Research Article

Caregiver expectations of recovery among persons with spinal cord injury at three and six months post-injury: A brief report

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Objective: Caregivers of patients with spinal cord injury (SCI) have increased risk of depression, anxiety, and diminished quality of life. Unmet expectations for recovery may contribute to poorer outcomes.

Design: Prospective, longitudinal observation study.

Settings: Trauma/Critical care ICU at baseline, telephone for follow-ups.

Participants: Caregivers of patients with SCI ($n = 13$).

Interventions: None.

Outcome Measures: Expectations for recovery were assessed across four primary domains identified in a review of the literature including: pain severity, level of engagement in social/recreational activities, sleep quality, and ability to return to work/school. Caregivers' forecasts of future recovery were compared to later perceived actual recovery.

Results: At three months, 75% of caregivers had unmet expectations for social engagement recovery, 50% had unmet expectations for pain decrease, and 42% had unmet expectations for sleep improvement and resuming work. Rates of unmet expectations were similar at six months, with 70% of caregivers reporting unmet expectations for social engagement recovery, 50% with unmet expectations for pain decrease, and 40% with unmet expectations for sleep improvement.

Conclusion: Unmet caregiver expectations for recovery could pose a risk for caregiver recovery and adjustment. Our results show that caregiver expectations merit further investigation for their link with caregiver mental health.

Keywords: Family members, Caregivers, Caregiver expectations, Recovery, Spinal cord injury

Introduction

Despite advances in medical science, traumatic spinal cord injury (SCI) often results in enduring changes in health, function, employment, and community participation.¹ Subsequently, any aspect of recovery, such as re-integration into the community can be a challenging prospect for patient and family alike.² For example, people with SCI have reported difficulty with social participation following injury due to factors such as pain,

difficulty sleeping, trouble returning to work, and lack of engagement in social/recreational activities.^{3,4}

Families also struggle with the challenges of adjustment as a result of their loved one's experiences. For example, determinants of health-related quality of life (HRQOL) such as physical functioning and reported pain in persons with SCI have been linked to their family caregiver's burden, satisfaction with life, depression, self-esteem, and anxiety.⁵ Studies have also reported higher depression rates in caregivers compared to individuals with SCI, emphasizing the emotional burden on the caregiver.⁶⁻⁸ In addition, poorer recovery outcomes such as participation in fewer rewarding activities⁹ and decreased

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mobility have been associated with higher depression among people with SCI,¹⁰ although little is known about the effect of caregiver's expectations of recovery on the caregiver's mental health. To our knowledge, there is no protocol in place to create accurate expectations for recovery in caregivers of people with SCI.

Unmet expectations for patient improvement are a potential contributor to risk for depression in caregivers. Therefore, the objectives of this brief report are to (1) describe caregiver expectations during acute hospitalization for patient recovery in terms of pain attenuation, engagement in social and recreational activities, sleep, and return to work or school and (2) compare these caregiver expectations to perceived recovery at three- and six-month follow-ups.

Methods

Participants

Data from family members of individuals with traumatic SCI were extracted from a larger, longitudinal study of family members of trauma/critical care patients in the intensive care unit (ICU) of an urban Level I trauma center. Family members were defined according to the Institute of Patient and Family Centered Care as "two or more persons who are related in any way-biologically, legally, or emotionally,"¹¹ and are referred to as caregivers for the purposes of the study. Caregivers were screened between March 2013 and November 2014. Traumatic SCI was identified using ICD-9 codes 806 and 952.¹² Inclusion criteria were adult family members (*i.e.* ≥ 18 years), of adult patients admitted to the ICU service for greater than 48 h with an expected survival greater than 96 h, who anticipated spending time with the patient in a caregiver or supportive role (*e.g.* emotional, social, financial) after discharge. Exclusion criteria included the inability to understand written or spoken English at the 8th grade level and the inability to provide at least two forms of contact information for follow-ups. Caregivers approached for the study were also given resources and opportunity to speak to psychology staff regardless of their participation.

Approval to complete the study was obtained from the medical center's Institutional Review Board. Caregivers who met inclusion criteria were consented and enrolled in a private room during the patients' initial inpatient admission to the trauma/critical care ICU. Three- and six-month follow-up assessments were completed via telephone.

Measures

Caregiving expectations

Given the lack of standard measures for unmet expectations among caregivers, the caregiving expectations

measures were investigator-constructed measures of baseline-expected caregiving burden relative to follow-up actual caregiving burden. Caregivers were asked, "what percentage of your time do you expect to be in a caregiving role?" at baseline and again at subsequent follow-ups to determine their caregiving expectations over the following three-month period. At three- and six-month follow-ups, caregivers were also asked to report their actual amount of caregiving by asking "what percentage of your time have you spent in a caregiving role for your loved one?". Caregivers could respond from 0–100%, with greater caregiving than expected calculated as actual caregiving that surpassed their previous expectations at three- and six-month follow-ups.

Recovery expectations

Expectations of SCI recovery were similarly assessed across four primary domains identified in a review of the literature^{13–17} including: pain severity, level of engagement in social/recreational activities, sleep quality, and ability to return to work/school. Questions were administered at baseline with the prompt, "To what percent do you believe the following will improve in three months?" The same question was asked at the three-month follow-up. To assess perceived improvement, the question "To what percent have the following improved in the past three months?" was asked at each follow-up. Caregivers could respond from 0–100%, with unmet expectations for improvement among our four domains determined by subtracting the expected amount of improvement by next follow-up from the actual amount of improvement at the time of follow-up.

Data analysis

Descriptive analysis was completed for all caregiver data including frequencies, medians, means, standard deviations, interquartile ranges (IQR) and percentages for caregiver and recovery expectations.

Results

Thirteen family members were enrolled in the study, accounting for 10 patients with SCI, as 2 persons had more than one family member included in this analysis. Of those 13, 12 completed a three-month follow-up and 10 completed a six-month follow-up. Reasons for attrition included (a) one person with SCI passing away prior to 3-month follow-up and (b) two being unable to contact for 6-month follow-up. The sample was primarily female (77%) and Caucasian (54%) with a mean age of 42.4 ± 8.3 years. Seven participants were

caregivers of persons with complete tetraplegia, five with incomplete tetraplegia, and one with incomplete paraplegia. Forty six percent of the sample were parents, 38% were spouses, and 8% were siblings. Baseline measures were administered a median of 15 days following patient admission to the ICU.

Baseline

Within the first three months after injury, caregivers expected to be responsible for 100% of the caregiving required, that patients' pain would decrease by a Median Equal Error Rate (EER) of 60% (IQR = 50–85), engagement in social/recreational activities would improve by 60% (IQR = 50–77.5), sleep would improve by 70% (IQR = 30–90), and work/school responsibilities would resume by 20% (IQR 0–77.5).

Three- and six-month follow-up

At three months, the median time spent in a caregiving role for the entire sample was 80% (IQR = 35–90), with 45% ($n = 5$) of caregivers considering themselves to be the primary caregiver, and 75% of their loved ones still in an inpatient setting. At six months, the median time spent in a caregiving role for the entire sample was 33% (IQR = 10–58), with 60% ($n = 6$) of caregivers considering themselves to be the primary caregiver.

Seventeen percent of caregivers at three months and 10% percent of caregivers at six months reported that they gave more care than expected, respectively. Across SCI recovery domains, 75% of caregivers had unmet expectations for engagement in social activity, 50% had unmet expectations for pain decrease, and 42% had unmet expectations for sleep improvement and resuming work at the three-month follow-up. The rates of unmet expectations for recovery were similar at the six-month follow-up. Table 1 outlines the expected caregiving improvement at baseline to perceived caregiving and improvement at three and six months.

Discussion

To our knowledge, the present study is the first to explore expectations of caregivers of persons with a traumatic SCI, specifically as it applies to the acute phase of injury and recovery. Results indicate that, while some caregivers of patients with SCI aptly estimated the extent of their future caregiving responsibilities, others tended to overestimate the extent to which their loved ones would recover three and six months after injury, particularly with their social recovery and pain management. Given the association between the HRQOL between persons with SCI and their family caregivers,⁵ overestimation in expectations of recovery is a likely

Table 1 Unmet expectations for recovery.

Expectancy domain	3-month ($n = 12$)	6-month ($n = 10$)
Care more than expected	2 (17%)	1 (10%)
Pain decreased less than expected	6 (50%)	5 (50%)
Engage in social activity less than expected	9 (75%)	7 (70%)
Sleep improved less than expected	5 (42%)	4 (40%)
Resumed less work responsibilities than expected	5 (42%)	2 (20%)

Actual recovery at three months was compared to expectations at baseline, and actual recovery at six months was compared to expectations at three months.

Note: Table values denotes sample size and frequency within given timepoint.

influential factor between patient recovery and caregiver well-being, e.g. whether unmet expectations are predictive of poorer outcomes for their loved ones' outcomes, as well as their own well-being.⁵

Further investigation is encouraged given several limitations present within the study, most noteworthy of which were the investigator-created expectancies measures that lack psychometric support and require additional validation. The study effects are strongly attenuated by its sample size and sex disproportionality (*i.e.* largely female), limiting the ability to assess individual differences (e.g. experience, specific responsibilities); however, we believe are enough to provide an example of *perceptions* of improvement after SCI. Further, larger samples can help parse apart differences between different forms and readiness for caregiving, such as financial or daily physical caregiving, differences in education, differences in caregiver experiences by sex, experience or available resources and assistance, and other expectations beyond time involvement and improvement.

Conclusions

Despite these limitations, these preliminary findings suggest that unrealistic expectations of SCI recovery from family members following injury warrants further research as a potential risk to caregiver wellbeing and adjustment. Such research highlights the need for education and realistic goal-setting in the acute care setting.

Disclaimer statements

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