



Recent technological advances have dramatically increased the ability of persons with physical disabilities to live satisfying lives. However, physical limitations can have a significant psychosocial impact both on those affected and other members of the family. For children with physical disabilities in particular, problems and demands associated with physical and psy-

about 26,000 people (Harvey et al., 1990; Vogel & De Vivo, 1996). Although motor vehicle accidents are the most common cause of spinal cord injury (Vogel & De Vivo, 1996), violent etiologies, predominantly gunshots, have dramatically increased from 10 percent to 36 percent over the past 20 years (Vogel & De Vivo, 1996). They also account for a disproport-

## Long-Term Adjustment of Families of Children With Spinal Cord Injury

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Finally, this article is dedicated to Michael Murrin, who worked as a research assistant for this project and who knew firsthand the experience of living with a spinal cord injury. Michael died of a brain tumor in February 2002.

chosocial development can be more complicated than for children without physical disabilities. As they grow through adolescence and young adulthood, they face a variety of situations that impose physical and psychological challenges.

For children with spinal cord injury, it is primarily the families who watch, support and accompany them as they develop to adulthood. Parents must learn how to assist their children and how to cope with the special conditions and demands their children place on them in everyday activities. It is important that parents support their children in facing and overcoming problems and issues in each psychosocial developmental stage. This study addressed the long-term needs and psychological consequences of families of children with spinal cord injury by conducting surveys with 46 families of children who received inpatient rehabilitation services one to 10 years earlier at the Rehabilitation Institute of Chicago. This study examined the level of family functioning and adaptation as reflected in caregivers' reports of the psychological well-being of the children, families and themselves.

### Incidence and Prevalence of Spinal Cord Injury Among Children

The annual incidence of spinal cord injury in the United States among children younger than 15 years old is 230 to 500 cases, and 1,500 to 2,000 in individuals less than 20 years of age (Go et al., 1995; Price et al., 1994). The prevalence in individuals 24 years old or younger is

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tionate share of injuries to adolescents and preadolescents (15 to 27 percent) as compared with adults (12 percent), and to African-Americans (28 percent) as compared with Caucasians (7 percent; Apple et al., 1995). Children and adolescents comprise a small proportion of the spinal cord injury population, and accordingly they have received less attention. We know little about the special characteristics that distinguish young patients from the adult population with spinal cord injury.

### Effects of Children's Spinal Cord Injury on Their Families

Studies that have investigated the impact of child spinal cord injury on families have focused on initial reactions to the injury and psychological adjustment during acute and rehabilitation care. Injury often brings radical changes to the life of the affected child and the family, and the sudden impact and consequent burden may be severe considering the life span ahead of children (Flett, 1992). Parents are uncertain about their child's needs and the changes confronting them (Flett, 1992; Gordon, 1987). The family's adaptation may be affected by many factors, such as the child's emotional and independent functioning. McGowan and Roth (1987) found a positive association between independent functioning of indi-

viduals with spinal cord injury and the family functioning.

Factors that have received empirical attention as potential mediators of psychological adaptation are social support, family strength, and acceptance of disability. Social support may buffer stress (Cohen & Wills, 1985; Kazak & Marvin, 1984; Rintala, 1996). Family support and resources can buffer families' adaptation to crisis (Bristol, 1987; Minnes, 1988). Some families of children with disabilities are isolated socially and may be more vulnerable to stress-related disorders (Friedrich & Friedrich, 1981; Kazak & Marvin, 1984). Gordon (1987) noted that psychological support and treatment for children with spinal cord injury and their families are important from the acute stage of rehabilitation, providing help for the child suffering stress and adapting to profound injury, and for parents coping with difficult challenges.

Family strength can play an important role in the family adjustment. Stewart (1988) emphasized the importance of considering family relationships during adjustment in individuals with spinal cord injuries. McGowan and Roth (1987) reported a significant correlation between the quality of family relationships and achieved levels of functional independence of children, suggesting that the quality of family relationship influences the long-term adjustment of individuals with spinal cord injury. In addition, several family factors – affective responsiveness, roles and communication – were correlated significantly with functional outcome (Cleveland, 1979; Mailick, 1979).

A few studies that examined the long-term outcomes of spinal cord injury of children on families found that duration of disability is associated with greater acceptance of spinal cord injury (Wooderich & Patterson, 1980). However, Rosenteil and Roth (1981) found that some patients actually deteriorated in their adjustment over time. As other studies found (Kerr & Thompson, 1972; Stewart, 1977), it takes several years before an individual realizes and adapts sufficiently to the demanding conditions of spinal cord injury.

McGowan and Roth (1987) found that greater duration of disability was associated with greater family concern to solve

problems, delineate roles, and maintain standards of behavior control. In contrast, Killen (1990) examined role changes in families after spinal cord injury and found that not all respondents viewed spinal cord injury negatively. Although anecdotally documented, the study found that injury resulted in increased strength and family solidarity; many commented that their faith increased and helped them deal effectively with the crisis.

There is considerable variability in adaptation of families to childhood disability, with some families functioning well and other families exhibiting psychological maladjustment. Thus it was important to examine why the adaptation of some families improves with time but other families' adaptation worsens. This study attempted to identify child and family characteristics that were associated with favorable family adaptation. In addition, family resources and support, as well as the caregiver's acceptance of disability, were examined as mediators of family adaptation.

## Participants and Procedures

The participants consisted of 46 families of adolescents and young adults whose spinal cord injury was the result of trauma and who were treated in the Pediatrics Program of the Rehabilitation Institute of Chicago (RIC). RIC provides care for a large urban population; about 60 percent of pediatric patients with spinal cord injury from the Chicago area receive care at RIC.

Initially 146 patients were identified from medical records during the 1990s

compiled by Outcomes Management, Statistical Management and the Pediatric Unit. We mailed invitation letters to the caregivers and children, and made follow-up phone calls to ask caregivers to participate in the study. For those patients whose letters were returned, we tried to locate them through the Public Aid records, online white pages, and by using the emergency contacts in the medical records. There were patients whose letters were not returned but were not reachable. In this case, we attempted to leave five messages/phone calls before we gave up. There were families who did not have phone information. In this case we also mailed the survey questionnaires with a pediatrician's letter that explained the study.

The families we could not reach through mail, phone calls, and phone messages totaled 62 (42 percent). Among the 84 patients we could locate, five children were dead (.6 percent), three (.04 percent) refused to participate in the study, and two (.02 percent) thought that their children were too independent to consider themselves caregivers. Twenty-four caregivers agreed to participate in the study, but did not return or complete the survey (29 percent). Forty-nine caregivers agreed and completed the survey (58 percent). We eliminated three cases because they did not meet the criteria of the study: children who became adolescent or young adults (age range: 12 to 25 years) and those who had traumatic spinal cord injury. The mean age of the child was 19 years with a range of 12 to 24. The mean age at time of injury was 13.8 years (age range: 2 to 21 years).

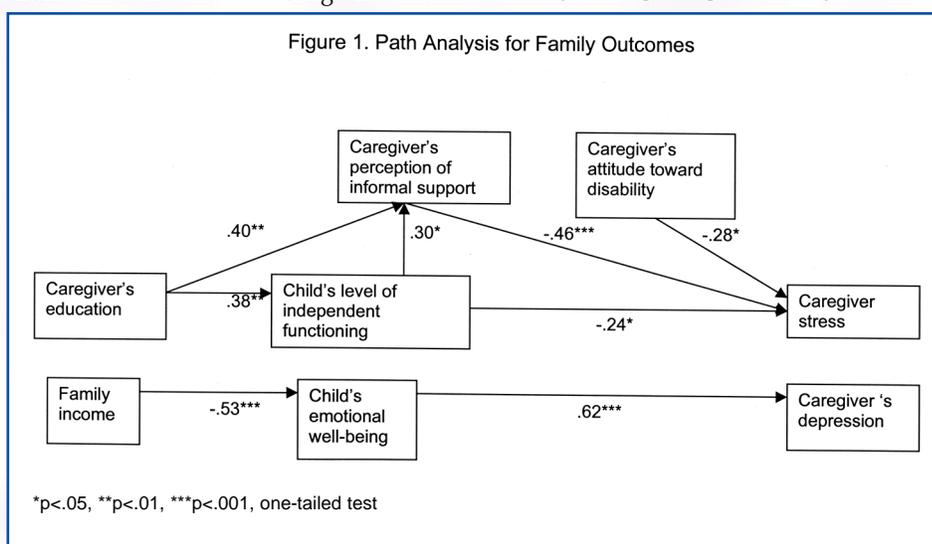


Table 1. Sample Characteristics

	Caregiver
Age (n=46)	
Mean	46
SD	7.1
Range	35-74
Relationship to the child (n=46)	
Mother	44 (96%)
Grandmother	2 (4%)
Ethnicity (n=45)	
Caucasian	30 (67%)
African-American	10 (22%)
Hispanic	4 (9%)
Other	1 (2%)
Marital status (n=46)	
Married	25 (54%)
Widowed	3 (7%)
Divorced	6 (13%)
Separated	4 (9%)
Remarried	2 (4%)
Never Married	6 (13%)
Residential areas (n=45)	
Chicago	9 (20%)
Chicago suburbs	27 (59%)
Other areas in Illinois	1 (2%)
Other state	9 (20%)
Highest education (n=46)	
<high school	5 (11%)
high school	15 (33%)
vocational or junior college	12 (26%)
college	12 (26%)
professional or graduate	2 (4%)
Employment (n=46)	
Full-time homemaker	8 (17%)
Retired	2 (4%)
On disability from work	3 (7%)
Employed part-time	9 (20%)
Employed full-time	22 (48%)
Other	2 (4%)
Family income (n=35)	
<\$15,000	6 (13%)
>\$15,000 and <\$29,999	5 (11%)
>\$29,999 and <\$44,999	10 (22%)
>\$44,999 and <\$60,000	12 (27%)
>\$60,000	12 (27%)

The demographic information on caregivers and children is provided in Table 1. All of the caregivers were mothers (96 percent) or grandmothers (4 percent). The average age of caregivers was 46 years with a range of 35 to 74. One-third completed high school, 26 percent junior college, 26 percent college, and 4 percent professional or graduate program. The mean age of the child was 19 years with a range of 12 to 24 years. There were more males (61 percent) than females (39 percent). Forty-six percent were in high school and 39 percent in college. Among the different causes of injury, the rate of motor vehicle accident (52 percent) was highest, followed by medical conditions (14 percent, e.g., transverse myelitis and surgical complication), gun shot (10 percent), sport injury (10 percent) and falls (7 percent). Most children were living with

Table 1. Sample Characteristics

	Child
Age (n=46)	
Mean	19
SD	2.8
Range	12-24
Gender (n=46)	
Female	18 (39%)
Male	28 (61%)
Ethnicity (n=45)	
Caucasian	30 (67%)
African-American	11 (24%)
Hispanic	4 (9%)
Educational status (n=46)	
In high school	21 (46%)
In college	18 (39%)
Others	7 (15%)
Cause of injury (n=44)	
Motor vehicle accident	23 (52%)
Gun shot	5 (11%)
Fall	3 (7%)
Sport accident	5 (11%)
Medical condition	6 (14%)
Other	2 (5%)
Community mobility (n=46)	
Wheelchair	21 (46%)
Wheelchair or brace	18 (39%)
Braces	7 (15%)
No assistance	0
Current living situation (n=46)	
Living alone	1 (2%)
Living with a roommate	3 (7%)
Living independently at home	10 (22%)
Living at home with parental assistance	28 (61%)
Other	4 (9%)

their parents, either independently (22 percent) or with parental assistance (61 percent). Seven percent were living with a roommate, and 2 percent lived alone. As a means of mobility, the largest proportion of the sample (46 percent) used wheelchairs, followed by wheelchair or brace (39 percent), and braces (15 percent).

## Results and Discussion

The child and family factors that contributed to the caregiver outcome were examined. As children were more independent, caregivers experienced less stress and depression. When children had more emotional problems, this was related to depression, separate from the parenting stress that was rather specifically related to burden and stress in caring for their children with injury. Overall the child variables affected how well the caregivers were doing. As families had greater informal support and less service needs, caregivers were less likely to experience stress and depression. The more caregivers were able to rely on informal and professional

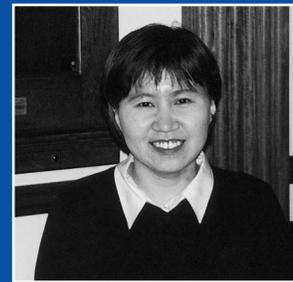
resources to care for their children, they were able to experience better psychological well-being. Caregivers who had more positive attitudes toward disability were also less stressed and depressed. The disability perceptions of caregivers affected their experience of stress and depression.

The results of path analysis (Figure 1) revealed that child, family resource and attitude variables all affected the outcome of caregivers. The path model suggests that the two functional domains of children affected the two outcomes of caregivers differently. As children were more independent, the caregivers felt less caregiver stress, which is directly related to the burden of caring for their children. As children were not doing well emotionally, this affected the general emotional well-being of caregivers. The caregivers' educational level and family income were important variables associated with the outcomes of children and caregivers. Being poor places the family at risk of psychological strain. When children have special health needs, this increases the risk of developing emotional problems; the risks increase further when children are from poor families and have special health needs. The study showed that the financially poor condition of the family causes children to not adapt well psychologically, which in turn affects the psychological well-being of the caregivers.

A longitudinal study would be ideal to compare individual differences and development over different lifetime periods. If the study could reveal whether the poor stayed poor, or those who were less educated were frustrated to begin with and continued to be frustrated later, then it would be clearer to identify the risk factor for the long-term care and intervention. This study began to document the long-term outcome of children with spinal cord injury and their families. Future studies on long-term outcome of this population are needed to confirm and extend the results in this study. In particular, future studies that examine family strengths and service components associated with successful outcomes are needed to enhance child and family outcomes.

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Jin Shin has a veritable interest in promoting research and clinical studies in the field of disability and rehabilitation in her home country, Korea. Her pursuit in attaining this particular career goal inspired her to organize three separate workshops in the United States (in 1998, 2000, 2001), to expose Korean professionals to U.S. philosophies and policies on disability and rehabilitation.

Professor Shin earned a B.A. in English from Pusan National University in Korea, an M.A. in English from Bradley University, and an M.A. and Ph.D. in psychology from the University of Illinois at Chicago. She received a postdoctoral fellowship at the Institute for Health Services Research and Policy Studies at Northwestern University. Her dissertation, "Social Support for Mothers of Children With Mental Retardation in the United States and Korea," yielded, among other critical information, insight on the support services available in each culture. This was yet another reason for her to develop workshops for Korean professionals, as mentioned above.

Professor Shin gained invaluable experience through extensive research conducted at the Rehabilitation Institute of Chicago and Northwestern University during her postdoctoral fellowship. She examined U.S. health services and policies and how they affect the families of patients who incur physical disabilities through trauma.

During her second year in the postdoctoral fellowship program, Professor Shin served as principal investigator on a research project titled "Adjustment and Service Needs of Families of Children with Spinal Cord Injury," funded by the Spinal Cord Research Foundation and the Blum-Kovler Foundation, from which this article is derived.

Professor Shin has authored numerous articles and delivered presentations in her field of study and is currently expanding her research activities to include families of children with disabilities from different ethnic and national backgrounds. She is a member of the American Psychological Association, International Association for Cross-Cultural Psychology, and American Association on Mental Retardation. -SK