



Long-term adjustment of families of children with spinal cord injury

SHIN, J.Y., HEINEMAN, A.W., GAEBLER-SPIRA, D.,
SISUNG, C., & SIMPSON, J.

Abstract

We examined the long-term adaptation of families of children with spinal cord injury as a function of multiple factors, including caregiver emotional well-being, and child functional status and emotional well-being. Forty-six caregivers of children who received inpatient rehabilitation services 1 to 10 years earlier at a rehabilitation hospital in the US participated in an interview. Children who were more independent had caregivers with less parenting stress. Children with more emotional problems negatively affected the emotional well-being of caregivers. The caregiver's educational level and family income were negatively associated with child adaptation, which in turn affected the psychological well-being of the caregivers.

Key words: spinal cord injury, children with special needs, families of children with special needs, long-term outcome

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 on those affected and on other members of the family. For children with physical disabilities, in particular, problems and demands associated with physical and psychosocial development can be more complicated than for children without the disabilities. As they grow through adolescence and young adulthood, they face a variety of issues that are related to both developmental and psychosocial challenges.

Parents play critical roles as they watch, support, and accompany their children's development into adulthood. For children with spinal cord injury (SCI), parents must learn how to cope with the special conditions and demands their children bring to their everyday lives. It is also important that they support their children so that the children cope with their developmental and disability related issues. This study was designed to help us understand how families of children with SCI manage the long-term impact of childhood disability. We examined the psychological adaptation of 46 families of children who received inpatient rehabilitation services 1 to 10 years earlier at a Midwestern, free-standing rehabilitation hospital. The level of family adaptation was studied as reflected in caregivers' reports of their psychological well-being and of their children.

Wallander and Varni (1998; Wallander, Varni, Babani, Tweddle Banis, & Wilcox, 1989) have proposed a conceptual model to explain the psychosocial adjustment of chronically ill and handicapped children in terms of risk and resistance factors. According to the model, disease or disability parameters, functional independence, and psychosocial stress are major risk factors. The model also includes a variety of resistance factors: stable person factors, stress pro-

cessing (such as cognitive appraisal or coping behaviors), and social-ecological factors. Social-ecological factors include family resources and social support (Wallander et al., 1989). Another family resource in the model is the practical resources available to deal with acute and chronic problems and issues (Wallander et al., 1989). Financial resources can be used to buy better services and to provide a better education to the child. The educational level of parents may contribute to cognitive ability related to appropriate parenting or care of a chronically ill child (Wallander et al., 1989; Wallander & Marullo, 1997). In the present study, we adapted Wallander and Varni's (1998) model and applied it to the adjustment of the caregivers to examine how certain resistant factors affect the caregivers who have been providing long-term care to their children who suffered from traumatic spinal cord injury.

There are many child factors that affect family outcomes. Thompson et al. found that the level of maternal maladjustment was affected by the child's disorder (Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson, Zeman, Fanurik, & Sirotkin-Roses, 1992). Rolland (1994) identified the degree of a child's incapacitation as one of the critical factors in understanding family functioning when a member has a chronic disorder. McGowan and Roth (1987) also found a significant association between independent functioning of the individuals with SCI and the family functioning.

In addition, it has been widely known that the period of adolescence in the U.S. and many industrialized countries is often related to a high level of psychosocial issues. As adolescents develop, they experience increased psychosocial stresses from conflict with their parents and pressures to be engaged in many peer-related social activities (Paikoff & Brooks-Gunn, 1991; Hecht, Inderbitzen, & Bukowski, 1998). When it is important for adolescents to be accepted to their peers and friends, for those who have physical disabilities, their physical limitations may prohibit their independence and social participation, which in turn cause their psychological stresses. According to Hostler, Gessard, Hassler, and Linden (1989), adolescents with a physical disability often feel isolated and lonely, have fewer friends, show an increased dependence on others, and have unrealistic future plans. Therefore it is important to consider the emotional aspects of these children from both disability and developmental perspectives. In this study, while the independent functioning of the child served as a disability related risk factor, we also included the emotional functioning of the child as another risk factor that would have an impact on adjustment among caregivers. Therefore, the child factors that are defined as risk factors are operationalized as the child's independent and emotional functioning in this study.

The social-ecological factors conceptualized by Wallander and Varni (1998; Wallander et al., 1989) as risk-resistance factors are operationalized in terms of family resources and social support. In a study with individuals with SCI, Stewart (1988) emphasized the importance of considering family relationships during adjustment. McGowan and Roth (1987) also 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 the individuals with SCI. In addition, several family factors – affective responsiveness, roles, and communication – were correlated significantly with functional outcome (Cleveland, 1979; Mailick, 1979).

Social support has been widely acknowledged as a factor that buffers stress (Cohen & Wills, 1985; Rintala, 1996). Family support and resources can buffer families' adaptation to crisis (Minnes, 1988). Some families of children with disabilities are socially isolated 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 SCI and their families is 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 problems. It is considered that social support also has a long-range effect on the adjustment of both children with SCI and their caregivers.

The outcome component of the theoretical model suggested by Wallander and Varni (1998, Wallander et al., 1989) was operationalized by two separate dimensions of caregivers' adjust-

ment: parenting stress and depression. Parenting stress is a particularly salient variable when working with families that include children who have disabilities. It was also assumed that risk and risk-resistance factors would influence the outcome of caregivers in general ways that may differentiate the parenting stress that is specific to the children's disability. Therefore, depression factor was considered in this study as a global measure of the adjustment of the caregivers.

Many studies that have investigated the impact of a child's SCIs on families have focused on the family's initial reactions to injury and the 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 the consequent burden may be severe, considering the life span ahead for children (Flett, 1992). Parents are uncertain about their children's needs and the changes confronting them (Flett 1992; Gordon, 1987). The adjustment of children with SCI and their families changes over time, as problems become resolved or the consequences of unresolved problems accumulate. It is likely that the children will have more demanding life experiences as they grow up, especially when they enter adolescence and young adulthood. Their life expands beyond that of family to developing relationships with friends that involves a variety of social activities. This challenge can lead to an acceleration of adjustment problems that, in turn, increases family stress. Thus, consideration of long-term outcomes and family capacity to meet the needs of children as they enter the pre-adult stage is critical.

A few studies that examined the long-term outcomes of children's SCI on families found that the duration of the disability is associated with greater acceptance of SCI (Woodrich & 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 & Rossier, 1978; Trieschman, 1974), it takes several years before an individual realizes and adapts sufficiently to the demanding conditions of SCI. 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 the present study, we examined the long-term outcome of children with spinal cord injury and their families as affected by multiple psychosocial factors. We also attempted to delineate the relative weight of both family and child variables that determined the adjustment of the caregivers in this study. It was expected that greater child function as measured by independent and emotional functioning would be associated with less parenting stress and maternal depression and that caregivers who had stronger family relationships and perceived a higher level of social support would experience less parental stress and maternal depression. We hypothesized that social support and family strength would mediate child functioning and parenting stress and depression. We also considered that age at the onset of injury and passage of time since the injury would play important roles in affecting the outcome; thus we expected that the younger a child was when injured and the longer the time since the injury, the less caregivers would experience parenting stress and depression.

Methods

Procedures

The participants consisted of 46 mothers or grandmothers of adolescents and young adults whose SCI was the result of trauma and who were treated in the Pediatrics Program of the Rehabilitation Institute of Chicago (RIC). The RIC provides care for a large urban population; about 60% of pediatric patients who have SCI and who come from the Chicago area receive care at the RIC.

Initially we identified 146 patients from medical records compiled by the Outcomes Management and Statistical Management program and the Pediatric Unit. We mailed invitation letters to the caregivers and made follow-up phone calls to ask caregivers to participate in the study. For those whose letters were returned as undeliverable, we tried to locate them through public aid records, online white pages, and emergency contacts in the medical records. Some patients' letters were not returned but were not reachable. In this case, we left up to five telephone messages. For families that did not have telephones, we mailed the survey questionnaires with a pediatrician's letter that explained the study.

The first and last authors and two research assistants contacted the caregivers, explained the study, and asked for participation. We attempted to arrange interviews at the hospital, but when the caregivers could not travel, the first author arranged a home visit interview. If the caregivers preferred to respond by mail or if the caregivers lived further than 2 hours away, we mailed the questionnaires. When we considered a community too dangerous to visit, we encouraged caregivers to visit the hospital by providing taxi fare.

Among the caregivers of the 84 patients we could locate, 5 children were deceased (0.6%), 3 caregivers (0.04%) refused to participate, and 2 (0.02%) thought that their children were too independent to consider themselves providing care. Twenty-four caregivers agreed to participate in the study, but did not return or complete the survey (29%). Forty-nine caregivers agreed and completed the survey (58%). We eliminated three cases because they did not meet the study criteria: age at injury from 12 to 25 years and traumatic etiology. The mean age of the child in the study was 19 years, with a range of 12 to 24 years. The mean age at time of injury was 13.8 years (range: 2 to 21 years).

Subjects

Demographic characteristics of caregivers and children are provided in Table 1. Almost all (96%) of the caregivers were mothers. The average age of caregivers was 46 years, with a range of 35 to 74 years and most (67%) of the respondents were Caucasian. A little over half (54%) of the sample was married and more than half (59%) resided in suburban areas of Chicago. One third had completed only high school; the majority had an education ranging from junior college to professional or graduate programs. About two thirds of the caregivers were employed full-time (48%) or part-time (20%).

There were more male patients (61%) than females (39%) and most (67%) of the children were Caucasian. Nearly half (46%) were in high school and 39% in college. Among the different etiologies of injury, the largest proportion sustained SCI due to motor vehicle injuries (52%). Most children were living with their parents with parental assistance (61%) or independently (22%). For mobility, the largest proportion of the sample (46%) used wheelchairs.

Measures

Demographic Information included information about age, education, and occupation of the available caregiver. Information on the child with the SCI, included age, year of injury, and cause of injury.

The Independent Behavior Inventory (IBI; Lollar, Reinoehl, Leverette, Martin, & Posid, 1989) is a 32-item measure that assesses the degree to which children are able to care for themselves. This scale includes items that assess the degree of independence in hygiene (e.g., "My child always maintains his/her physical appearance and body hygiene"), bladder and bowel care (e.g., "My child completes his/her own bladder care without help and has no accidents"), and home maintenance skills (e.g., "my child cooks better than others at his/her age"). Other items assess social and community independence (e.g., "My child has a group of friends

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 jr. 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%)

Table 1
Sample Characteristics (continued)

	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%)

his/her age and she/he is good at starting and keeping friendships"). The scale has adequate reliability and validity, and demonstrated a high internal consistency of .93 in this study.

The Child Health Questionnaire (CHQ-PF50; Landgraf, Abetz, & Ware, 1996a) is a generic health assessment questionnaire that provides a 14-concept profile and a 2-component summary score of physical and psychosocial health. Sixteen items that assess emotional well-being (e.g., "During the past four weeks, how much of the time do you think your child acted bothered or upset?") were used in this study. Internal consistency estimates range from .88 to .96;

discriminant validity estimates range from .94 to .96 (Landgraf, Abetz, & Ware, 1996b). Because the self-esteem subscale demonstrated low reliability (.48) in this sample, only the subscales of behavior and well-being were used to measure emotional functioning (internal consistency = .73 and .84, respectively).

The Family Strength Assessment (part of Child and Adolescent Strength Assessment CASA; Lyons, Nickels, & Meyers, 1999) was developed to identify the strengths of a child or adolescent as a comprehensive assessment for service planning. The family strength domain was used to assess the strength of families of children with spinal cord injury. The internal reliability of the scale was estimated at .91; the scale correlates with the Child Behavior Checklist (Lyons, Kisiel, & West, 1997). This family domain is made of six items on relationships, communications, and sense of belongings among family members (e.g., "My child has a strong positive relation with at least one parent"). The internal consistency of the scale in this study was very low, with $\alpha = .23$. Further deletion of additional items would not improve the alpha level, thus this scale was not used in the main data analyses.

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) was used to assess informal support the caregivers perceived. The MSPSS has adequate internal reliability (.88) and stability over time (.95). The construct and convergent validity of this scale have also been demonstrated (Cecil, Stanley, Carrion, & Swann, 1995; Zimet et al., 1988). This scale consists of 12 items and measures three components of informal social support: support from a special person, family, and friend (e.g., "I can count on my friends when things go wrong"). The scale demonstrated high reliability of .94 in this sample.

The Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) is a 20-item self-report scale that assesses the frequency of reported depressive symptoms of caregivers in the previous week (e.g., "I was bothered by things that don't usually bother me"). The CES-D is a widely used scale for screening and assessing depressive symptoms in outcome studies of caregivers as well as general and patient populations. The scale also has well-established reliability and discriminant validity for general and patient populations. It has national norms to categorize the severity of depressive symptoms (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). The reliability of the scale in this sample was .91.

Parenting stress was measured with the *Parental Stress Index/Short Form* (PSI/SF; Abidin, 1990). Items assessing restriction of role, sense of competence, and social isolation were used to estimate caregivers' level of stress (e.g., "Since my children's injury, I feel that I am almost never able to do things that I like to do"). In past research, the PSI has effectively discriminated parental stress between families of children with and without disabilities (Kazak & Marvin, 1984). The internal consistency of the subscales ranges from .70 to .93. The internal consistency of the scale in this sample was .90.

Results

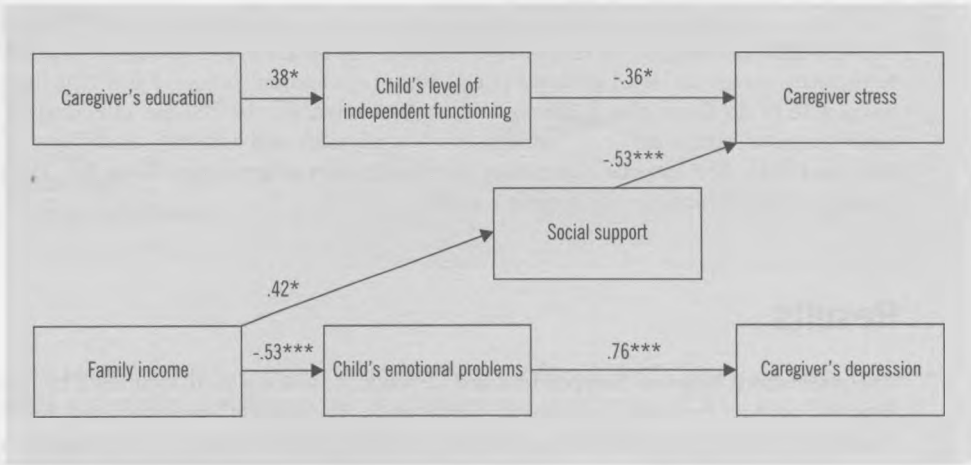
The associations between independent and dependent variables were examined by computing Pearson product-moment correlation coefficients; the results are presented in Table 2. Children's level of independent functioning was significantly related to both parenting stress, $r = -.54, p < .001$, and depression, $r = -.29, p < .05$. The caregivers who had a lower level of independent functioning reported more stress and depression. The emotional functioning of the children was significantly related to depression, $r = .76, p < .001$, but not parenting stress, $r = .27, p > .05$. The caregivers with better psychological well-being were less depressed, but did not necessarily experienced less parenting stress. Social support was signifi-

cantly related to both parenting stress, $r = -.65, p < .001$, and depression, $r = -.42, p < .01$. The caregivers who perceived a higher level of social support experienced less parenting stress and less depression. To examine the influence of family resources and perception of stressors, path analysis using multiple regression techniques was performed. The path analysis was designed to specify causal relationships between a number of variables. Family adjustment was predicted by taking into account the moderating and mediating variables, such as family income, caregivers' education, and social support. The variables in this study were entered into a multiple regression equation in the order of their causal explanation based on the theoretical

Table 2
Means, Standard Deviations, and Correlations among Important Variables

Variable	<i>M</i>	<i>SD</i>	01	02	03	04	05	06	07	08	09	10
01 Caregiver's Education	2.8	1.1	—									
02 Family Income	3.4	1.4	.17	—								
03 Gender of Child (0 = female)	.61	.49	-.15	-.08	—							
04 Age of Child	19.1	2.8	-.34	-.04	.16	—						
05 Number of Years since Injury	5.2	3.4	-.21	-.03	.12	.38	—					
06 Child's Physical Functioning	113.3	23.7	.39	.05	-.37	-.03	-.11	—				
07 Child's Emotional Problems	21.3	5.9	-.05	-.52	-.06	-.15	-.26	-.20	—			
08 Perceived Social Support	58.0	11.7	.23	.45	-.13	.09	.07	.33	-.33	—		
09 Parental Stress	64.0	17.8	-.36	-.25	.19	.09	-.03	-.54	.27	-.65	—	
10 Caregiver's Depression	32.8	10.8	-.25	-.50	.03	-.15	-.18	-.29	.76	-.42	.54	—

Correlations are underlined when $p < .05$, two-tailed test.



* $p < .05$. ** $p < .01$. *** $p < .001$, two-tailed test.

Figure 1
Path Analysis for Family Outcomes

framework suggested by Wallander et al. (1989). Caregivers' educational level and family income were significantly related to the majority of the independent and dependent variables, thus they were added to the path analyses.

The independent variables (children's independent and emotional functioning, and caregivers' perceived social support) were entered in that order in a series of multiple regression equations with perceived stress and depression as the dependent variables, respectively. Children's age and time since injury were not treated as covariates since there were no significant associations between these variables and other outcome variables (children's level of independence and emotional functioning) and the dependent variables (stress and depression of the caregiver). Family income and maternal educational level were treated as exogenous variables and antecedent of child variables since they were considered to have long enduring impact on child and caregiver outcomes. Figure 1 displays the standardized path coefficients (direct effects) among predictor and outcome variables.

The moderating effects of caregiver's education and family income were examined. There were no significant interaction effects between caregivers' education and child's independent functioning, but family income interacted significantly with social support to predict parenting stress. Those who had lower family income (< \$ 29,999) experienced parenting stress regardless of their perceived social support. For those who had higher family income (> \$ 30,000), parenting stress was attributable to their perceived social support along with their income level.

The mediating effects of social support between the child's independent functioning and parenting stress, and between family income and stress were examined. There are four conditions that must be met for a variable to be considered a mediator: (a) the predictor must be significantly associated with the hypothesized mediator, (b) the mediator must be significantly associated with the predictor variable, (c) the mediator must be significantly associated with the dependent variable, and (d) the impact of the predictor on the dependent measure is less after controlling for the mediator (Baron & Kenny, 1986; Holmbeck, 1997). Following these recommendations, we tested the mediating effects of social support between child's independent functioning and parenting stress, of social support between family income and parenting stress, of child's independent functioning between caregiver's education and parenting stress, and of child's emotional functioning between family income and caregiver's depression. All of the mediating effects were significant except the effect of social support between family income and parenting stress.

As Figure 1 shows, somewhat different pathways explained two different outcomes, depression and parenting stress. For parenting stress, the children's level of independent functioning had both a direct and indirect effect. Caregivers whose children were less independent had a higher level of stress. Caregivers' education did not have a direct effect on stress, but had an indirect effect via children's level of independent functioning. Those caregivers with a higher level of education were less stressed, attributable to children's independent functioning. Perceived social support also had a direct impact on caregivers' stress: caregivers who perceived less social support were more stressed.

Children's emotional well-being had a direct effect on caregiver depression: those who perceived better emotional well-being of their child reported less depression. Family income did not have a direct impact on caregiver depression, but had an indirect effect via children's emotional well-being: those who had lower family income experienced more depression, attributable to children's emotional well-being.

Discussion

Overall, the results revealed that child and family characteristics affected how well the caregivers were doing. As children became more independent, the caregivers experienced less

parenting stress and depression. Caregivers of children with greater emotional problems were more likely to suffer from depression, a separate issue from the parenting stress that was rather specifically related to burden and the stress of caring for their children with injuries. It was also confirmed that as families had greater social support, caregivers were less likely to experience stress. The more caregivers were able to rely on social support, the greater was their tendency to experience psychological well-being.

The path analysis also revealed that child and family resource variables affected the outcome of caregivers, and they did so in different ways. The independent functioning of children and their emotional well-being were not significantly related, indicating that they are different domains of functioning that need to be treated separately. Although the outcome variables, parenting stress and depression, were highly correlated ($r = .54, p < .001$), the path model suggests that the two functional domains of children affected the two outcomes of caregivers differently (Figure 1). As children became more independent, the caregivers felt less parenting stress that was directly related to the burden of caring for their children. When children were not doing well emotionally, the general emotional well-being of caregivers was affected, as measured by the depression scale. Age and the onset time of the injury did not affect the overall outcomes of the caregivers. It appears that how well children were doing independently and emotionally were more important indicators for child and caregiver outcomes than age and time variables.

The study results also revealed the importance of the family's utilitarian resource variables that affect the well-being of children and caregivers. In particular, the caregivers' education and family income summarize ecological and enduring factors that may act beyond the conditions of the children's disability, affecting the long-term adjustment of both child and caregivers. The caregivers' level of education influenced parental stress indirectly through the children's level of independent functioning. Caregivers that were more educated were more likely to help their children to become independent, which in turn led to their experiencing less parenting stress.

It has been well documented that poverty affects the outcome of child development and family (Bornstein, & Bradley, 2003). Poverty places individuals at risk of psychological strain. When individuals have special health needs, the risk of developing emotional problems increases; the risk increases further when children are from poor families and also have special health needs (Cadman, Boyle, Szatmari, & Offord, 1987; Cadman, Rosenbaum, Boyle, & Offord, 1991; Lipman, Offord, & Boyle, 1994). The current study showed that a financially poor family condition hinders children from being well-adapted psychologically, which in turn affects the psychological well-being of the caregivers.

Helping families receive the training and education they need to teach their children to manage their personal care and social skills is important. However, a look at the long-term adjustment indicates that the issues may go beyond the stress and burden caused by disability. Education and financial stability are factors that may have global and long-term effects on how caregivers cope with childhood disability and with their own emotional well-being, and these factors should be addressed and advocated when rehabilitation workers begin to work with families. In addition to disability-related training programs, encouraging caregivers to further enhance their educational and economic goals could probably bring long-term benefits in coping with their children's disability and related issues.

The results of the study support the need for designing services or strategies to better serve low socioeconomic status children with SCI and their families. Considering the increasing rate of gunshot related SCI that has taken a steep toll in the United States, clinicians who serve this population are likely to face more and more clients who come from low socioeconomic status and high-risk communities. In particular, the less educated caregivers are at risk of suffering from frustration due to a relative lack of resources and information. Adding poverty to a family's plight also increases the risk to both children and caregivers of negative emotional consequences. Those who have less education and a low economic status are apt to need more and longer professional support to help their children achieve independence and maximize

their well-being. Ironically, families from poor economic conditions were more likely to be among the participants who could not be reached for the follow-up study, which suggests that they are also more likely to be lost in follow-up services. In addition, five children who made up 6% of the participants we could locate were reportedly killed while engaging in gang/drug related activities. The goal of rehabilitation services is to help clients to go back to their communities and to live normal lives. However, those clinics that serve urban high-risk populations may need to revisit their ways of returning these patients to their original lives, which are more likely to be in high-crime areas. It must be noted that helping children and families who are from high-risk communities should not be limited to the services provided by clinicians in the rehabilitation program. An important objective for rehabilitation programs should be to establish a program that specifically targets these high-risk children and finds ways to keep them in social and educational programs along with the existing psychosocial support programs, thus preventing those children from going back to poverty-stricken lives and from staying poor in the future.

This study attempted to use causal modeling by applying the path analysis to examine the multiple indicators that affected the outcomes of the caregivers. Although the causal relationships can be inferred based on the theoretical framework, caution should be used in interpreting the causal relationships among the variables. The study also had a relatively low number of participants compared to the relatively large number of variables in the path model. The results were almost exclusively based on the mother's reports; a future study may benefit from having more than one informant to understand how the family as a whole copes with demanding situations. The long-term influence of the family strength/relationship variables was not examined in this study because the scale we used had poor psychometric properties. In future studies, it will be important to examine how family variables, such as strength or coherence of the family relationship, affect the long-term outcome of these children. A longitudinal study would be an ideal way to compare individual differences in the long-term period adjustment. A study with this design should not only reveal whether families in lower income brackets remained in that status, and whether those with less education were frustrated to begin with and continued to be frustrated later on; it should also clarify the developmental pathways of these families to enable workers to identify risk and resistance factors for long-term care intervention.

References

- ABIDIN, R. (1990). *Parenting Stress Index/Short Form*. Lutz, FL: Psychological Assessment Resources, Inc.
- BARON, & KENNY (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- BORNSTEIN, M.H., & BRADLEY, R.H. (Eds.) (2003). *Socioeconomic status, parenting, and child development*. Mahwah, NJ: Lawrence Erlbaum Associates.
- CADMAN, D., BOYLE, M.H., SZATMARI, P., & OFFORD, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics*, 79, 805-813.
- CADMAN, D., ROSENBAUM, P., BOYLE, M.H., & OFFORD, D.R. (1991). Children with chronic illness: Family and parent demographic characteristics and psychosocial adjustment. *Pediatrics*, 87, 884-889.
- CECIL, H., STANLEY, M.A., CARRION, P.G., & SWANN, A. (1995). Psychometric properties of the MSPSS and NOS in psychiatric outpatients. *Journal of Clinical Psychology*, 51, 593-602.
- CLEVELAND, M. (1979). Family adaptation to the traumatic spinal cord injury of a son or daughter. *Social Work in Health Care*, 4, 459-471.

- COHEN, S., & WILLS, T.A. (1985). Stress, social support and buffering hypothesis. *Psychological Bulletin*, 98, 310-317.
- FLETT, P.J. (1992). The rehabilitation of children with spinal cord injury. *Journal of Paediatric Child Health*, 28, 141-146.
- FRIEDRICH, W.N., & FRIEDRICH, W.L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. *American Journal of Mental Deficiency*, 85, 551-553.
- GORDON, K.H. (1987). Medical feature, psychiatric care for children with spinal injuries. *Pennsylvania Medicine*, 91, 60-62.
- HECHT, D.B., INDERBITZEN, H.M., & BUKOWSKI, A.L. (1998). The relationship between peers status and depressive symptoms in children and adolescents. *Journal of Abnormal Child Psychology*, 26, 153-160.
- HOLMBECK (1997). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1986.
- HOSTLER, S., GESSARD, R., HASSLER, C., & LINDEN, P. (1989). Adolescent autonomy project: Transition skills for adolescents with physical disabilities. *Children's Health Care*, 18, 12-18.
- KAZAK, A.E., & MARVIN, R.S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations*, 33, 67-77.
- KERR, W., & THOMPSON, M. (1972). Acceptance of disability of sudden onset in paraplegia. *International Journal of Paraplegia*, 10, 94-102.
- LANDGRAF, J.M., ABETZ, L., & WARE, J.E. (1996a). *The CHQ user's manual*. Boston: The Health Institute, New England Medical Center.
- LANDGRAF, J.M., ABETZ, L., & WARE, J.E. (1996b). *Psychometric results of the CHQ-PF50 form in a normative U.S. sample of children and its clinical application across several condition groups*. Paper presented at the third annual symposium of contributed papers, Quality of Life Evaluation, Boston.
- LIPMAN, E.L., OFFORD, D.R., & BOYLE, M.H. (1994). Relation between economic disadvantage and psychosocial morbidity in children. *Canadian Medical Association Journal*, 151, 431-437.
- LOLLAR, D.J., REINOEHL, J.K., LEVERETTE, A.T., MARTIN, J.C., & POSID, V.A. (1989). Facilitating and assessing progress toward independence: SPARX. *Zeitschrift fur Kinderchirurgie Surgery in Infancy and Childhood*, 44, Suppl I, 18-20.
- LYONS, J.S., KISIEL, C., & WEST, C. (1997). Child and adolescent strengths assessment. *Family Matters*, Fall, 30-32.
- LYONS, J.S., NICKELS, M., & MEYERS, P. (1999). *Multi-level family assessment: A family functioning outcome measure for complex family circumstances*. Chicago: Mental Health Services and Policy Program, Northwestern University.
- MAILICK, M. (1979). The impact of severe illness on the individual and family: An overview. *Social Work in Health Care*, 5, 117-128.
- MCGOWAN, M.B., & ROTH, S. (1987). Family functioning and functional independence in spinal cord injury adjustment. *Paraplegia*, 25, 357-365.
- MINNES, P.M. (1988). Family resources and stress associated with having a mentally retarded child. *American Journal of Mental Retardation*, 93, 184-192.
- PAIKOFF, R.L., & BROOKS-GUNN, L. (1991). Do parent-child relationships change during puberty? *Psychological Bulletin*, 110, 47-66.
- RADLOFF, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.
- RINTALA, D.H. (1996). Family relationships and adaptation to spinal cord injury: A qualitative study. *Rehabilitation Nursing*, 21, 67-74.
- ROLLAND, J.S. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.
- ROSENTEIL, A.K., & ROTH, S. (1981). Relationship between cognitive activity and adjustment in four spinal-cord injured individuals: A longitudinal investigation. *Journal of Human Stress*, 3, 35-43.

- STEWART, T.D. (1988). Psychiatric diagnosis and treatment following spinal cord injury. *Psychosomatics*, 29, 214-220.
- STEWART, T.D., & ROSSIER, A. (1978). Psychological considerations in the adjustment to a spinal cord injury. *Rehabilitation Literature*, 39, 75-80.
- THOMPSON, R.J. Jr., GUSTAFSON, K.E., HAMLETT, K.W., & SPOCK, A. (1992). Stress, coping, and family functioning in the psychological adjustment of mothers of children with cystic fibrosis. *Journal of Pediatric Psychology*, 17, 573-585.
- THOMPSON, R.J. Jr., ZEMAN, J.S., FANURIK, D., & SIROTKIN-ROSES, M. (1992). The role of parent stress and coping and family functioning in parent and child adjustment to Duchenne Muscular Dystrophy. *Journal of Clinical Psychology*, 48, 11-19.
- TRIESCHMAN, R.B. (1974). Coping with a disability: A sliding scale of goals. *Archives of Physical Medicine and Rehabilitation*, 55, 556-560.
- WALLANDER, J.L., & MARULLO (1997). Handicap-related problems in mothers of children with physical impairments. *Research in Developmental Disabilities*, 18, 151-165.
- WALLANDER, J.L., & VARNI, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry*, 39, 29-46.
- WALLANDER, J.L., VARNI, J.W., BABANI, L., TWEDDLE BANIS, H., & WILCOX, T. (1989). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology*, 14, 157-173.
- WEISSMAN, M.M., SHOLOMSKAS, D., POTTENGER, M., PRUSOFF, B.A., & LOCKE, B.Z. (1977). Assessing depression symptoms in the psychiatric population: A validation study. *American Journal of Epidemiology*, 106, 203-214.
- WOODRICH, F., & PATTERSON, J.B. (1980). Variables related to acceptance of disability in persons with spinal cord injuries. *Journal of Rehabilitation*, 3, 26-39.
- ZIMET, G.D., DAHLEM, N.W., ZIMET, S.G., & FARLEY, G.K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52, 30-41.

Author note

Jin Y. Shin

Assistant professor of psychology

New College of Hofstra University

Research associate

New York State Institute for Basic Research in Developmental Disabilities

U.S.A.

Allen W. Heineman

Deborah Gaebler-Spira

Charles Sisung

Department of Physical Medicine and Rehabilitation of Northwestern University and Rehabilitation Institute of Chicago

Janet Simpson

Rehabilitation Institute of Chicago

U.S.A.

This project was funded by the Spinal Cord Research Foundation (grant 2108-01) while the first author was on a post-doctoral fellowship funded by the National Institute on Disability and Rehabilitation Research. The Blum-Kovler Foundation in Chicago provided supplemental funding to complete the project. We extend our thanks to Erma Wilson, Maureen Stress, Michael Murrin, Beverly Murrin and Suzanne Kawaguchi for their assistance coordinating family recruitment and interview and data

management. We thank all the patients and families who were willing to participate in this study and to share their experiences. Additional information about this project and copies of this report may be obtained from

Jin Y. Shin

New College, 130

Hofstra University

Hempstead, NY 11590

U.S.A.

Tel: 516-463-5848

Fax: 516-463-4832

E-mail: Jin.Y.Shin@Hofstra.edu