanette Napier-Klemic

Key Words: activity configuration analysis • personality development

Objectives. This study explored the disruption of gender identity and gender role as a result of traumatic brain injury (TBI).

Method. Four adults (two men, two women) who sustained a TBI between the ages of 18 and 30 years and were at least 1 year postinjury participated in six 1-hr interviews concerning changes in (a) perceived masculinity or femininity, (b) involvement in intimate relationships, (c) enactment of gender roles, and (d) organization of activities that support gender roles.

Results. The men expressed greater feelings of gender inadequacy postinjury than did the women and appeared to have greater difficulty resolving rites of passage (e.g., achievement of the adult work role, marriage, parenting) and developmental issues characteristic of the life stage at which they experienced their injury. The men appeared to depend more heavily on traditional gender-specific activities before and after injury to define and support gender role; the women relied more on cross-gender activities. The women appeared to be able to maintain more preinjury activities postinjury than did the men.

Conclusion. Postinjury possession of a personally satisfying sense of gender appears to be related to the ability to maintain much of the preinjury activities that defined and supported the participants sense of masculinity or femininity. The ability to satisfactorily resolve rites of passage or developmental issues characteristic of the life stage at which the brain injury occurred appears to be related to the ability to participate in activities that define and express gender role during that particular life stage.

Sexuality is an integral element of being human and encompasses the way in which people perceive themselves as men or women (Neistadt, 1986; Strauss, 1991; Zasler, 1991). The development of gender identity (the perception of self as masculine or feminine) and the way people learn to express that identity through culture-specific gender roles are important developmental milestones occurring normally during the human life span (Evans, 1985; Money, 1984, 1988). Masculinity or femininity is expressed through the enactment of gender roles in all daily activities, vocational and academic pursuits, leisure interests, familial and social relationships, and intimacy with members of a particular gender group (Cole, 1991; Medlar, 1993; Strauss, 1991). Genderality is the way humans relate as a male or female to every person and object in the environment.

The acquisition of a chronic disability considerably disrupts one’s ability to relate to others as a man or woman with behaviors learned before the onset of disability (Evans, 1985; Finger, 1993a; Kahn, 1992; Krefting,
groups: (a) clinicians who advocated for the sexual rights and how it is experienced (Ducharme, 1992; Hahn, 1981). This lack of assistance may largely be due to the general taboos surrounding sexuality and gender in western society and the inadequate education of most health care professionals about sexuality and disability (Chan-dani, McKenna, & Maas, 1989; Davis, 1990; Howard, 1992; Lefebvre, 1990; Medlar, 1993; Neistadt, 1988; Payne, Greer, & Corbin, 1988; Strauss, 1991; Weinstein, 1992). For health care professionals to address the impairment of gender identity and gender role that accompany chronic disability, it is essential to understand it and how it is experienced (Ducharme, 1992; Hahn, 1981; Strauss, 1991).

The Development of Sexuality and Disability Research

Health care professionals began to generate interest in how disability affects sexual expression in the late 1960s—a time when increased advocacy for persons with disabilities coincided with a greater sexual openness in the United States (Kempton & Kahn, 1991). Concurrently, gaining popularity among U.S. health care professionals was the Scandinavian normalization movement that contended that health care for persons with disabilities should promote opportunities for a natural rhythm of daily work, leisure, and self-care as well as a natural life cycle that encompasses all the developmental life stages and life tasks to be achieved in each stage (Rhodes, 1993). Sexual expression began to be recognized as a normal element of human life for persons with disabilities.

Research and clinical intervention for sexual impairment resulting from disability diverged into two separate groups: (a) clinicians who advocated for the sexual rights of persons with developmental disabilities and (b) medical researchers and practitioners who treated the physiologic impairment of genital and reproductive functioning resulting from acquired chronic disability. These two groups produced distinct sets of knowledge. Advocates for persons with developmental disabilities, who delivered services on the basis of an educational or community care model, largely treated persons residing in institutional or community-based settings. These professionals addressed implementation of sexual education programs, dissemination of reproductive information (including birth control), and opportunities for privacy and intimacy within institutional settings (Champagne & Hirsch-Walker, 1982; Demtral, Driesen, & Gott, 1982; Flinn, 1982; Green, 1982; Hepner, 1978; Neistadt & Freeda, 1987; Rhodes, 1993; Walter, 1982). Practitioners who treated on the basis of the medical model, delivered services to persons who acquired their chronic disability in adulthood after gender identity and roles had been established. These professionals produced a body of literature that examined the effect of specific medical diagnoses on genital and reproductive functioning (Aloni, Ring, Rozenthul, & Schwartz, 1993; Boldrini, Basaglia, & Calanca, 1991; Clark, 1993; Cole & Cole, 1993; Drench, 1992; Finger, 1993b; Graves, 1993; Tepper, 1992).

Despite the valuable body of literature generated by both groups, information is lacking about how persons who acquired a chronic disability in adulthood perceive their established gender identity and gender roles to have been impaired by disability. How does chronic disability affect the perception of self as a man or woman with regard to spousal, familial, work, leisure, and social roles? What is necessary for them to reorganize daily activities and goals to be able to maintain an acceptable sense of gender identity and gender role enactment? How do they reinvent their concept of maleness or femaleness in a society that links health and attractiveness to masculinity and femininity? These questions address the social aspect of sexuality and broaden the comprehension of sexuality as more than simply a physical act (Ducharme, 1992; Hahn, 1981).

Head Injury and Impairment of Gender Identity and Role

Several qualitative studies have explored the way in which persons describe their experience of chronic disability (Ducharme, 1992; Finger, 1993a; Hahn, 1981; Krefling, 1989). Such studies revealed that persons perceived low self-esteem, poor body image, social isolation, and lack of relational intimacy as the most difficult aspects of living with a long-term chronic illness (Davis, 1990; Ducharme, 1992; Strauss, 1991; Stravos, 1991; Valenreich & Gripton, 1984). Self-esteem, body image, and the ability to interact comfortably with others and form and sustain social relationships all relate to the ability to engage in relationships and activities that express and support one’s gender identity and gender role (Andamo, 1980; Medlar, 1993; Strauss, 1991). Persons who have sustained head injuries report that the long-term social ramifications can be more devastating than the physical injuries (Stambrook et al., 1991).

Most persons who have sustained a head injury are...
between the ages of 18 and 30 years—a time in human development when people typically engage in activities that define and express gender identity and roles through the formation of intimate relationships, the creation of families and acquisition of the parenting role, a commitment to vocational activities, and an involvement in social relationships and community roles (Davis, 1990; Ducharme, 1990; Joe, 1992; Kahn, 1992; Mapou, 1990). It is also a time in which people enter society as individuals and contribute to the community by using the resources developed during previous developmental stages. Persons who have sustained head injuries during this developmental stage may be thwarted in their transition into adulthood (Krefting, 1989). The typical rites of passage into adulthood as men and women (defined in Western culture by marriage or pair bonding, acquisition of the worker role, parenting) often become inaccessible or restricted by the larger society (Diasio-Serrett, Schallert, & Shively, 1994; Goffman, 1963; Krefting, 1989). Family members and health care professionals can inadvertently reduce opportunities for these roles through attempts to protect the person.

A poorly resolved and emotionally traumatic sequel of the head injury experience commonly emerges from the person’s ability to remember what his or her life was like before the injury (Davis, 1990). Healing the incongruence between present and preinjury life satisfaction is a difficult but necessary process. Redefining self-concept, releasing long-desired life goals and replacing them with meaningful ones, and creating ways to support and reinforce a sense of identity as a man or woman are all necessary processes for the re-creation of a new identity that is personally acceptable. Yet, little is known about the nature of these processes, how persons with chronic disabilities experience these processes, and how health care professionals can provide opportunities in the environment to facilitate these processes.

Because the typical age of head injury occurs at a critical developmental life stage, it can undermine the person’s concept of becoming an adult man or woman. Understanding how a person’s identity as an adult man or woman affects one’s ability to rebuild a life of personal meaning is important when assisting the person to rebuild a new self-concept after the onset of traumatic disability, when gender identity and role have been well established.

Method

Participants

Study participants were recruited in the Northeast through posted announcements in a residential facility for persons with head injury. The study criteria required that the participants (a) be their own legal guardian, (b) have sustained their head injury between the ages of 18 and 30 years (and be at least 1 year postinjury), and (c) demonstrate a cognitive level high enough to understand and articulate answers to interview questions.

Four persons (two men and two women) participated in the study. All had sustained a head injury during a motor vehicle accident and demonstrated similar levels of cognitive and physical function. Although each participant had attained independence in a number of basic community living skills (e.g., shopping, community travel), all required the daily structure and supervision of a residential care facility. All participants resided in community group homes with others who sustained head injuries; however, none of the participants lived together. All participants were high school educated and were actively employed before their injuries. Their names have been changed to preserve confidentiality.

Jon, a 46-year-old white Italian-American man who was injured at age 28, had served in the military and worked in an import-export shipping company preinjury. He had dated sporadically and was sexually active before injury but had not established a formal or long-standing relationship. Jon had been married for 2 years at the age of 42 and then divorced. By his choice, Jon currently does not work.

Mic, a 33-year-old Polish-American man who was injured at age 21, had worked as a driver for a tire company, resided in his parent’s house, had limited dating experience, and had neither established a serious relationship nor was sexually active preinjury. Currently, he works in a community laundromat.

Pam, a 36-year-old African-American woman who was injured at age 26, had completed a year of college and had entered the military as an administrative assistant preinjury. At the time of her injury, she was living with a man and their infant son. Before this relationship, Pam had dated sporadically but formed no serious attachments; she had been sexually active and had an abortion. After injury, she lost contact with her child and the child’s father. She currently works as an administrative aide.

Ann, a 46-year-old white Irish-American woman who was injured at age 30, had worked as an administrative assistant and had been married and divorced twice preinjury. She currently performs piecework in a vocational center.

Data Collection

Six 1-hr open-ended interviews were conducted with...
each participant over a 2-month period to allow time for rapport building and data saturation. With the use of an interview protocol, the two authors interviewed the participants in a private, but informal setting (e.g., the participant's residence, an empty recreational room in the facility). Each interviewer conducted two interviews singly and two jointly to determine whether the presence of either interviewer had inhibitory or facilitatory effects on the participants' responses. No differences in interviewer effect were noted. Interviews were audiotaped and transcribed. A field log was maintained to record each interviewer's objective observation of each session (Bailey, 1985). Analytic memos were used to note the interviewers' subjective experience of the interview process and personal response to the participants (Strauss, 1987).

Data Analysis

Grounded theory, or constant comparative analysis, was used to analyze data. Collected information was coded and compared to identify common themes and to explore the relationship between themes (Bogdan & Biklen, 1992; Strauss, 1987). Peer debriefing, support group participation, triangulation, and negative case analysis were used to verify the credibility of the data collection and analysis and to establish trustworthiness. For peer debriefing, five colleagues with expertise in clinical treatment, research investigation, or both evaluated the research process and findings pertinent to their area of expertise. A support group consisting of seven peers studying health care issues provided evaluation and analysis throughout the study. Triangulation—the reiteration of one piece of information by the same source over time—was used to verify emergent themes. Negative case analysis was used to reexamine gathered material when data did not fit with information earlier stated. Data from both the field logs and analytic memos were examined for investigator bias.

Thematic Constructs

Thematic constructs are categories of phenomena that describe the participants' reported experience over time. Seven thematic constructs emerged from the data:

1. Genderality: sense of masculinity or femininity
2. Use of gender-specific activity to define genderality
3. Qualitative versus quantitative differences in male and female activities
4. Other-oriented versus self-oriented activities
5. Degree of participation in preinjury and postinjury activities
6. Rites of passage
7. Temporal urgency in completion of life goals

In addition to the thematic constructs, data analysis revealed differences between the male and female experience of head injury. Such gender differences are described throughout the following discussion.

Results

Genderality: Sense of Masculinity or Femininity

The women conveyed strikingly similar senses of self as women postinjury. For example, Pam said, "I feel like a woman. I feel feminine without something else making me feel like a woman." The men described a sense of inadequacy as men postinjury. For example, Jon stated:

Jon: I know that if I could have the opportunity to prove myself the man I know myself to be...to be the married man, the family man, to be the workaholic I was before my head injury, I know I could be the man I know myself to truly be.

Use of Gender-Specific Activity to Define Genderality

Both men appeared to depend more on traditionally masculine activities to define and support their masculinity before and after injury than did the women. Examples of the men's preinjury and postinjury activities were sports (e.g., football, baseball, boxing), auto mechanics, pool playing, card games, and military service (see Table 1). The men appeared more likely to express feeling like less of a man if they were not presently (postinjury) engaging in the activities they once used to define and express masculinity.

Conversely, the women did not appear to be as dependent on traditionally feminine activities to define and express their femininity before and after injury. Both their preinjury and postinjury activity constellations showed an array of activities that cross gender lines, including exercising (calisthenics); playing tennis, pool, chess, cards,
Table 1
Participants' Adult Preinjury and Postinjury Activity Constellation

<table>
<thead>
<tr>
<th>Participant</th>
<th>Preinjury Activity</th>
<th>Postinjury Activity (Present)</th>
</tr>
</thead>
</table>
| Men Jon     | Parrying (bar hopping)  
Playing pool, cards  
Dating  
Serving in military  
Attending boxing matches, horse races  
Working (businessperson)  
Maintaining apartment | Painting (fine arts)  
Visiting family  
Watching television  
Listening to music  
Maintaining room in community group home |
| Men Mic     | Playing sports (football, baseball, bowling), board games  
Dating  
Working (salesperson, cashier-clerk, driver, auto mechanic, landscaper)  
Doing household chores in parents' home (taking out trash, cutting grass, baby-sitting, doing laundry, cooking, cleaning)  
Maintaining apartment | Watching television  
Visiting family  
Working in laundromat  
Maintaining room in community group home |
| Women Pam   | Playing sports (tennis, racquetball, bowling), board games  
Cards, board games  
Attending or watching football and baseball games  
Attending vegetarian group meetings  
Studying in college (1 year)  
Serving in military (administrative work)  
Maintaining apartment with male partner and infant | Cooking  
Exercising (video exercise tape)  
Playing sports (tennis, bowling), pool, cards, chess, board games  
Attending or watching football and baseball games  
Attending shows and films  
Eating out  
Attending recreational group  
Shopping (personal items)  
Maintaining medical care (medication routine, diabetic diet)  
Attending community college computer classes  
Visiting family  
Spending weekends with male partner  
Working (administrative aide)  
Maintaining room in community group home |
| Women Ann   | Cooking  
Gardening  
Sewing, crocheting  
Playing chess  
Shopping  
Maintaining appearance (makeup, hair styling)  
Baby-sitting  
Bartending  
Working (administrative assistant)  
Hanging out with friends  
Practicing yoga  
Maintaining own home  
Maintaining marriages | Cooking  
Caring for indoor plants  
Crocheting, knitting  
Shopping (personal items)  
Maintaining appearance (body care, hair care)  
Maintaining medical care (maintenance of tracheostomy, molded ankle-foot orthosis, medication routine)  
Performing piecework in vocational center  
Visiting family  
Practicing yoga  
Exercising and walking  
Attending shows and films  
Watching gymnastics, figure skating  
Eating out  
Reading  
Maintaining room in community group home |

and board games; attending baseball and football games; cooking, needleworking, going to shows, watching films, gardening, bartending, learning computers, and serving in the military (see Table 1). This finding may reflect larger societal changes in the activity constellations for all women.

Both women described themselves as having been tomboys as children. Pam continues to perceive herself as a tomboy but does not consider herself to be any less feminine:

I've always been a tomboy, you know, liking sports and stuff. I still do...I don't like makeup and hairdos; that's not me. But I feel like a woman. I don't need things to make me feel feminine.

Qualitative Versus Quantitative Differences in Male and Female Activities

The women described their present activities with qualitative terms; that is, they discussed them with regard to personal satisfaction and meaningfulness:

Pam: I like to go out to dinner and eat good foods. Ann: I enjoy going to shows or movies with friends. Ann: The time I can spend with my sister is important to me.
Pam and Ann also participated in activities (before and after injury) with the expressed purpose of enhancing their skills, moods, or physical attractiveness, including caring for hair and body (e.g., coloring one's hair; moisturizing one's skin); exercising; and working to learn new vocational skills, for example:

Ann: I have always done yoga. Yoga puts you in touch with your feelings and your body—especially the postures. I can't [physically] do most of the postures now, but I still do the breathing exercises.

Pam: I am enjoying learning how to use the computer at work. I bought my own personal computer...and I'm taking classes to learn the computer at night because doing work I enjoy is important to me.

The men, however, emphasized the quantitative aspects of their preinjury and postinjury activities. They described occupations in which they were either working or not working, succeeding or failing, and winning or losing, with little or no expression of their feelings regarding these activities:

Mic: I was a wide receiver [in high school]. I caught the winning touchdown football. We won the state championship.

Jon: I worked for an import-export company. I was a landing agent. It used to take two guys to do my job when I wasn't on that night. I would definitely have been in an executive-level position in that company if I hadn't had a head injury.

Many of the activities Mic and Jon discussed were described with a sense of present loss. When asked what types of things he presently enjoys, Jon answered in the past tense:

I used to pick out the horses and fight here and there. I used to work my ass off all the time. Getting the old paycheck, going out to a club, dancing a little, having a cocktail. I used to be good at playing pool. I haven't done these things in years.

Other-Oriented Versus Self-Oriented Activities

Both women appeared to participate in activities that in some way connected them to others more frequently than did the men. The women also described activities in terms of whether those activities forged social connections for them, for example:

Pam: I like to cook dinner for other people.

Ann: I make afghans, you know blankets, for my friends.

Pam: I like to go out to see shows with the recreational group.

Pam: I can go to another house [community group home] and people there will play cards with me.

The men each described at least one preinjury activity that served to forge social connections (e.g., high school team sports, military service); however, neither indicated that he was presently engaged in activities that facilitate social ties to others. Much of their postinjury activities were self-oriented or isolative (e.g., watching television, listening to music in room).

Not surprisingly, the men reported feeling a greater sense of loneliness than did the women. The men attributed their loneliness to lack of an intimate relationship, whereas the women framed their loneliness differently. Rather than speaking of being alone as a negative experience, the women described it as a condition from which they learned how to be independent. For example, Pam said, "I was always on my own. I went to school and came home. I learned how to take care of myself. You know what I'm saying? I don't mind being alone." Further, rather than attributing aloneness to lack of another person, the women spoke of being alone as though it was an internal quality:

Ann: I'm not interested in a relationship now. I'm okay to be alone. You know sometimes you can be in a room full of people and still feel alone. I feel that everyday of my life, even though I have friends.

Degree of Participation in Preinjury and Postinjury Activities

A striking disparity between the men's and women's activity constellations emerged between preinjury and postinjury activity participation. The women maintained a large number of preinjury activities, or some aspect of the activity, after their accidents and rehabilitation processes. Both have also added a number of activities to their present postinjury activity constellation (see Table 1). Conversely, the men have not maintained many of the preinjury activities that they used to define their masculine identities; in fact, they participated in fewer activities postinjury. As stated earlier, the activities that have become part of their postinjury activity constellations are self-oriented and do not connect them socially to others.

Rites of Passage

The men appeared to express a greater sense of not having achieved certain life expectations or rites of passage common in our society than did the women. The men appeared to be struggling with the rites of passage typical of the life stage at which they had their accident. For example, Jon, who at age 28 was actively establishing his career and forming intimate relationships, expressed the following at age 46:

There's so much of my life that didn't go the way it should have...I'm a man who has been baring to prove myself a man for the last 18 years because of this head injury. I should have already fallen in love and gotten married, had a family, gone down that route. I know I would have been in an executive-level position at
work by now....I'd like to be able to show that I'm not the kind of man who is professionally and financially kept. You know, being a member of a community somewhere. [And my father could say,] "Oh yeah, that's where [Jonny] lives." You know, a normal community residence somewhere. It just feels like a part of my life was not fulfilled.

Mic, who at age 21 was in transition from adolescence to young adulthood—a stage characterized by separation from parental ties, exploration of independence, and development of gender and social roles (Davis, 1990)—described his life goals at age 33 as being: "To get my driver's license, my own place [an apartment], and a woman, and eventually get married."

Neither woman appeared to be struggling with the rites of passage characteristic of young adulthood—the stage at which both experienced their injuries. Neither identified the formation of intimate relationships, marriage, parenting, career success, or the establishment of community member roles as personal goals. When asked to describe her present life goals, Pam answered:

I'm the type of person who likes to take care of myself. I like to work. I like to cook. I like to entertain myself. I want to remain single, not have kids....I'm trying to take care of myself now. I'm getting into a position at work where I'm learning computers. There's just stuff I never learned how to do. I'm trying to learn now, and I'm enjoying learning.

When asked about her life goals, Ann replied, "I'd like to be around more people who are my age [46], who I can talk to."

Temporal Urgency in Completion of Life Goals

The men demonstrated a sense of temporal urgency regarding completion of goals as though they were pressured by a time limit:

Jon: I should have achieved all that [marriage, family, career] by now. I imagine all of the guys [old friends] eventually hooked up with one woman and had the family and all that. All but [Jonny] here. [Jonny's] here with the head injury career.

Mic: I'm overdue. I'm the oldest of four brothers. They're all married and have families. I feel like, when's it gonna be me?

Jon: I feel I have to get things right—before my father dies. I have to prove to him that I am the man he and I both know I can be.

This temporal urgency to complete life goals was not apparent in either woman's discussion.

Other Common Themes

Lack of counseling. Of the other themes that emerged, one repeated in all four participants' interviews revealed that throughout the rehabilitation process, each participant received little, if any, counseling regarding how to deal with gender-related issues, particularly how they would experience their bodies in relation to their environment and to other persons, how their relationships as men or women would change with girlfriends or boyfriends and spouses, and how their feelings about themselves as men and women would be altered in relation to the ability to achieve old and new life goals. At the same time, each participant expressed appreciation for the opportunity to discuss these issues with the interviewers:

Jon: Really, there's no one to talk to. Talking to you now has been such a relief because I don't think I've discussed my feelings about what we've been talking about for—it's too many years now.

Lack of privacy and autonomy. Another theme that continuously recurred throughout all four participants' interviews was lack of privacy and autonomy and feeling like they had been treated as health care clients rather than as people. When asked about her ability to find privacy with her boyfriend of 6 years, Pam stated:

We're dependent on staff members to be together. Either someone has to take me to my boyfriend or, if he comes over, someone has to take him home. He can't stay over in my room [in the community group home] and I'm not allowed to spend nights at his apartment because I have my meds to take and I have a curfew.

The following is Jon's account of having to "sneak around" to find privacy with a woman he had been dating at a residential care facility: "We planned to be together alone at night....We were found [by staff members] and separated. Do you know how that makes me feel? I'm 46 and she's 43. I feel like we're children." Further, Jon expressed how he felt like a client rather than a person:

I can recall once or twice being this close to suicide. I was in this program and that program, and after you get done with another program you say to yourself, "Well [Jon], when is this gonna be, or that gonna be?" And nothing happens. When is my life gonna be my own and not [that of] a client? If you're a client, you're not a person. You're looked at in a very clinical way.

Discussion

Expression of Gender Identity and Role Through Activity

One reason the men may have experienced greater feelings of gender inadequacy postinjury than did the women may relate to the greater number of socially accepted activities that enable women to express and support gender identity and role, including cross-gender activities. The men's dependence on rigidly defined, traditionally masculine activities may have prevented them from adopting cross-gender activities that could enhance postinjury gender identity and role satisfaction. The men may have believed that they have a limited array of postinjury activities that allow the expression of masculine gender
roles. Conversely, the women’s activity constellations were less disrupted by injury. Activities they used to define and support preinjury gender identity and role were maintained postinjury.

Another reason why the men did not maintain or replace lost preinjury activities may relate to male perceptions of personal performance levels. The quantitative terms that the men used to describe their preinjury activity participation (such as succeeding–failing; winning–losing) may provide clues about what participation means for them. Participation in traditionally masculine activities may have been perceived as unsatisfactory if their postinjury performance level ceased to meet personal preinjury standards. Failure to meet these standards may suggest masculine inadequacy; hence, as one participant expressed, feeling like “less of a man.”

Conversely, the women, who used qualitative terms to describe their activity participation (such as important, enjoy, like), may have been able to derive personal meaning from maintaining preinjury activities despite inability to perform them at preinjury performance levels. Nevertheless, despite reasons accounting for why the women were able to maintain a greater number of preinjury activities than did the men, there appears to be a distinct relationship between maintenance of preinjury activity constellations and postinjury gender identity and role satisfaction. The greater the ability to maintain preinjury activities, the greater gender identity and role satisfaction is expressed.

It was not surprising that the men attributed their feelings of loneliness to the lack of an intimate relationship because their present constellation of activities was composed of things that do not socially connect them to others (e.g., watching television, listening to music in room). The women, who participated in a number of activities useful in forging social connections (e.g., eating out with friends, playing cards, participating in recreational groups), did not express feelings of loneliness. When the women spoke of being alone, they did not attribute it to a lack of relationship perhaps because they have been able to create more social connections than did the men. The women also conveyed that simply being with others does not in and of itself alleviate the feeling of being separate and apart.

Need for Guidelines for Practice and Further Research

The finding that participants lacked opportunities within their health care experience to discuss the impact of chronic disability on their sense of masculinity or femininity and welcomed opportunities to do so in the interviews suggests the need for formation of guidelines for practice regarding genderality and chronic disability. The following are suggested areas in which guidelines for practice should be developed; however, the development of such guidelines requires further research regarding genderality and traumatic brain injury (TBI).

Guidelines can be formulated to assist persons with TBI to organize a postinjury activity constellation that defines and supports gender identity and role in much of the same way they used their preinjury activity constellation. In particular, men whose preinjury activity constellation appears to be disrupted after injury may be assisted in adopting postinjury activities that facilitate personal feelings of masculinity instead of resuming preinjury activities that enhance a sense of diminished masculinity.

Another guideline should address opportunities to experience the developmental events and rites of the particular life stage at which persons experienced their injury because maintenance of preinjury activity constellations seems connected to the successful resolution of these experiences. Such opportunities may be necessary for the person with TBI to transition through and move beyond that stage. Additionally, new and equally meaningful rites of passage that signify personal growth in gender identification can be created if those rites common in the person’s culture (e.g., parenting, acquiring particular work roles, living alone in the community) cannot transpire (Krefting, 1989). Initiation into community life and celebration of important dates and accomplishments can serve as rites of passage or developmental signposts that remind persons with TBI that they have made personal growth during a particular life stage. Concurrently, those developmental stages through which persons have already transitioned must be respected. The feelings of lack of privacy and autonomy expressed by all four participants suggest that clinicians may not be recognizing clients as adults who have already advanced through specific developmental stages into adulthood.

Interestingly, three of the participants expected to acquire traditional family lifestyles. The other participant neither expected to marry nor have children; paradoxically, she is the only one who has been able to sustain a longstanding (6-year) relationship postinjury. However, here is not a traditional relationship—she wants neither to marry nor live with her male partner, who is of a different race than she. Instead, she describes her relationship as a monogamous, committed one in which both partners view each other as family, despite the lack of legal formalities. Just as gender roles can be satisfactorily expressed in nontraditional ways when the traditional means are no longer possible or personally fulfilling, guidelines can be developed to assist persons with TBI.
toward accepting nontraditional lifestyles when traditional ones are neither possible nor beneficial. ▲

Acknowledgments

We thank Jim Hinojosa, PhD, OTR/L, FAOTA, Dawn Leger, PhD, Margaret Kaplan, PhD, OTR/L, Chris Perets, MS, OTR/L, Ruth Levine Schemm, EdD, OTR/L, FAOTA, Judith Dicker Friedman, MA, OTR/L, Peggy Swarbrick, MA, OTR/L, Theresa Roth, MA, OTR/L, CHT, Tom Blash, PhD, and Scott Spreat, EdD, for guidance and review. We also thank the four participants who willingly shared part of their lives with us.

This article was completed as part of the first author's requirements for an advanced master's degree in occupational therapy at New York University, New York, New York.

References


**Coming in September**

- Presidential Address: Trends, Tools, and Technology
- Legitimizing Occupational Therapy's Knowledge
- An Analysis of Score Patterns of Children With Attention Disorders on the Sensory Integration and Praxis Tests
- Teaching Strategies for the Development of Clinical Reasoning

Turn to *AJOT* for the latest information on occupational therapy treatment modalities, aids and equipment, legal and social issues, education, and research.