



Psychosocial Aspects of Traumatic Spinal Cord Injury With Onset During Adolescence: A Qualitative Study

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Abstract

Background/Objective: Spinal cord injury (SCI) occurring during adolescence poses additional challenges because of the concurrent age-specific bio-psychosocial development. Full understanding of the psychosocial dimensions of rehabilitation requires exploration of the patient perspective. The objective of this study was to focus on psychosocial factors from the patient perspective in persons who had previously sustained a SCI during early and mid-adolescence (11–15 years of age).

Methods: Twenty-four of the 28 persons who had sustained a SCI in Sweden from 1985 to 1996 participated in the study. Semistructured interviews were made an average of 10 years after injury. Narratives were analyzed qualitatively according to content analysis.

Results: Parents and peers were found to have formed a crucial network. Parents frequently acted as advocates in interactions with health care providers, as supporters, and as containers of sorrow, frustration, and anger. Peers acted as promoters of activity and identity development. However, health care providers were perceived as not making sufficient use of this network.

Conclusions: Rehabilitation professionals might be encouraged to increase their knowledge of adolescence medicine to better meet the specific needs and demands of persons in this age group. It is further suggested that parents and peers be considered important partners in the joint rehabilitation effort.

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INTRODUCTION

Persons in early to mid-adolescence (ie, 10–17 years of age) experience major biological and psychosocial changes in transition from childhood to adulthood. Such changes include the maturation of sexuality and reproductive capacity, rapidly changing emotional needs, and a gradual shift from concrete to abstract reasoning capabilities. Psychologically, there is a strong striving for independence. Socially, peer acceptance plays an increasingly important role (1–4).

The World Health Organization (WHO) has identified clinically relevant features of adolescence in its *Orientation Program on Adolescent Health for Healthcare Providers*

(5). The program was created to improve and adapt health care services to young people's special needs and concerns. These factors are depicted in Table 1.

When major injury or illness occurs during adolescence, it poses unique challenges because of the concurrent physical and psychosocial development processes (6–8). Principles of psychosocial rehabilitation during adolescence are to some extent generic (ie, irrespective of diagnosis) (9). Literature on chronic illness during adolescence underscores the importance of giving attention to the biological, emotional, and social needs of the young person (7,10–15). Furthermore, the social context has been identified as a key factor that sometimes is not given enough attention when caring for young persons (16–21).

Spinal cord injury (SCI) affecting adolescents is a devastating and life-altering event (8). The importance of age-related issues and the need for developmentally

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Table 1. Characteristics of Phases of Adolescence (5)

Category of change	Early (10–13 to 14–15 years)	Middle (14–15 to 17 years)	Late (17–21 years, variable)
Growth	Secondary sexual characteristics appear Growth accelerates and reaches a peak	Secondary sexual characteristics advanced Growth slows down, approximately 95% of adult stature attained	Physically mature
Cognition	Concrete thinking Existential orientation Long-range implications of actions not perceived	Thinking is more abstract Capable of long-range thinking Reverts to concrete thinking when stressed	Established abstract thinking Future-oriented Perceives long-range options
Psychosocial	Preoccupied with rapid physical growth, body image, disrupted change	Re-establishes body image Preoccupation with fantasy and idealism Sense of all-powerfulness	Intellectual and functional identify established
Family	Defining boundaries of independence/dependence	Conflicts over control	Transposition of child–parent relationship to adult–adult relationships.
Peer group	Seeks affiliation to counter instability	Needs identification to affirm self image Peer group define behavioural code	Peer group recedes in favour of individual friendship
Sexuality	Self-exploration and evaluation	Preoccupation with romantic fantasy Testing ability to attract opposite sex	Forms stable relationships Mutuality and reciprocity Plans for future

based care for SCI has been elaborated in several articles and studies (8,22–31).

Previous research has mainly focused on adjustment later in life (32–35) and on the transition to adult care settings (36–38), rather than on the primary rehabilitation process and the early readjustment thereafter. Few studies have specifically focused on psychosocial aspects of care from the perspective of the young persons themselves (13,14,18–20,39).

Little is known about the patient or first-person perspective of sustaining a SCI during adolescence. Our main purpose was to explore and describe adolescent SCI from that perspective. This motivated the choice of a qualitative study design. Specifically, we aimed at exploring psychosocial factors deemed as facilitating and impeding the rehabilitation process, respectively.

METHODS

Qualitative research is exploratory and inductive in nature. This approach allows more in-depth and comprehensive information. Respondents express their thoughts and experiences in their own words rather than by predefined response alternatives (40). The “experienced adolescent” has been found to be imaginative in suggesting ideas and solutions, many of which may not be obvious to health care professionals (12). Thus, individual narratives were obtained by semistructured open-ended personal interviews. Narratives were analyzed according to content analysis (ie, a well-established

method of identifying, coding, and categorizing patterns in qualitative data) (40).

Interviewees

In an earlier incidence study, we identified persons who, at the age of 0 to 15 years, had sustained a SCI in Sweden in the period from 1985 through 1996. Data from population registers, County Habilitation Centers, and from several informal sources were used (41). A total of 37 persons who survived at least 2 years after injury were thus identified. This group was made up of the total national prevalence population of pediatric-onset SCI during the time surveyed.

Twenty-eight of these 37 persons were 11 to 15 years of age at the time of injury and were contacted for inclusion in this study. One man was excluded because of severe comorbid mental retardation, 1 man had died, and 2 men declined participation, leaving 24 persons to participate in this study. Nine persons had a complete lesion according to American Spinal Injury Association (ASIA) standards (42). Fifteen persons were wheelchair users. Twenty-two persons had been treated in adult care settings: 19 in SCI units, and 3 in orthopedic departments. Five persons had subsequently been referred to Habilitation Centers for follow-up. Further descriptors are depicted in Table 2.

Data Collection

Interviews lasted 60 to 90 minutes and were conducted by 1 of the authors (M.A.) at the venue of choice of the

Table 2. Interviewee Descriptors by Age at Injury, Age at Interview, Sex, Level of Injury, and Etiology (n = 242)

Descriptors	
Age at injury (years)	
Average age, total group	14.1 ± 4.0 (range, 11–15)
Male	14.5 ± 0.5 (range, 14–15)
Female	13.5 ± 1.1 (range, 11–15)
Age at interview (years)	
Average age	24.2 ± 4.0 (range, 17–30)
Sex (n)	
Male	14
Female	10
Level of injury (n)	
Tetraplegia	9
Paraplegia	15
Etiology (n)	
Traffic accidents	10
Falls	1
Sports	11
Surgery	2

interviewee, typically his/her home. The recorded interviews were transcribed verbatim. Interviews were performed during 2002 to 2004, an average of 10 years (range, 4–15 years) after injury. Three themes were addressed: (a) factors felt to have been beneficial to the care and rehabilitation process; (b) factors felt to have been impeding the care and rehabilitation process; (c) suggestions for improvement of care and rehabilitation process. The dialogue was expanded by use of further open-ended questions, eg, “What do you mean by that?”; “Can you describe a little bit more about this?”; “What did you think about that?”

Data Analysis

Transcripts were analyzed by content analysis (40). This method is made up of a stepwise process where subcategories, categories, and core categories are identified inductively. It aims at revealing distinct themes within data: common patterns, topics, and categories emerge. Observed repetitive sequences, or regularities, allow for systematization and classification (40).

Narrative analysis was made in 5 steps, identifying manifest messages from the recollections (40): all tapes and transcripts were listened to and read iteratively for an overall understanding (43); a preliminary coding of each transcript was made, highlighting sentences that captured key concepts; the text was read through several

times and so-called meaning units were identified (each such unit is comprised of words, sentences or paragraphs that cover aspects that are connected through content and context) (44); units were grouped into thematic subcategories (subcategories were further aggregated into categories and core categories) (40); and the process was iterated until no new patterns or themes emerged.

To assess concordance within and between narratives, frequency counts of the categorical aggregates were obtained. To further clarify categorical content, verbatim citations illustrative of each subcategory were selected. They are presented throughout the Results section of this paper.

Data Validation

Categories were subsequently validated by a consensus strategy, whereby the authors discussed and re-examined coding discrepancies to reach consistency.

Ethical Considerations

The study was approved by the regional research ethics committee. Interviewees gave informed consent and were granted confidentiality. Individual interviewees would not be identifiable in the subsequent report. Interviewees were informed that they could terminate their participation in the study at any time. The interviewer (MA) was not involved in the medical care of any interviewee at any time.

RESULTS

Seven core categories were identified: (a) the young person, (b) the family, (c) peers, (d) romantic partners, (e) other significant adults, (f) school, and (g) health care professionals. Specific actions within core categories were made up of a number of psychosocially relevant subcategories. These are summarized in Tables 3 and 4 and will be elaborated on in more detail in the following section.

The Young Person

Personality. The interviewee’s ability to deal with the consequences of injury was reflected in statements, such as “stubborn until you get what you want,” “pigheadedness,” “having a lot of guts,” and “being contrary.” A positive self-image, an optimistic outlook, and an ability to see possibilities rather than obstacles (15/24) were important assets. Seven of 24 interviewees recalled reacting with shame, isolation, or docility. Anger toward parents and health care professionals occurred frequently (13/24), and some interviewees described themselves as having been “difficult,” “obstinate,” and “rebellious.” Some (7/24) reacted by trying to gain control over their environment, eg, by checking medical procedures in detail, showing distrust for staff, becoming picky with food, even developing eating disorders: “I think I lost about 10 kilos during that period. . . . There must be something I can make my own decisions about! I think—I think that’s why I did it. You have to be able to control

Table 3. Core Categories, Categories, and Subcategories Facilitating or Impeding Rehabilitation and Early Readjustment After SCI

Core Category	Category	Subcategories
The young person	Personality characteristics	Facilitators: energy/will, optimism, self-confidence Impeders: shame, isolation, anger, anxiety, fear—distrust of staff, docility, obsessive-compulsive behavior (eg, eating disorders, obsession with medical procedures)
	Growth and pubertal development	Impeder: negative appreciation of appearance
	Impact of injury	Facilitator: experience of emotional growth Impeder: physical impairments regarding mobility, bodily functions, appearance, sexuality, identity, integrity
Family	Parents	Facilitators: spokespeople; advocates for the adolescents; pep talk—moral support; “punching bags” Impeders: parents as caregiver, violating integrity, overinvolvement
	Siblings	Facilitators: pep talk—moral support, older sibling discussing sexuality Impeder: sibling as caregiver
Peers		Facilitators: connectedness and continuity, identity promotion, activity promotion Impeders: prejudices, noninvolvement, long hospitalization, long distances from home, awkward visiting hours, lack of knowledge and understanding
Romantic partner*		Facilitator: intimacy Impeders: shame, isolation, breaking up
Other significant adults		Facilitators: pep talk—moral support, role models for identity development
School	Teachers	
	Classmates	Facilitators: involvement, connectedness, and continuity; identity promotion Impeders: long hospitalization, lack of knowledge
Health care professionals	Knowledge	Facilitators: biopsychosocial development in adolescence, age-appropriate demands and challenges, adolescents sexual development, family interaction during adolescence, impact of SCI on adolescent and on family function, importance of peers and significant others
	Attitudes	Facilitators: being empathic without being intrusive, respecting integrity and autonomy of the patient, respecting adolescents’ sensitivity about naked body and bodily functions, providing flexibility and extra time when needed, respecting parents’ expertise and parenting style, recognizing peers and romantic partners as instrumental for age-appropriate development Impeders: feeling sorry for the patient, seeing parents as a burden rather than as a resource, excluding the family
	Skills	Facilitators: providing concrete discussions with checklists on relevant tasks; being able to discuss sexuality in an age-appropriate way; providing age-appropriate recreational activities, if possible with age-mates; balancing independence vs assistance; providing family support; involving the family in an age-appropriate way; providing schooling in hospital with individual tutoring; facilitating school re-entry process Impeders: talking with parents over the patient’s head, inability to cope with emotional reactions of the patient, not involving the patient in age-appropriate decisions (ie, food choices, visiting hours), working according to protocols without concern for patients’ actual needs

*Boyfriend or girlfriend.

Table 4. Frequencies of Core Categories Recalled by the Interviewees as Having Promoted the Rehabilitation and Early Readjustment After SCI

Core Categories of Recalled Importance to the Rehabilitation and Early Readjustment to Daily Life	Number of Interviewees (n = 24)
The young person	15
Family	20
Peers	24
Romantic partner	2
Other significant adults	12
School	6
Health care professionals	12

something yourself and decide about it, don't you think?" (female, 13 years at injury, interviewed 4 years later).

Growth and Pubertal Development. No direct comments relating to pubertal development were found. However, one interviewee indirectly related to this issue: "I thought it was good to be able to stand up (on the tilt table) and have a quick look at my body to try to get an idea of what it was like. You miss out on the daily routines of getting up and taking a shower in the morning, washing yourself, and getting dressed. There is no contact with your body at any time; your body doesn't exist in the intensive care because you're nursed so much. I didn't feel my body then either. It was pretty weird when I started looking down at my body ... Jesus, I've got some hair on my stomach kind of thing, I've never seen that before. You were always being tucked in with loads of blankets" (male, 15 years at injury, interviewed 10 years later).

Seven of 24 interviewees had felt physically unattractive, eg, by having a bad hairdo, wearing ugly hospital clothes, looking stupid walking with aids, or by not being able to wear tight jeans any more.

Impact of Injury. All interviewees (24/24) related to difficulties caused by neurologic impairment, eg, trying to master activities of daily living (ADL) techniques, experiencing altered or lost bodily function, eg, bladder and bowel control, as well as having to endure nursing procedures violating personal physical space. "Putting catheters in ... I thought that was so gross. I refused to do it, I didn't want to touch myself or see myself down there. When I was staying in the hospital and wanted to go to the bathroom and pressed the buzzer, I hated it when a guy came. I think it's really degrading" (female, 13 years at injury, interviewed 10 years later).

Fifteen of 24 interviewees reported that they hadn't been adequately informed about sexual function: "It was different back in 1985. I was full of questions but never got any answers" (male, 15 years at injury, interviewed 15 years later). "Of course it (sexual issues) is something

you think about when you're 13, I did anyway. It's obviously a big deal when you're that age. You're just starting to date guys ..." (female, 13 years at injury, interviewed 10 years later).

In contrast to the frequent reports of various negative consequences of injury, some interviewees (8/24) attributed certain positive effects: "My self-confidence grew in some ways. I went through so much that I knew subconsciously that I could handle a lot of things and so I think I calmed down a bit. Yeah, I became more mature and maybe more myself" (male, 14 years at injury, interviewed 7 years later). "I'd love not to have this disability ... but I don't regret having the accident as such, since it has had such a (positive) impact on me" (female, 13 years at injury, interviewed 4 years later).

One interviewee expressed grief over a "lost adolescence": "I feel like I skipped some years between 14 and 18 years. Others could test different things; I had to be grown up fast; to be an adult at once" (female, 14 years at injury, interviewed 12 years later).

In summary, having a "fighting spirit" was frequently seen as a beneficial factor. Outwardly directed anger and aggression was common. Psychosocial problems related to physical disability were frequently recalled but also comments reflecting resilience.

Family

Parents. Parents were typically (20/24) recalled as having played a key role in helping the young person cope with the injury.

Parents acted as spokespeople and advocates (7/24) for their child in communications with staff. Parents also acted as trusted supporters (13/24), as discussion partners, and as "pep talkers": "My father told me: Don't give up hope until you know the facts for sure. That made me able to struggle on" (male, 15 years at injury, interviewed 10 years later). "But (my father) has always said: you'll find someone who will like you and love you and have a family with you and you'll be very happy and have children and everything. But I'm like: nah, that won't happen to me, and you know that too. I said: Nobody will like me. He answered: Don't say that! He kinda saw all the good things in me, which I, like, couldn't see then" (female, 11 years at injury, interviewed 11 years later).

Parents "absorbed" the sorrow, frustration, and anger that interviewees hesitated to share with staff (10/24): "I think I turned a lot of this anger and frustration against my parents. They got more than their fair share. That's why I fell out so badly with my mom. There were periods when I couldn't even talk to her, didn't want her!! It was easier to take it out on my parents or some other relative or my friends than to take it out on the staff" (male, 15 years at injury, interviewed 14 years later).

One male interviewee reported to have become irritated when his mother repeatedly pushed him to follow the instructions of the physical therapist: "And then mom comes and says, "Look, you're going to ride

the bike. I've spoken to the physical therapist now and she says you have to ride the bike so now you're going to ride the bike." Like—ride the f***** bike yourself!" (male, 15 years at injury, interviewed 14 years later).

Eight of 24 parents took on, or were given, the role as caregivers, something that could be for better or worse: "They (the staff) dumped a lot of stuff like that (catheterization) on them (my parents) then. They took responsibility so that I could come home on visits and stuff. So they just learned how to do it" (female, 13 years at injury, interviewed 10 years later).

"Yeah, it feels really stupid, it felt really stupid with my mom helping me shower and stuff. But Mom told me that I shouldn't find it embarrassing because she did it when I was a baby . . . But it was really embarrassing, actually" (female, 15 years at injury, interviewed 4 years later).

The balance between adequate parental support vs overinvolvement was commented on by one interviewee: "When something like this happens in a family, you're so emotionally involved in each other's lives. That's what's happened here, so we have a problem. We're too close to each other, we interfere in each other's lives, it gets to be too much" (female, 13 years at injury, interviewed 10 years later).

In summary, parents played a key role. Frequently, hospital staff was perceived to have been insensitive in accommodating the important role of the parents. The role of parents as caregivers was double-edged.

Siblings. Overall, there was little mention of siblings in the narratives. However, 2 interviewees told of older siblings who helped out with daily care, moral support, or advice in sexual issues: "I don't know what I would have done without my sister. She told me about sex" (female, 13 years at injury, interviewed 10 years later).

Peers. All (24/24) interviewees expressed that peers and friends had played a key role. One man reported that he was very depressed, isolated himself, and refused to talk with the staff. When one of his old friends eventually visited him, this had a very positive impact: "When he entered, I just said "Hi, how are you" and suddenly I became my old self again" (male, 15 years at injury, interviewed 13 years later).

Fifteen of 24 narratives gave peers credit for having put them "back on the track": "Many times, I felt that I just wanted to stay at home, but they (the friends) more or less carried and dragged me and the wheelchair out of the house. This, to have my friends around, was probably what made me come back again. They didn't let me sit at home; they basically forced me to get moving. This was the best of all, and it had to be done" (male, 15 years at injury, interviewed 15 years later).

Occasionally (4/24), feelings of shame led to isolation from peers: "I distanced myself from my friends, 'cause I didn't think I could do very much and that kind of thing. And like be seen in a wheelchair. I've always been the tough little girl, and then all of a sudden I became like the

complete opposite" (female, 15 years at injury, interviewed 4 years later).

Eleven of 24 interviewees commented that they subsequently found a new circle of friends after injury. Twelve of 24 interviewees reported having lost contact with many of their peers after injury. Several reasons for this were given, such as spending long periods as an in-patient, traveling long distances from the hospital to the home environment, and restricted visiting hours. Five of 24 interviewees thought that their peers' lack of knowledge about SCI made them reluctant to maintain contact.

In summary, peers were of prime importance. Many interviewees apparently lost contact with their old circle of friends but managed to find a new social context.

Romantic Partner

Only 3 interviewees had a romantic partner (ie, boyfriend or girlfriend) at the time of injury. Two interviewees felt that their boyfriends were very important for emotional support and intimacy, even if time together was restricted, eg, by visiting hours: "I had a boyfriend at the time and I could talk about anything with him. I talked to him over the telephone and then everything went much better. There wasn't anyone else I could talk to. He wasn't allowed to sleep over. They had visiting hours, you know, but people could stay until 8 or 9 anyway. So the phone bill was pretty expensive" (female, 15 years at injury, interviewed 4 years later). One male interviewee ended his relationship, and explained this as follows: "I had a girlfriend when I was 15. I didn't want her to come and visit me. I felt so immobilized. It is a typical reaction that you isolate yourself in desperation instead" (male, 15 years at injury, interviewed 10 years later).

Other Significant Adults

Twelve of 24 interviewees mentioned that persons outside their core family had acted as support and provided pep talk. These were friends of the family, coaches, or health care professionals who continued this relationship after discharge from hospital. "My coach came almost every day. He was totally amazing. Every day he brought along some of my teammates. He was always positive . . . We're still in touch" (male, 14 years at injury, interviewed 9 years later).

Fourteen of 24 interviewees reported that they had been introduced to patient's organizations, role models, and training camps at an early stage. Reactions to this were mixed. The response was unfavorable if the role model was too old or had a different kind of disability. Male interviewees, in particular, reported benefits from being introduced to role models and praised them and camp attendance as being very important.

The importance of a role model could be significant: "She had two children then. She was around 38 (the role model) . . . She was a really open and very happy person. "Now I'm going to the bathroom and I'll be really quick" . . . amazing . . . she really showed what an easy life she had, nothing's a problem and she's like "I'm just going

out for a while” and then she just went out to like get something. One kid hopped on by himself and she just rolled off you know, and “we don’t need to take the wheelchair” and just backed out the car, and I just, really cool, and then I thought: Can it really be like this? ...” (female, 11 years at injury interviewed 11 years later).

Psychologic benefits of camp visits were sometimes substantial: “The camp with other people with spinal cord injuries was a great kick. Dad said that when I came back home from camp he recognized me again and got very happy—I was finally back. I had found myself again” (male, 15 years at injury, interviewed 10 years later).

In summary, persons other than family members were often helpful in the rehabilitation process. Role models could be very important. Matching age and disability were recalled by some interviewees as necessary.

School Network

The social network at school, including teachers and classmates, was mentioned by 6 of 24 interviewees as being important, and return to school was vividly recollected. The importance of staying in touch with teachers and classmates was emphasized.

The way reintroduction to school occurred was of importance, in particular, allowing for the natural curiosity of peers and feeling in charge of the situation: “I told them (my classmates) what had happened and I received a lot of respect because of that. They thought it was exciting ... Everyone asked me questions about the injury. I think this helped ...” (male, 15 years at injury, interviewed 15 years later).

Twenty-one of 24 interviewees returned to their previous school, but 10/24 did not graduate with their class. In 1 case, architectural barriers precluded return to the previous school. Two interviewees mentioned that the long in-patient rehabilitation stay had complicated subsequent return to school, and another 2 interviewees felt that there was a lack of coordination between the rehabilitation facility and the school.

Health Care Professionals

Health care professionals were recalled in a positive way by 12 of 24 interviewees. Most comments reflected the importance of getting enough time; of being listened to; and of being allowed to actively participate in decision-making.

Eight of 24 interviewees emphasized the importance of the personality of the individual caregiver: “What’s good (in rehabilitation) is the people; you can’t ever get away from the fact that the people that work with this—they are the ones that made it good” (female, 14 years at injury, interviewed 11 years later).

Six of 24 interviewees complained that staff seemed to have lacked experience working with teenagers. One illustrative comment was: “They’d never had a stubborn 13-year-old with a temper before, they didn’t know how to handle it” (female, 13 years at injury, interviewed 13 years later).

Positive factors, on the other hand, included the ability to support empowerment and peer involvement: “The physical therapist was great (because she said): “Now we’re going to solve the problem of how you can get out of bed by yourself, how can we solve that?” (male, 15 years at injury, interviewed 10 years later).

“I got permission to have a TV and video and I put up loads of posters all over the room, and I got to keep a single-bed room the whole time I was there and I could have people come and sleep over. We watched videos and ate popcorn. I still remember my friends really well; I even remember which films we watched. It was so cool that everyone lived nearby and could visit. I can’t remember ever lying there bored” (female, 14 years at injury, interviewed 14 years later).

Provision of clear rules of conduct and a straight-talking attitude was also perceived as being helpful: “I was a nightmare patient for over 6 months ... was a real pain in the ass, causing trouble the whole f***** time, yelling at everyone and being overall unpleasant. I thought everyone was stupid, so they all tried to make a fuss of me and stuff. “Hello, honey, how are you today?” What the hell do you care? It’s just your f***** job to ask. The only ones I had any respect for were the ones who fought back, “Jesus, what a b***** you are today. If you don’t have anything nice to say don’t bother opening your mouth.” I could respect them because I felt they were for real” (female, 14 years at injury, interviewed 11 years later).

Eight of 24 narratives reflected conflicts between parents and staff. Staff, in these cases, was felt to regard parents as a burden rather than a resource.

Fourteen of 24 interviewees reported having been “forced” by staff to see a psychologist for crisis intervention. Some interviewees thought that counseling by the regular staff would have been preferable. “What should I talk about; I don’t want to talk. I don’t know her (the therapist) and it’s demanding, they force themselves on you ... Here she comes because it’s on the schedule” (female, 11 years at injury, interviewed 11 years later). “I didn’t like her (the therapist), even if she was very cheerful, and I couldn’t talk to her. I could talk about what had happened that day, but nothing about other things. Even if I had a lot to say ...” (female, 13 years at injury, interviewed 4 years later).

In summary, staff was generally appreciated for being knowledgeable, concrete, structured, and empathetic. However, there were also frequent reports of clashes between staff and patients, as well as negative memories of having been “forced” to meet with a psychologist.

DISCUSSION

To our knowledge, this is the first qualitative study of the psychosocial needs of young adolescents sustaining a SCI, focusing on the views and experiences of the young persons themselves. The 24 interviewees in this study constitute almost all persons who sustained a SCI in

Sweden during 1985 to 1996 in their early or mid-adolescence. The findings illuminate the importance of the personal strengths of the young persons themselves, as well as that of their social network in helping them through rehabilitation and early readjustment to daily life.

Parents and peers in particular were found to play a crucial role. Parents were frequently recalled as acting as advocates in interactions with health care providers. They were also recalled as supporters and as absorbers of sorrow, frustration, and anger that the interviewees hesitated to share with staff. Peers played a key role as promoters of activity and identity development. However, health care providers were not perceived as promoting involvement of this network.

Apart from the inherent and inevitable limitations of a qualitative methodology, the most obvious limitation of this study is perhaps the recall bias imposed by the years gone by from injury to interview. However, recollections as such are of significance, regardless of their "objective" validity. Furthermore, the results reflect experiences consequential to the Swedish health care system of 10 to 20 years ago. According to a recent study from our group regarding pediatric SCI care in Europe (45), however, this health care system seem to differ little from what is typically the case in Sweden and parts of Europe today.

No attempts were made to relate the recollections of the early rehabilitation process to the present quality of life of the interviewees. It was felt that too many confounding factors, unrelated to the initial events, would have influenced the findings as to make them meaningful in this context.

Specialized SCI units have a high level of medical competence regarding the injury and its consequences in the view of the informants. However, insufficient biopsychosocial management as it pertains to young patients was reflected in this study. Because pediatric SCI remains a rare disorder in Sweden and elsewhere, young persons are still (41) typically treated in adult settings. It is doubtful, however, whether age-specific knowledge and skills are as yet incorporated in clinical management. During early adolescence, the young person is typically concerned with changes in body and body image (1,3,46). There is uncertainty about appearance and attractiveness, preoccupation with self, and an increased interest in sexuality. A young person with SCI may face these challenges in a situation where the injury has imposed drastic physical changes. In addition, a need for assistance with intimate body functions puts further stress on this issue, something that was reflected in the narratives. For health care professionals treating adolescents with SCI, it is thus important to understand and respect the need for privacy and acknowledge the sensitive issue of the naked body.

The expressed lack of information regarding sexual issues is notable, because sexuality is of central concern

during adolescence and because SCI typically impairs sexual function. This issue has been highlighted in a previous Swedish study (47). Specifically, adolescents with SCI may benefit from having contact with other persons with SCI who can facilitate discussions and describe real-life experiences regarding sexuality and reproduction (8).

There were many examples in the narratives that communication with persons in early adolescence typically needs to be more distinct, concrete, and structured than what is typically necessary when addressing adults. Furthermore, there were many instances where the young person's inclination to act out led to conflicts with parents and staff. Behavioral expressions of distress, such as denial, depression, regression, anger, and withdrawal, are likewise common in chronic illness during adolescence and should as a rule be seen as an adaptive psychologic response to injury (7). It needs to be handled in an age-appropriate way (6). Initial refusal to comply with treatment may also often be regarded as developmentally appropriate in adolescence (12). Routine referral to a psychologist, as recalled in this study, may be counterproductive.

Contrary to what may be explicitly expressed, young persons typically do seek and need support and guidance from their parents (48). This was reflected in many interviews. These findings are in accordance with previous studies of young persons with chronic illness (16–21). A more active involvement of parents in the rehabilitation process and provision of support for them when needed might prevent many conflicts and misunderstandings (18). Typically, parents and the young person may become involved in power struggles about who should be in control of the treatment and rehabilitation process (7,22). Improved outcomes have been shown when parents are able to be supportive and maintain an appropriate balance between medical management requirements and the young person's developmental needs (7,16). However, as was reflected in our results, it is questionable from a developmental point of view if parents should take on a role as personal assistants, especially regarding intimate body functions.

The importance of connectedness with peers is emphasized in the literature on young persons with chronic illness (1–3,11,12,16–21,49). This was also reflected in many narratives in this study. All interviewees mentioned the positive impact of peer contact.

The key part played by role models in the rehabilitation of patients with SCI, both in promoting an active lifestyle and in helping to establish a new identity, has been proposed previously (50,51). Importantly, as was reflected in this study, the role model seems to achieve credibility by matching the patient with regard to age, sex, and type of disease.

Early school involvement has been reported as successful in facilitating the transition from rehabilitation to school (52–54). Only 6 interviewees in this study

provided specific and strong comments on school re-entry as having been important for readjustment.

CONCLUSIONS

Rehabilitation of adolescents with SCI might be improved by encouraging staff to acquire knowledge in adolescent medicine to better understand the specific needs and demands of persons of this age. Because parents and peers seem to play an important role, it is suggested that their active participation is facilitated in the joint rehabilitation effort of the young person with a SCI.

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