

A Preliminary Study of Acute Family Needs After Spinal Cord Injury: Analysis and Implications

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Objective: To address the paucity of research on family needs following spinal cord injury (SCI). **Study Design:** Prospective cross-sectional design. **Setting:** Inpatient SCI rehabilitation unit within a Level 1 trauma center. **Participants:** Family members of 17 inpatients with SCI. **Main Outcome Measure:** Family Needs Questionnaire (FNQ). **Results:** Eighteen of the 40 FNQ needs were rated as important or very important by 100% of the respondents. Health Information Needs were rated as most important and Instrumental Support Needs as least important. Involvement With Care Needs were most often met, whereas Emotional Support Needs were most often unmet. **Conclusions:** The FNQ is a promising measure of family members' needs after SCI and treatment planning and program evaluation tool. Findings affirm that family education is important during rehabilitation.

As a result of advances in medical care, survival rates for individuals with spinal cord injury (SCI) have increased dramatically (DeVivo & Stover, 1995; DeVivo, Stover, & Black, 1992). Nonetheless, many survivors face impairments that cause varying degrees of dependence on others for activities of daily living (Chan, 2000; Chan, Lee, & Lieh-Mak, 2000; Cleveland, 1980; DeVivo, Hawkins, Richards, & Go, 1995; El Ghatit & Hanson, 1975, 1976; Gill, 1999; Kreuter, 2000; Sullivan, 1990; Trieschmann, 1980; Tucker, 1987; Weller & Miller, 1977a, 1977b). Decreased lengths of hospital stays have left family members increasingly responsible for providing care and assistance to their loved ones (Eastwood, Hagglund, Ragnarsson, Gordon, & Marino, 1999). Their lives are disrupted not only by the stress of injury, but also by the necessity of taking on new and unfamiliar responsibilities. Rehabilitation professionals agree that families have an important role in rehabilitation and that attention to their needs results in better outcomes (Stanton, 1984). However, little empirical information is available to characterize the needs of family members.

Hart (1981) was among the first to examine the needs of family members following SCI. Seven family members were interviewed within 5 to 40 days postinjury. A semistructured interview was used to examine the following needs: feeling informed, feeling helpful, being able to cope with responsibilities, receiving emotional support, and believing that patient care is adequate. The interview also addressed past experience with crisis and coping

methods and concerns regarding the future impact of the injury. Needs for realistic information regarding the patient's condition and prognosis, assurance regarding quality of care, and emotional support were commonly reported. The majority of respondents described their important needs as being met.

In a qualitative phenomenological study, Vargo (1984) investigated the adjustment and adaptation of 10 women whose husbands had sustained SCIs after their marriages. The women were interviewed 2 months to 10 years postinjury using a semistructured open-ended format. Participants were asked to describe their feelings and thoughts about life after injury. In the face of a difficult experience, wives reported significant lifestyle and value changes resulting in emotional growth. Vargo described two important sets of needs. During the course of the patients' hospitalizations, the need for assistance of family and friends was highlighted. Needs for companionship, empathy, understanding, an "emotional outlet," hope, encouragement, and assistance with child care and transportation were also noted. Vargo provided little or no information regarding injury characteristics or sample demographics.

Stanton (1984) developed the 24-item Needs Assessment Questionnaire (NAQ) and examined the needs of 10 family members in a hospital setting 4 to 24 weeks postinjury. Derived from instruments used with medical-surgical and critical care populations (Molter, 1979; Wolfer & Davis, 1970), the measure provides information regarding psychosocial needs rated according to importance on a 1 (*not important*) to 4 (*very important*) scale. Family members rated needs related to communication and interactions with health professionals as most important. Specific needs cited as very important by 70% or more of respondents included acceptance by the rehabilitation unit personnel; demonstrated concern for the patient; honest and informed communication about patients' treatment, care, and progress; reassurance from staff; and knowing available resource personnel within the hospital. In addition, more than half of the respondents described having a consistent contact person and knowing the staff caring for the patient as very important. The need to visit the patient whenever desired and the need for someone to talk to were rated as important or very important by the majority of respondents. Stanton empha-

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sized the importance of regularly monitoring family needs within the rehabilitation setting to facilitate treatment and discharge planning. The investigator provided little information about the psychometric properties of the NAQ.

Weitzenkamp, Gerhart, Charlifue, Whiteneck, and Savic (1997) examined the impact of caregiving on the spouses of 124 individuals with SCI more than 2 decades postinjury. Eighty of the spouses reported being caregivers, whereas 44 were classified as noncaregivers. Participants responded to a series of surveys and questionnaires, including the Quality of Life and Individual Needs Questionnaire (Flanagan, 1978, 1982), which addresses 15 different needs categories (e.g., material comforts, relationships, activities). A majority of spouses rated health, safety, and relationship needs as very important. The need to have children was also rated as very important. Needs for family relationships, relationship with spouse, material comforts, and having children were rated as very well met by the majority of spouses. Comparisons between caregiving and noncaregiving spouses revealed no differences regarding importance ratings or the extent to which needs were met. Level of injury was not associated with any between-group differences, and there were no differences between the groups regarding age, duration of injury, or length of marriage.

In most of the existing SCI family needs studies, family needs have been a secondary focus. Sample sizes have been very small, with a majority of studies having samples of 10 or fewer participants. Investigators have rarely provided information regarding the psychometric properties of assessment tools. In fact, although Weitzenkamp et al. (1997) studied the largest sample, they did so using a generic measure designed for the general population and did not examine injury-related needs.

The needs of families following traumatic brain injury (TBI) have been examined more extensively (Campbell, 1988; Engli & Kirsivali-Farmer, 1993; Junque, Bruna, & Mataro, 1997; Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Kreutzer, 1988; Kreutzer, Serio, & Berquist, 1994; Mathis, 1984; Mauss-Clum & Ryan, 1981; Moules & Chandler, 1999; Serio, Kreutzer, & Gervasio, 1995; Serio, Kreutzer, & Witol, 1997; Sinnakaruppan & Williams, 2001; Stebbins & Leung, 1998; Witol, Sander, & Kreutzer, 1996). The Family Needs Questionnaire (FNQ) was developed by Kreutzer (1988) specifically for brain injury and has been a prevalent assessment tool in these studies (Kolakowsky-Hayner et al., 2001; Kreutzer et al., 1994; Moules & Chandler, 1999; Serio et al., 1995, 1997; Stebbins & Leung, 1998; Witol et al., 1996). A series of investigations has revealed that the need for health information, reassurance, and clear and honest portrayal of complete information are often rated as most important (Kreutzer et al., 1994; Witol et al., 1996). In contrast, personal needs are commonly rated as less important (e.g., having help with housekeeping, spending time with friends, discussing his or her feelings, and having others understand how difficult the situation is for them; Kreutzer et al., 1994; Witol et al., 1996). Longitudinal analyses revealed that needs change over time (Witol et al., 1996), suggesting that serial assessment of family needs is necessary. Another investigation by Serio et al. (1995) found that relatives' appraisals of patients' neurobehavioral status were a strong predictor of family needs. Finally, Moules and Chandler (1999) found that high levels of unmet needs were associated with significantly higher levels of psychiatric morbidity and perceived lower quality of life.

Prior SCI studies have provided some guidance regarding fam-

ily needs. However, in nearly all studies, family needs were a secondary focus of investigation. This article describes an investigation of family members' needs during acute rehabilitation following SCI. The primary objective of the investigation was to evaluate the perceived importance of family needs and the extent to which needs were met. A secondary purpose was to evaluate the applicability of the FNQ, which was standardized on TBI populations.

Method

Participants

Family members, identified by the patient as the primary caregiver, were eligible to participate if they met the following criteria: (a) The patient had a medically documented SCI and (b) both the family member and patient were aged 18 years or older. Only 1 family member participated from each family. Two family members declined to participate. Seventeen adult family members of patients with a primary diagnosis of SCI participated in the study. Mean age of participants was 43.94 years, with a range from 20 to 83 years ($SD = 15.68$). Mean time since injury was 44.81 days (range = 13–76 days). Family members were primarily mothers (35%) or wives (29%) of patients. The remainder of participants consisted of husbands (6%), sisters (12%), girlfriends (12%), and others (6%). Most (84%) lived with the patient at the time of the injury. Family income was coded categorically. Approximately one third (36%) of family members reported income between \$0 and \$19,999. Twenty-nine percent reported annual income greater than \$50,000. Educational level was primarily high school or above (77%). With regard to employment, 35% of participants worked full time, 18% worked part time, 29% were not working and not seeking work, 6% were not working and seeking work, and 12% were retired, homemakers, or students.

Patients

Patients were individuals with SCI on a Commission on Accreditation of Rehabilitation Facilities (CARF)-accredited inpatient rehabilitation unit of a designated SCI Model Systems. The greatest number of patients was male (77%) and African American (47%). Mean age of patients was 36.0 years (range = 19–81 years, $SD = 17.16$). Marital status was fairly evenly divided between married (35%) and single (29%); 6% ($n = 1$ each) fell into the categories of divorced, separated, cohabitating, and in a steady relationship, and data were missing from 2 individuals. Most injuries resulted from motor vehicle accidents (35%), gunshot wounds (24%), or falls (24%). Level of injury varied greatly, ranging from C4 to L2, with the greatest number of patients having complete injuries (ASIA A; 41%) and paraplegia (77%).

Instruments

The FNQ (Kreutzer, 1988) is a 40-item self-report questionnaire originally developed for use with families of patients with brain injury to assess their perceived needs. The statements were designed to address diverse psychosocial and educational needs apparent in the acute and postacute phases after injury. Family members rate the extent to which needs are perceived as important on a scale with values ranging from 1 to 4 (i.e., 1 = not important, 2 = slightly important, 3 = important, and 4 = very important). Respondents also rate the degree to which each need has been met (not met, partly met, or met).

An early investigation (Kreutzer et al., 1994) provided evidence of content and construct validity. Internal consistency was indicated by a Spearman-Brown split-half reliability of .75. A later factor analytic investigation (Serio et al., 1997) revealed six independent factors comprising six

scales: Health Information, Emotional Support, Instrumental Support, Professional Support, Community Support Network, and Involvement With Care (Serio et al., 1997). Internal consistency for individual factors was indicated by Cronbach's alphas ranging from .78 to .89. Three of the 40 items did not load on one of the six factors. Nevertheless, they were retained because of their potential value.

Procedure

A prospective design was used. Family members of consecutive patients on the acute inpatient unit were identified, the study was presented to them by a trained research assistant, and informed consent was obtained. Family members were asked to complete the FNQ at that time. Demographic and injury-related information was gathered from medical charts and interviews with patients and family members.

Data Analyses

Descriptive statistics, including means, standard deviations, ranges, and frequency distributions, were generated to characterize study participants and the sample of patients. Means and standard deviations were calculated for the six FNQ scale ratings of importance and degree to which needs were met. Items from the FNQ were rank ordered to determine the relative importance of individual needs and the extent to which individual needs were perceived as met. Frequency distributions were generated to characterize the extent to which needs were met.

Results

The first set of analyses examined importance ratings and focused on the six FNQ scales. The Health Information scale had the highest mean importance rating ($M = 3.82$, $SD = 0.21$), and the Instrumental Support scale had the lowest ($M = 3.16$, $SD = 0.57$). Mean importance ratings for the Emotional Support, Professional Support, Community Support Network, and Involvement With Care scales were 3.38 ($SD = 0.43$), 3.77 ($SD = 0.31$), 3.56 ($SD = 0.45$), and 3.59 ($SD = 0.53$), respectively.

Mean importance ratings for each of the 40 items were calculated, and values ranged from 2.71 to 4.00. FNQ items were then rank ordered on the basis of the mean importance ratings. Table 1 shows the 10 needs rated by family members as most important

(range = 3.81–4.00); 7 were components of the Health Information scale. Professional Support and Community Support Network items also had high mean values.

Analysis provided evidence that the FNQ addressed issues relevant to participants. For example, 18 of the 40 FNQ items were rated as important or very important by all participants. The remaining 22 items were rated as important or very important by at least half of the participants. All participants rated the need "to have my questions answered honestly" as very important. None of the mean importance ratings fell below 2.71.

A list of needs with the lowest mean importance ratings are shown in Table 2 (range = 2.71–3.40). Half of the items were components of the Instrumental Support scale. The remaining five were components of the Emotional Support and Community Support Network scales.

The final set of analyses focused on the extent to which needs were rated as met, partly met, or unmet. Mean percentage of needs rated as met for the six scales ranged from 43% to 68%. Values for the Health Information, Community Support Network, and Involvement With Care scales were all greater than 60%. Two of the scales, Emotional Support and Instrumental Support, had mean percentages lower than 50%.

FNQ items were then rank ordered on the basis of the extent to which each need was rated as met, partly met, or unmet. Table 3 depicts the needs described as met by at least 70% of family members. Health Information scale items were best represented.

Needs most often rated as not met are given in Table 4. Analysis of the items reveals several themes underlying the most salient unmet needs. First, family members voiced a great need for encouragement to be assertive in requesting assistance from others. A need for greater support and understanding from family, friends, employers, coworkers, and teachers was expressed. Second, concern was noted about having sufficient resources to address patients' physical, emotional, cognitive, and behavioral needs. Finally, family members expressed a need for help preparing for a difficult and uncertain future. Overall, the mean percentage of needs rated as met, partly met, or unmet were 47% ($SD = .28$), 26% ($SD = .23$), and 11% ($SD = .17$), respectively.

Table 1
Needs With the Highest Importance Ratings

I need . . .	<i>M</i>	Scale
To have my questions answered honestly.	4.00	Health Information
To have complete information on the patient's physical problems.	3.94	Health Information
To have complete information on the medical care of traumatic injuries.	3.94	Health Information
To be assured that the best possible medical care is being given to the patient.	3.88	Health Information
To have explanations from professionals given in terms I can understand.	3.88	Health Information
To have a professional to turn to for advice or services when the patient needs help.	3.88	Community Support Network
To have complete information on the patient's problems in thinking.	3.82	Health Information
To have different professionals agree on the best way to help the patient. ^a	3.82	
To be told about all changes in the patient's medical status.	3.82	Health Information
To have enough resources for myself or the family.	3.81	Professional Support

^a Not a component of any of the six scales.

Table 2
Needs With the Lowest Importance Ratings

I need . . .	M	Scale
To spend time with my friends.	2.71	Instrumental Support
To be reassured that it is usual to have strong negative feelings about the patient.	2.81	Emotional Support
To have help keeping the house.	2.82	Instrumental Support
To be encouraged to ask others to help out.	3.07	Emotional Support
To get a break from my problems and responsibilities.	3.18	Instrumental Support
To have help from other members of the family in taking care of the patient.	3.24	Instrumental Support
To discuss my feelings about the patient with other friends or family.	3.25	Community Support Network
To pay attention to my own needs, job or interests.	3.29	Instrumental Support
To have the patient's employer, coworkers, or teachers understand his/her problems.	3.36	Community Support Network
To have my partner or friends understand how difficult it is for me.	3.40	Emotional Support

Discussion

A variety of methodologies have been used to examine the needs of family members and significant others after SCI. Despite differences in methodology, the results of the present investigation are consistent with past studies. Hart (1981) identified two needs as paramount, the need to feel adequately informed and the need to know that patients were receiving high-quality care in a supportive environment. Respondents also highlighted the value of early and continuing communication about patients' conditions, prognoses, and care. The needs described by Hart are reflected in the FNQ's Health Information scale, which had the highest mean importance ratings in the present investigation. Needs rated as most important by the present sample of respondents included "to have my questions answered honestly," "to have complete information on the patient's physical problems," "to be assured that the best possible medical care is being given to the patient," and "to have a professional to turn to for advice or services when the patient needs help." In both studies, family members' needs for emotional support were rated as important but not as important as needs relating to patients' medical care. The findings of Vargo (1984) and Stanton (1984) also highlight family members' needs for health information.

Health information needs have also been identified as very important by family members of persons with brain injury. In their 1994 study, Kreutzer and colleagues, using the FNQ, described the needs most often rated as important by family members of outpatients averaging 16 months postinjury. Six of the 10 needs rated as most important were Health Information needs. Consistently, in the present investigation with an inpatient sample, Health Information needs comprised 7 of the 10 most important needs. Seven of the 10 needs rated as most important in both studies were identical, though the studies were conducted in different settings with different patient populations.

Similarities between brain injury and SCI samples were also observed with regard to the nature of met and unmet needs. In the present investigation, needs relating to professional guidance availability, consensus regarding treatment approach, medical care information, honest answers to questions, and information on physical problems were among those most frequently rated as met. The same needs were also rated as most frequently met in the TBI study by Kreutzer et al. (1994). Similarly, in the present investigation, the five needs most frequently rated as unmet related to seeking help from others, preparing for the worst, behavior management, housekeeping help, and resolving fears about the future.

Table 3
Family Needs Most Frequently Rated as Met

I need . . .	Endorsement (%)	Scale
To be shown that my opinions are used in planning the patient's treatment, rehabilitation, or education.	82	Involvement With Care
To have a professional to turn to for advice or services when the patient needs help.	82	Community Support Network
To have different professionals agree on the best way to help the patient. ^a	77	
To have complete information on the medical care of traumatic injuries.	77	Health Information
To have help in deciding how much to let the patient do by himself/herself.	77	Professional Support
To have my questions answered honestly.	71	Health Information
To have complete information on the patient's physical problems.	71	Health Information
To have help from other members of the family in taking care of the patient.	71	Instrumental Support

^a Not a component of any of the six scales.

Table 4
Family Needs Most Frequently Rated as Unmet

I need . . .	Endorsement (%)	Scale
To be encouraged to ask others to help out.	42	Emotional Support
To have enough resources for the patient.	38	Professional Support
Help preparing for the worst.	36	Emotional Support
To be shown what to do when the patient is upset or acting strange.	31	Professional Support
To have help keeping house.	27	Instrumental Support
Help getting over my doubts about the future.	27	Emotional Support
To have complete information on drug or alcohol problems and treatment.	27	Health Information
To have complete information on the patient's problems in thinking.	24	Health Information
To have the patient's employer, coworkers, or teachers understand his/her problems.	23	Community Support Network
To discuss my feelings about the patient with other friends or family.	21	Community Support Network

The same needs were among the 10 most frequently rated as unmet in the TBI study.

Family needs have been the focus of many studies in the brain injury literature but have received scant attention in the SCI literature. A vast majority of needs were rated as important, suggesting that the FNQ, a measure widely used in studies of families after brain injury, is relevant to the SCI population. Within the constraints of the small sample, ratings of needs' importance and the extent to which needs were met were strikingly similar to the pattern of findings reported by brain injury researchers (Kolakowsky-Hayner et al., 2001; Kreutzer et al., 1994; Witol et al., 1996). The findings support the applicability of the FNQ to SCI populations and indicate that the FNQ shows promise as a means of assessing families' needs following SCI.

The limitations of the present investigation require consideration. The sample was small and limited to patients who had visiting family members. Data were collected once in a single treatment setting from one family member. Future studies should involve larger samples, data collection at multiple research sites, and repeated measurement. Several family functioning measures should be administered and compared, allowing a more holistic appreciation of family functioning. Factor analytic procedures would help identify whether the factor structure for SCI families is comparable to that of TBI families. Future studies can also examine how injury, socioeconomic status, ethnicity, employment status, and other factors relate to family needs. Furthermore, comparisons between families in acute and postacute settings would enhance understanding of the impact of environmental factors. In addition, longitudinal studies would provide valuable information on changes in needs over time after SCI. The TBI family literature provides useful prototypes for longitudinal needs research (e.g., Witol et al., 1996).

Consideration should be given to adapting the FNQ for the SCI population. The FNQ was developed for families of persons with brain injury. Cognitive and neurobehavioral problems are more prominent among patients with brain injury, whereas mobility problems are more common among patients with SCI. Future SCI studies should examine the benefits of including new items especially relevant to SCI and omitting items specifically related to brain injury.

Early FNQ studies looked only at the needs met ratings for

needs identified as important or very important by each respondent. The present investigation examined needs met ratings for all items regardless of importance ratings. There may be a relationship between importance ratings and ratings of the extent to which needs are met. Future research should seek to ascertain whether needs rated as unmet are seen as important.

Findings derived from the present investigation have implications for clinical practice. Acute rehabilitation programs often include family education. The present findings provide evidence that family members highly value information from professionals relating to patients' clinical care, physical problems, and cognitive difficulties. The data suggest that family members prefer honest information provided in understandable terms. The present findings also indicate that many family members have unmet needs relating to emotional support and help with responsibilities. With decreasing inpatient lengths of stay, rehabilitation programs may be hard pressed to meet such needs. However, on a case-by-case basis, clinicians can examine FNQ responses to appreciate the needs of each family member and develop individualized support programs. Creative problem solving, developing extended support systems, and community referral can help to better address family members' needs.

The FNQ has potential value for program development and evaluation. In the context of program development, examining family members' FNQ responses can help professionals identify needs of greatest importance and areas where needs are most often unmet. Comparing family members' FNQ responses before and after program change can help program evaluators identify the benefits and shortcomings of those changes.

Rehabilitation professionals often agree that families are greatly affected by SCI and play an important role in rehabilitation and long-term care. However, we have little empirical information about family members' needs. Hopefully, the present investigation will serve as a catalyst for SCI researchers to systematically explore family members' needs using quantitative tools.

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