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ORIGINAL ARTICLE

Rehabilitation and future participation of youth following spinal cord injury: caregiver perspectives

LA House[1,2], HF Russell[1], EH Kelly[3], A Gerson[3] and LC Vogel[3,4]

[1]Shriners Hospitals for Children, Philadelphia, PA, USA; [2]Millersville University, Center for Counseling and Human Development, Lancaster, PA, USA; [3]Shriners Hospitals for Children, Chicago, IL, USA and [4]Rush Medical College, Chicago, IL, USA

Study design: Cross-sectional survey.
Objectives: To examine caregivers' perspectives on the effectiveness of rehabilitative support experienced by youth with spinal cord injury (SCI) during acute rehabilitation and after community reintegration in terms of their community participation.
Setting: Data collection took place at the three Shriners SCI hospitals: Chicago, Philadelphia, and Northern California.
Methods: A total of 132 primary caregivers of youth with SCI completed a survey on what their child had experienced during and after rehabilitation to enhance their community participation.
Results: Caregivers found technical support from staff (41%), motivation and encouragement from staff (25%), and education (17%) to be the most important factors during rehabilitation for encouraging their child's future participation in school or community activities. Caregivers found involvement in activities (30%), personal resilience (22%) and interactions with others with disabilities (13%) to be important experiences since rehabilitation in terms of their child's participation in school and community activities. Caregivers who responded that something they experienced during rehabilitation was helpful to participation had children who had been injured longer and who were older at time of injury. In addition, caregivers who reported that something they have experienced since their child's rehabilitation has been helpful in terms of participation also had children who were older at time of injury.
Conclusions: Findings from this study can be used to help professionals tailor rehabilitation programs to better meet the needs of youth with SCI and their families, thereby increasing chances of successful reintegration back into their communities.

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Introduction

Acquiring a spinal cord injury (SCI) as a child or adolescent has tremendous emotional, social and physical consequences for the injured youth, their family, siblings and peers.[1] An important resource during this difficult time, the rehabilitation process can be critical in enhancing recovery and promoting better functional outcomes. During initial inpatient rehabilitation a team of skilled professionals help newly injured youth develop the skills needed to maintain physical and emotional health, achieve functional independence, and prepare for future activities and relationships. For older youth, issues related to body image, sexuality and future career goals are an important focus.[2] Once youth reintegrate into their communities, outpatient rehabilitation continues to provide youth with the skills and resources needed to function independently and engage in community activities. This rehabilitation process must be multifaceted, accounting for the medical and physical needs of the youth with SCI, in addition to developmental and psychosocial issues.

One critical outcome for youth with SCI is community participation. For all children and adolescents, participating in community activities is important for physical and psychosocial development, as well as for learning social and coping skills.[3,4] Participation is a multidimensional concept that includes engaging in life activities and individuals' motivation to participate in interactions within their social and physical environments.[5] Although the exact nature of participation changes with age, both young children and adolescents can engage in community activities, which may include numerous events such as going to playgrounds, family or peer parties, playing or attending

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Correspondence: Dr LA House, Center for Counseling and Human Development, Millersville University, PO Box 1002, Lyle Hall, 3rd Floor, Millersville, PA 17551-0302, USA.
E-mail: Lisa.House@millersville.edu

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sports events and shopping. Previous studies suggest that youth with physical disabilities report higher levels of involvement in sedentary activities and have lower rates of community participation than both able-bodied youth and their peers with other disabilities such as vision, hearing and neurological impairments.[6–8]

Rehabilitation after acquiring an SCI is instrumental yet few studies have qualitatively examined the experience or its impact on future participation. Existing literature has primarily focused on caregiver evaluations of rehabilitation programs for individuals with cerebral palsy and traumatic brain injuries and has found factors such as service quality, functional improvements and information about community services to influence whether caregivers viewed rehabilitation as helpful.[9,10] Although much can be learned from these studies of families of youth with other types of disabilities, it is also important to understand the unique disease-specific consequences experienced by youth and their families. Specific research on the rehabilitation needs of youth with SCI is essential to making sure their psychosocial and physical needs are being met so that they can successfully transition into independent and productive adults.[11]

The goal of this study was to provide insight into rehabilitation factors that contribute to increased participation for children and adolescents with SCI, with the intent of identifying how rehabilitation might best address these issues and be more effective in meeting the needs of youth with SCI. This study examined caregiver reports of what has been perceived as effective in terms of facilitating their child's participation, both during and after rehabilitation. In addition, the relationship between rehabilitation experiences and demographic and injury-related variables was assessed to identify subgroup differences. This information is critical to the design of effective interventions.

Materials and methods

Procedure

This study is part of a longitudinal multisite research project. Data collection took place at the three SCI programs within Shriners Hospitals for Children, in Chicago Philadelphia and Northern California. Youth with SCI who were 18 years old or younger and had been injured at least 1 year were recruited along with their self-identified primary caregivers. After obtaining written informed consent and assent, study questionnaires were administered in person during inpatient hospitalizations or outpatient clinic visits. It should be noted that youth may or may not have completed their rehabilitation within a Shriners Hospital. The project secured approval from the institutional review boards at all three hospitals and we certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of the research.

Measures

The present study analyzed data collected using a study-specific questionnaire completed by caregivers that included questions on youth and caregiver demographics, as well as two open-ended questions about the rehabilitation process: 'Was there anything that you or your child experienced during rehabilitation that has helped encourage your child's participation in school or community activities?' and 'Is there anything that you or your child have experienced since rehabilitation that helped encourage your child's participation in school and community activities?' A review of patients' medical records was also conducted to gather information about level and date of injury.

Data analyses

This study used a mixed-method approach, primarily consisting of qualitative analyses. Specifically, content analysis was used, which involved subjective interpretation of the content of the responses to the open-ended questions through a systematic coding and classification process.[12] After the data were collected, core categories and subcategories were identified collaboratively by three researchers. Next, the three researchers independently assigned preliminary codes to participant responses. Finally, these researchers discussed and reexamined coding discrepancies to reach a level of consistency. Caregivers often indicated more than one answer to each question so some responses fell into multiple categories.

Descriptive statistics were used to summarize the demographic characteristics of the sample. Depending on whether the study variable was categorical or continuous, χ^2-analyses or *t*-tests were conducted for each open-ended question to determine if there were differences between caregivers who reported 'yes' versus 'no' in response to whether something during or since rehabilitation had been helpful.

Results

Participants

Participants consisted of 132 children and adolescents with SCI and their caregivers. Of them, 52% were male, 75% had paraplegia, mean age was 5.8 years at injury and 11.3 years at interview, and motor vehicle crashes were the most common injury etiology (Table 1).

Responders versus nonresponders

To examine differences between caregivers who did and did not respond to each of the open-ended questions, χ^2-analyses and *t*-tests were conducted. A comparison of demographic information provided on the questionnaire revealed that there were no significant differences between responders and nonresponders in terms of patient sex, current age, age at injury, and level of injury, or caregiver sex, marital status and relation to patient for either question.

Caregivers of young children versus caregivers of adolescents

χ^2-Test and *t*-test analyses were performed to examine whether differences existed between caregivers of younger children and caregivers of adolescents. Participants were divided into two categories based on their age at the time of the interview: younger children, age 1–12 ($n = 73$) and adolescents, age 13–18 years ($n = 59$). The two age groups were compared on all demographic variables and there were no significant findings.

Table 1 Participant characteristics ($n = 132$)

Demographic variable	*Percentage*	*Mean/s.d./range*
Sex (n = 132)		
Male	52	
Female	48	
Caregiver sex (n = 132)		
Male	14	
Female	86	
Caregiver relation to patient (n = 132)		
Mother	77	
Stepmother	2	
Grandmother	6	
Father	14	
Other	1	
Age at interview ($n = 132$)		11.3 years (s.d. = 4.3); 1–18
Time since injury[a] ($n = 130$)		5.8 years (s.d. = 4.3); 1–17
Patient age at injury ($n = 130$)		5.35 years (s.d. = 5.2); 1–17
Race (n = 132)		
Caucasian	66	
Latino	20	
African-American	3	
American Indian	3	
Asian	2	
Other	6	
Type of community (n = 132)		
Rural/Small town	58	
Urban/City	42	
Level of injury (n = 126)[b]		
Tetraplegia	25	
Paraplegia	75	
Etiology (n = 129)[c]		
Motor vehicle accidents	50	
Nontraumatic medical	33	
Violence	8	
Sports	5	
Fall/Flying object	2	
Other/Unknown	2	

[a] At the time of data analysis, data were not available for 2 patients in terms of time since injury and age at the time of injury.
[b] At the time of data analysis, data were not available for 6 patients in terms of level of injury.
[c] At the time of data analysis, data were not available for 3 patients in terms of cause of injury.

A comparison of answers to each of the two open-ended questions was also conducted. The only significant finding was that caregivers of adolescents were more likely to report that interaction with others with disabilities was helpful during rehabilitation ($\chi^2 = 5.28$, $P = 0.042$).

What was helpful during rehabilitation?

The first question asked: 'Was there anything that you or your child experienced during rehabilitation that has helped encourage your child's participation in school or community activities?' Of 132 caregivers, 102 (77%) answered this question. Of those who answered, 58% stated 'yes' ($n = 59$) and 42% said 'no' ($n = 43$). Seven core categories and eight subcategories were identified for responses to this question. The remaining percentages in this section were derived using data from those who answered 'yes' to this question ($n = 59$). The top five categories are addressed in the text.

The most endorsed category was technical support from staff (for example, teaching caregivers and patients how to use ambulation aids or devices), with 41% of caregivers reporting this was helpful during rehabilitation. One caregiver reported 'We received leg braces here and it was excited for her to learn how to use them,' whereas another stated it was helpful 'for him to get his wheelchair and learn how to maneuver around in it'. The second most endorsed category (25%) was motivation and encouragement from staff. For example, one caregiver stated 'Her physical therapist during her initial rehab was fantastic. He motivated her and made the process so much easier.' In addition, 17% of caregivers reported education, of which the majority stated education about their child's injury. One caregiver who talked about education regarding advocacy stated, 'Most of our rehab staff have encouraged fighting for accessibility and give us resources for wheelchair activities.' Twelve percent of caregivers also reported family support and interactions with others with disabilities during rehabilitation. For instance, one caregiver mentioned: 'Meeting other students that are in similar conditions and getting their perspectives of life' as being particularly helpful.

What has been helpful since rehabilitation?

The second question asked: 'Is there anything that you or your child have experienced since rehabilitation that helped encourage your child's participation in school and community activities?' Of the 94 caregivers who answered this question (71% of participants), 46 (49%) reported 'yes' and 48 (51%) said 'no'. For this question, eight core categories and six subcategories were identified. The remaining percentages in this section were derived using data from those who answered 'yes' to this question ($n = 46$). The top five categories are addressed in the text.

The most endorsed category was involvement in activities, as 30% of caregivers stated that past participation was key to future participation, with the majority of caregivers specifically mentioning community activities. For instance, one caregiver mentioned as helpful that his or her child was: 'Playing wheelchair basketball once a week, swimming twice a week at the YMCA, and playing t-ball in the summer.' The second most prevalent response had to do with personal resilience on the part of the child, reported by 22% of caregivers. For example one caregiver mentioned: 'My child tries to adapt himself to everything that the other kids do.' Next, 13% of caregivers said interactions with others with disabilities were important to their child's participation. Examples of comments included: 'Meeting other families with children with disabilities online and at clinic appointments'; and 'Being exposed to situations where there were adults with physical disabilities that are successful both in private lives and professional.' In addition, 13% of caregivers reported general encouragement as being important to participation, with half of the caregivers specifically mentioning support and encouragement from school. Mentioned less frequently but still noteworthy, 10% of caregivers specifically cited peer support as helping to encourage their child's participation since rehabilitation.

Relationship between caregiver report and child demographics and injury-related factors

Analyses were performed for each open-ended question to examine differences in terms of patient sex, level of injury or type of community between caregivers who did or did not report that something during rehabilitation was helpful. In terms of whether something was helpful during rehabilitation, the percentage of caregivers who reported 'yes' versus 'no' did not differ by their child's sex, level of injury or type of community. In terms of whether something had been helpful since rehabilitation, the percentage of participants who reported 'yes' versus 'no' similarly did not differ by child's sex, level of injury or type of community.

t-Tests were conducted to assess whether caregivers who said 'yes' differed from those who said 'no' that something experienced during rehabilitation encouraged their child's participation, in terms of their child's current age, age at injury and injury duration. Caregivers who responded that something was helpful during rehabilitation had children who had been injured longer ($\text{mean}_{\text{yes helpful}} = 7.08$ years, $\text{mean}_{\text{not helpful}} = 5.33$ years; $t = 2.03$, $P = 0.045$) ($t = 2.03$, $P = 0.045$) and were older at time of injury ($\text{mean}_{\text{yes helpful}} = 6.57$ years, $\text{mean}_{\text{not helpful}} = 3.38$ years; $t = -3.33$, $P = 0.001$). For whether something since rehabilitation had helped encourage participation, caregivers who said 'yes' had children who were significantly older at time of injury ($\text{mean}_{\text{yes helpful}} = 6.38$ years, $\text{mean}_{\text{not helpful}} = 4.17$ years; $t = -2.27$, $P = 0.026$) than caregivers who said 'no'.

Discussion

The present study adds to the existing body of research by qualitatively expanding the literature on youth with SCI and caregiver perceptions of their experiences with rehabilitation. These perspectives can provide valuable information about how to evaluate and plan the delivery of rehabilitation programs.

When asking caregivers whether anything was helpful during rehabilitation, technical and emotional support from staff were noted as very helpful in facilitating their children's participation. Rehabilitation professionals play an integral role in the care of SCI patients and future research should examine the impact of incorporating encouragement, reassurance and a 'can do' attitude into therapy sessions with youth.

Consistent with previous studies,[10] education about their child's injury was also mentioned by caregivers as an important factor. This highlights the value of informing caregivers about SCI-related issues, and also speaks to the importance of rehabilitation staff assessing whether the medical information they are providing is appropriately understood by caregivers and patients. A few participants in this study specifically mentioned the benefit of receiving information about health-care resources and advocacy, suggesting that caregiver education should not be limited to medical information.

Regarding whether anything has been helpful since rehabilitation, involvement in community activities arose as an important factor. This highlights the importance for rehabilitation teams to educate caregivers and youth with SCI about the opportunities for involvement in sporting activities, community organizations and recreational events in their local communities. Another factor discussed as important since rehabilitation was personal resilience. Individuals who are resilient are able to deal positively with the consequences of trauma, have a positive outlook on life and do not view themselves as victims.[13] Therefore, it may be beneficial to teach youth adaptive coping skills and provide them with resources that foster resilience early in the rehabilitation process to improve future outcomes.

Encouragement from school was also stated as helpful after rehabilitation. Reintegration into school can be made easier if individuals receive support from school personnel and classmates.[14] Communication between rehabilitation staff and schools may increase the physical and emotional accessibility of schools for youth with disabilities. Further, education provided by schools to the student body can help decrease the stigma associated with disability before youth reintegrate into school.

For both the 'during' and 'since' questions, interactions with others with disabilities were important to participation. Being able to interact with children or adolescents who can truly understand what it is like to have an SCI can be a motivating influence. For adolescents, feeling accepted by peers and being able to discuss issues such as sexuality, dating, driving and college with other teens with SCI is important for their developmental growth.[15,16] This might explain why caregivers of adolescents compared to caregivers of younger children were more likely to view interactions with others with disabilities as important during rehabilitation. In addition, meeting adults with disabilities was also mentioned as a promoting factor. Future studies should examine the impact of having adults with disabilities on staff or exposing youth to these individuals in some capacity.

The current study found that the needs of youth with SCI during rehabilitation differ compared to needs faced once they have reintegrated into their communities. This makes logical sense given that the youth and their families are likely in different emotional states related to the injury during and after the inpatient stay. Research and experience have demonstrated that the transition from an acute inpatient rehabilitation program to a home setting can be challenging.[1,2,9]

Analyses were also performed to examine the relationship between demographic and injury-related variables and the extent to which rehabilitation was viewed as helpful both during and after the initial process. The majority of demographic variables did not have a significant role; however, caregivers who reported being helped during rehabilitation had children who were older at time of injury and had been injured longer. Those who are injured during adolescence have already transitioned from being a dependent child to an independent young adult before injury, therefore requiring a great deal of support during initial rehabilitation to re-obtain that independent status. It has been suggested that rehabilitation plans should attempt to balance the medical and developmental needs of an adolescent to help them regain independence and foster personal growth.[2,16] Related to time since injury, passage of time may have decreased any negative perceptions of rehabilitation and enabled caregivers to better reflect and appreciate the rehabilitation process. In addition, caregivers with youth who have been injured longer may be able to see more progress and functional improvements in their children.

Limitations

This study was based on the responses of caregivers and did not directly consider the views of the youth with SCI. Recall biases cannot be ruled out as caregivers provided their viewpoints about their child's rehabilitation process that could have occurred several years ago. Results were based only on open-ended questions and not in-depth interviews, so specific categories and responses could not be explored. In addition, this study examined youth and their caregivers from a single hospital system and therefore may not be generalizable.

Conclusion

To date, published reports of caregiver opinions about pediatric SCI rehabilitation are scarce. Future research should explore the experience of rehabilitation from the youth's perspective. In addition, future studies are needed to understand what can be done to help the group of caregivers who reported that nothing was helpful. Finally, comparisons of youth and caregiver feedback would reveal both patterns of similarity and discrepancies and enable rehabilitation staff to tailor programs to meet the needs of youth in addition to their families, both key players in pediatric SCI rehabilitation.

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