

Research article

# Breaking the news: A pilot study on patient perspectives of discussing prognosis after traumatic spinal cord injury

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**Objective/Background:** In spinal cord injury (SCI) medicine, informing a patient with a neurologically complete SCI of the poor prognosis (“bad news”) for significant neurological recovery (e.g. ambulation) is difficult. Few guidelines exist for clinicians and the wishes of patients in receiving this information are currently not known. The goal of this pilot study was to determine when, by whom, and in what setting persons with neurologically complete traumatic SCI want to hear of their prognosis.

**Methods:** Subjects with a >3 months motor complete SCI above T10 were recruited to complete an online survey, from three geographically different acute rehabilitation centers, to obtain retrospective information on their experiences of receiving poor prognosis. A mixed methods approach was used to obtain data on individual experiences and a combination of quantitative and qualitative analyses was used to assess patterns in individual responses.

**Results:** 60 individuals were recruited for the study and 56 participants completed the survey. Most heard their prognosis from a physician, in the acute care hospital (61%), with the patient initiating the conversation (64%). Patient recommendations reveal that most individuals with traumatic SCI prefer to be given the poor prognosis for neurological recovery by a physician and early after injury. There were no differences in patient experience nor recommendations based on demographic background (i.e. sex, age, race, or education level).

**Conclusion:** The majority of patients surveyed report wanting to know their prognosis early after injury and to hear the information by a physician in a clear and sensitive manner. This study marks the first step towards defining how and when to break the news regarding poor prognosis for neurological recovery including ambulation after severe (neurological complete) traumatic SCI from the patients’ perspective.

**Keywords:** Communication, Complete paraplegia, Complete spinal cord injury, Complete tetraplegia, Physician-patient relations, Prognosis

## Introduction

Breaking “bad news” to patients and families is an inevitable and necessary task for professionals dealing with medical conditions that have a negative prognosis, such as permanent paralysis after a severe traumatic spinal cord injury (SCI). It is incumbent upon clinicians to deliver this information in a manner that is sensitive,

educational, and prepares the patient for the challenges that lie ahead.

To our knowledge there is no empirical literature providing patient perspectives or preferences on when and how to deliver bad news to patients who have sustained a traumatic SCI. Professional recommendations of discussing prognosis with patients with SCI are based upon clinical experience in SCI, and recommendations from the literature in other similar acute, chronic conditions.<sup>1–3</sup> At this juncture, there is a need for SCI-specific information, particularly from the perspective of persons with SCI.

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The topic of communicating life-altering issues with patients has been particularly well-studied in oncology and suggests that the way bad news is delivered affects the patient's ability to perceive and process the information and subsequent decision-making.<sup>4-11</sup> Approximately 80% of cancer patients want to know right away the details regarding their prognosis; whether the prognosis is good or bad.<sup>4,10,12</sup> Those who perceive an adequate encounter with the physician are less likely to report subsequent development of depression or anxiety. Patients most often wanted to know about treatments available, including current and future research.

Comparatively, in the field of Rehabilitation Medicine there has been minimal research attention and few guidelines for clinicians regarding when patients want to discuss their prognosis and how to best deliver the poor prognosis. Some research attention has been given to this issue in the stroke population. Post stroke, patients and caregivers reportedly want to know information regarding prognosis and recovery early in the acute period.<sup>13</sup> One report discussed delivering bad news in the stroke population<sup>14</sup> and another described a formal training program for a stroke rehabilitation team<sup>15</sup> using the COMFORT technique.<sup>16</sup> In the developmental disability literature (e.g. spina bifida, cerebral palsy and Down's Syndrome) there are a number of reports regarding the importance of relaying information to parents informing them of their child's disability.<sup>17-19</sup> There is general agreement that parents want to be told as soon as possible about the diagnosis, in a direct but sympathetic manner, along with enough information to help understand the situation.

This study was therefore undertaken to assess the recalled experiences of patients with SCI including preferences for the timing (when) and personnel (who) involved in discussing SCI prognosis with persons who sustained a neurologically complete SCI. We used a cross-sectional design of a convenience sample of persons living with chronic SCI to obtain a mix of qualitative and quantitative information on how they received the information of their chronic paralysis and what they would recommend for how SCI clinicians "break the news." This information would hopefully serve as a guide for SCI professionals for their future encounters.

## Methods

### Design

This study used a cross-sectional survey design. Due to a dearth of existing research in this area for SCI, this exploratory pilot study used a mixed methods approach to obtain descriptive information about patient

experiences and recommendations for communication following motor complete traumatic SCI. A series of closed and open-ended survey questions were developed by an SCI physiatrist and psychologist based on clinical feedback from prior patients. The survey questions were then pilot tested on a small convenience sample ( $n = 4$ ) of former patients and reviewed by research personnel with extensive SCI experience. Data was collected using a series of questions with pre-determined response categories combined with open-ended items to capture further descriptive information on individual experiences. All surveys were completed online. All study materials and procedures were approved by the institutional review boards at each collaborating site.

### Participants

A convenience sample of individuals with a diagnosis of a traumatic SCI, were recruited for this study via flyers placed in the outpatient clinics at three SCI medical rehabilitation facilities (New Jersey, North Carolina and California). Participants completed an informed consent and were included if they were between 18–80 years old, (males and females included), reported a neurologically complete SCI with a neurological level of injury above the tenth thoracic vertebrae (T10), with a neurological classification of American Spinal Injury Association (ASIA) Impairment Scale (AIS) A, were injured for at least 3 months, had the ability to recall the events of their discussion of prognosis for neurological recovery, completed acute inpatient rehabilitation, and reported no history of significant traumatic brain injury. Exclusionary criteria included non-traumatic injuries, AIS classification of B or motor incomplete injuries (AIS C, D), children younger than 18 years and adults over age 80, and persons with recent (i.e. less than 3 months) injuries. After meeting the criteria, each subject was given a unique anonymous sign-on to the website link. The only identifier was the site of recruitment. The consent form and questionnaire were administered via the Internet at <http://www.surveymonkey.com>.

With a recruitment goal of a pilot sample of 60 people, data collection was completed after four months. Four surveys were excluded due to lack of completion yielding a final sample of  $N = 56$  for analysis.

### Measures

Demographic information (gender, race/ethnicity, education level, and age) was self-reported using standard survey items (e.g. male or female; less than high school education) used in survey research. The remainder of the questions covered areas of the timing of the

initial and subsequent discussion of SCI prognosis, personnel who discussed this with them, whether they or clinicians initiated the conversation their initial emotional responses, as well as open ended questions on recommendations as to how and when this discussion should take place with persons with SCI.

### Analysis

Descriptive statistics and bivariate tests (i.e.  $\chi^2$ ) were used to assess patterns and group differences in the quantitative data obtained from the closed survey questions with pre-determined response categories. Open-ended responses were analyzed thematically and compared across cases to understand the ways in which persons with SCI experienced their prognosis and processed their discussion of the long-term implications of motor complete SCI.

## Results

### Sample characteristics

Fifty-six individuals with a diagnosis of a neurologically complete SCI completed the survey. The majority of the participants (73.2%) reported residing in the New Jersey metro area (the lead site for the study), with smaller percentages (17.9% and 8.9%) recruited from collaborating hospitals in Southern California and North Carolina, respectively. The demographic and injury-related characteristics of the participants are reported on Table 1. The sample was largely composed of males and persons under age 50, which is characteristic of the traumatic SCI population. Respondents predominantly identified as Non-Hispanic White (73.2%) and were well educated, with over 60% reporting some post-secondary education. The method of data collection which required Internet access to complete the survey which may have also resulted in a sample that was more highly educated and younger, in general, in comparison to the overall SCI population. Over half of the respondents reported lower-level cervical injuries (Table 1). The majority of respondents also represented persons who have lived with SCI for a number of years compared to newly injured individuals. Vehicular accidents represented the most common injury etiology.

### Patient experiences

The majority of respondents reported that they received news of their SCI prognosis from a physician—specifically a surgeon (39.3%) or a physiatrist (SCI specialist) (21.4%) (Table 2). The involvement of other health care professionals (e.g. neurologist, therapist, or nurse) was less commonly reported. Approximately 20% of individuals reported that a clinician did not break the news but

rather a family member or friend reportedly gave them their initial information regarding prognosis. In the majority of the experiences reported in this study, this discussion occurred during the patients' acute hospitalization (61%), suggesting that prognosis is most often discussed early after injury. The patients reported initiating this process (i.e. asking for prognosis) themselves more commonly (64%) as opposed to being approached by a clinician, and most reported understanding their prognosis after this first discussion (74.5%). Follow-up discussions were reported to occur in slightly less than half the cases (46%) and again were largely initiated by the patients. The majority of these follow up discussions occurred with a physiatrist (61.5%) and in the rehabilitation setting. Differences in prognosis experiences by demographic subgroups (i.e. sex, age, race/ethnicity, and education level) were tested and found to be not significant.

### Patient recommendations

The second step in this analysis was to assess patient recommendations for how SCI prognosis should be handled—specifically, from whom and when. The results of  $\chi^2$  tests to assess differences in these recommendations by prior patient experiences are presented on Table 3a. The majority of the sample recommended that the discussion of SCI prognosis occur with a surgeon or physiatrist, and the results suggest that this was partially influenced by prior experience. The majority of the persons who received their prognosis from another health professional (e.g. psychologist or other therapist) recommended that the news should be delivered from a physician, and nearly all of the individuals who received the news from another source (e.g. family member or friend) indicated a preference for the news to be conveyed by a physician.

As indicated on Table 3b, the sample was evenly divided between wanting to know their prognosis after injury during the acute care phase (51%) or during inpatient rehabilitation (47%). Tests of association between participants' reported experiences and recommendations, indicated a modest influence of how patients received their SCI prognosis and how they believed the interaction should occur ( $\chi^2 = 17.1388$ ,  $df = 9$ ,  $P = 0.047$ ). There is an approximate 60/40 split among persons who received prognosis early (during acute hospitalization). Although the majority (~60%) of those who received prognosis during acute hospitalization felt that this was appropriate while close to 40% would have preferred this discussion take place during rehabilitation. Similarly, slightly greater than 50% of individuals who had the initial discussion in the rehabilitation setting recommend this time frame (Table 3b).

**Table 1 Sample characteristics (N = 56)**

	<b>N (%)</b>
<i>Demographic Characteristics</i>	
Sex	
Male	49 (87.5)
Female	7 (12.5)
Age (years)	
18–30	10 (17.8)
31–40	17 (30.4)
41–50	17 (30.4)
50 and older	12 (21.4)
Race/ethnicity	
Non-Hispanic White	41 (73.2)
Black	9 (16.1)
Hispanic	5 (8.9)
Asian	1 (1.8)
Education	
Less than high school	2 (3.6)
High school graduate	19 (33.9)
Some college or more	35 (62.5)
<i>Injury Characteristics</i>	
Injury level	
C1-C4	5 (8.9)
C5-C8	31 (55.4)
T1-T9	20 (35.7)
Affected limbs	
Legs only	24 (42.9)
Arms and legs	32 (57.1)
Injury duration (years)	
Less than 3	9 (16.0)
3–10	17 (30.4)
11 or more	30 (53.6)
Etiology	
Falls	10 (17.9)
Vehicular	27 (48.2)
Violence	5 (8.9)
Recreational	12 (21.4)
Other	2 (3.5)

**Table 2 Patient reported experiences with spinal cord injury prognosis**

	<b>First discussion (N = 56)</b>	<b>Second discussion (N = 26)</b>
	<b>N (%)</b>	<b>N (%)</b>
Who discussed prognosis		
Surgeon	22 (39.3)	1 (3.9)
Physiatrist	12 (21.4)	16 (61.5)
Neurologist	5 (8.9)	6 (23.1)
Nurse/PT/OT	6 (10.7)	0 (0.0)
Other	11 (19.6)	2 (11.5)
Timing of discussion <sup>a</sup>		
Acute care	33 (61.1)	4 (15.4)
Rehabilitation hospital	19 (35.2)	21 (80.8)
Post-rehabilitation	2 (3.7)	1 (3.8)
Initiation of discussion <sup>a</sup>		
Patient	23 (63.9)	18 (85.7)
Physician or clinician	13 (36.1)	3 (14.3)
Understanding of discussion <sup>a,b</sup>		
Yes	38 (74.5)	23 (88.5)
No	13 (25.5)	3 (11.5)
Follow-up discussion <sup>a</sup>		
Yes	26 (47.3)	--
No	29 (52.7)	--

<sup>a,b</sup>N varies slightly due to non-response on certain items data.

**Table 3 Correspondence between patient experiences and patient recommendations**

	Recommended			
	Surgeon	Physiatrist	Other Clinician <sup>b</sup>	Other
<b>3a. Who discusses prognosis (N = 55) [Row Percentages]</b>				
Total Sample (%)	40.0	32.7	18.2	9.1
Actual (%)				
Surgeon	52.4	28.6	4.7	14.3
Physiatrist	33.3	58.3	0.0	8.3
Other Clinician <sup>a</sup>	36.7	18.2	45.5	0.0
Other	27.3	27.3	36.4	9.1*
	Acute care	Rehabilitation	Post-rehabilitation	
<b>3b. Timing of discussion (N = 51) [Row Percentages]</b>				
Total Sample (%)	51.0	47.0	2.0	
Actual (%)				
Acute care	58.1	41.9	0.0	
Rehabilitation hospital	44.4	50.0	5.6	
Post-rehabilitation	0.0	100.0	0.0	

$\chi^2$  tests of significance used to test group differences.

<sup>a</sup>Combines neurologist, nurse, PT, OT

<sup>b</sup>Combines neurologist, psychologist

\*P < 0.05

The most consistency was among persons who received the news from a surgeon or physiatrist. Most commonly, people who recommended that the physician discuss the prognosis had a physician present this in their personal experience (Table 3a). A few participants reported that the prognostic news was discussed with them by a nurse or a therapist (PT or OT), however no one recommended that these professionals should deliver the information. Additionally, no one reported that a psychologist led the discussion but a few suggested that they should be present for this discussion. Finally, the groups of patients who received their prognosis during acute versus rehab

did not differ overall in their recommendations for when the news of chronic paralysis should be given (Table 3,  $\chi^2 = 4.7061$ ,  $df = 4$ ,  $P = 0.319$ ).

#### **Suggested recommendations based upon open-ended responses**

In completion of the survey, 45/56 (80%) of the participants responded to the open-ended questions regarding their personal recommendations. Although a portion of these 45 respondents (29%) reported to “change nothing,” the majority of this subgroup gave recommendations for SCI prognosis discussions that were analyzed

**Table 4 Participant comments**

Be straight forward

“...be more stern on the fact that regaining of function is very unlikely. ... I got lost and depressed in the chance that I might regain function ... all this did was slow my emotional and mental recovery.”

“I would request the prognosis not be so vague.”

“I prefer honest and up front presentation of the facts.”

Show sensitivity

“More of a discussion/dialogue with more acknowledgment of the emotions involved.”

“Show some heart, don't discuss your golf game with an associate as you're walking out of the room.”

“...be a little less cold but I guess when you are shot people don't think of you as a really feeling person.”

Be more positive

“I would prefer the initial statement to be addressing the positive aspect of the condition. e.g. 'you are capable of doing almost all you did before the accident'.”

“The doctor should have stressed the continued opportunity for living a full life.”

“Hard to say bad news is bad news but don't make it life ending.”

Be prepared (patient and physician)

“...give me some time to rest. Ask if I'm ready to know my prognosis at this point; if I have someone in mind that I would want to be present. Find out if I know anything about SCI.”

(Note: commenter informed of prognosis on first night)

“... doctor should be] knowledgeable about it, accurate and readily available for questions should they not be thought of at the time the information is relayed. Explaining to a loved one...in my presence ... so that they could also formulate questions and an understanding of what is happening.”

(Note: This subject was informed in acute care.)

and divided into a number of common themes (Table 4). These categories include the recommendations for the physician to be straightforward, positive, and prepared when having this discussion with the patients. These comments are extremely noteworthy in understanding some of the patients descriptions of their experiences.

## Discussion

As the prognosis for a person who sustains a neurologically complete traumatic SCI for significant lower extremity motor recovery and functional ambulation is poor, communicating this bad news to patients and families is a challenging and stressful task. Currently, there are no definitive guidelines regarding how or when to deliver this message for practitioners of SCI medicine. Subsequently, there is little formal training of clinicians in this area. This pilot study, largely descriptive in nature, provides preliminary information about how physicians currently communicate with individuals with SCI regarding prognosis based upon patient recollection.

From the results of this survey, there are no demographic associations to determine a “profile” of an individual who would prefer to learn of the prognosis in a certain time. Most of the sample reported wanting to know their prognosis early and hear the information by a physician (surgeon and physiatrist most commonly). Furthermore, these patients recommend that SCI prognosis be delivered in a clear and sensitive manner. Patients seemingly feel comfortable asking the question regarding prognosis when they are ready to know the information. It is not surprising that more than half of the patients asked about their prognosis early after injury, as these results are consistent with the reports on persons of other conditions with poor prognosis for significant recovery. Our data indicated that for the majority of people their opinion was consistent with their experience (e.g. those who wanted to know in acute hospitalization and had discussion during their acute hospitalization), suggesting that most were pleased with their experience. However, there is a proportion that would have preferred the opposite of what they experienced. Further analysis did not yield any discernible pattern though by demographic and injury characteristics.

Although the patients reportedly understood their prognosis from the first discussion, they often wanted a follow up discussion, most commonly with the physiatrist in the rehabilitation setting. In addition, the recommendation of a psychologist being present may be of importance for clinicians to consider.

This pilot study was limited by a small, convenience sample, and recall bias related to the large number of

chronically injured individuals in the study. There are few patients close to their injury date (only 16%) and many patients greater than 10 years post-injury. Future studies would benefit from a sample that is more representative of the SCI population, particularly involving individuals who were more recently injured. Nonetheless, this study was an important first step in identifying patient’s perceptions and preferences for how and when they would like to receive the “bad news.” The combination of quantitative and qualitative data enabled us to compare experiences that have been previously documented in other patient populations as well as capture information that is specific to SCI. Finally, this investigation is one of the few studies that focused on patient’s preferences as the recipient of the news rather than solely on the physician’s perspective.

## Conclusion

The patient experience in SCI is similar to that of other similar conditions. The majority of the patients surveyed reported wanting to know their prognosis soon after injury and to hear the information by a physician in a clear and sensitive manner. It is hoped that additional work takes place in defining methods to break the news regarding poor prognosis for significant neurological recovery after severe traumatic SCI.

## Disclaimer statements

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