

2018

Development of a questionnaire to measure impact and outcomes of brachial plexus injury

Carol A. Mancuso

Weill Cornell Medical College

Steve K. Lee

Weill Cornell Medical College

Eliana B. Saltzman

Icahn School of Medicine at Mount Sinai

Zina Model

Rutgers Robert Wood Johnson Medical School

Zoe A. Landers

Hospital for Special Surgery, New York, NY

See next page for additional authors

Follow this and additional works at: https://digitalcommons.wustl.edu/open_access_pubs

Recommended Citation

Mancuso, Carol A.; Lee, Steve K.; Saltzman, Eliana B.; Model, Zina; Landers, Zoe A.; Dy, Christopher J.; and Wolfe, Scott W., "Development of a questionnaire to measure impact and outcomes of brachial plexus injury." *The Journal of Bone and Joint Surgery*.100,3. e14. (2018).

https://digitalcommons.wustl.edu/open_access_pubs/6645

Authors

Carol A. Mancuso, Steve K. Lee, Eliana B. Saltzman, Zina Model, Zoe A. Landers, Christopher J. Dy, and Scott W. Wolfe

Development of a Questionnaire to Measure Impact and Outcomes of Brachial Plexus Injury

Carol A. Mancuso, MD, Steve K. Lee, MD, Eliana B. Saltzman, BS, Zina Model, BA, Zoe A. Landers, MSW, Christopher J. Dy, MD, MPH, and Scott W. Wolfe, MD

Investigation performed at the Hospital for Special Surgery, New York, NY

Background: The physical and psychological impact of brachial plexus injury (BPI) has not been comprehensively measured with BPI-specific scales. Our objective was to develop and test a patient-derived questionnaire to measure the impact and outcomes of BPI.

Methods: We developed a questionnaire in 3 phases with preoperative and postoperative patients. Phase 1 included interviews of patients using open-ended questions addressing the impact of BPI and improvement expected (preoperative patients) or received (postoperative patients). Phase 2 involved assembling a draft questionnaire and administering the questionnaire twice to establish test-retest reliability. Phase 3 involved selecting final items, developing a scoring system, and assessing validity. Patient scores using the questionnaire were assessed in comparison with scores of the Disabilities of the Arm, Shoulder and Hand (DASH) and RAND-36 measures.

Results: Patients with partial or complete plexopathy participated. In Phase 1 (23 patients), discrete categories were discerned from open-ended responses and became items for the preoperative and postoperative versions of the questionnaire. In Phase 2 (50 patients [14 from Phase 1]), test-retest reliability was established, with weighted kappa values of ≥ 0.50 for all items. In Phase 3, 43 items were retained and grouped into 4 subscales: symptoms, limitations, emotion, and improvement expected (preoperative) or improvement received (postoperative). A score for each subscale, ranging from 0 to 100, can be calculated, with higher scores indicating more symptoms, limitations, and emotional distress, and greater improvement expected (or received). Preoperative scores were worse than postoperative scores for the symptoms, limitations, and emotion subscales (composite score of 48 compared with 38; $p = 0.05$), and more improvement was expected than was received (69 compared with 53; $p = 0.01$). Correlations with the DASH (0.44 to 0.74) and RAND-36 (0.23 to 0.80) for related scales were consistent and moderate, indicating that the new questionnaire is valid and distinct.

Conclusions: We developed a patient-derived questionnaire that measures the physical and psychological impact of BPI on preoperative and postoperative patients and the amount of improvement expected or received from surgery. This BPI-specific questionnaire enhances the comprehensive assessment of this population.

Brachial plexus injury (BPI) has a profound impact on all aspects and quality of life^{1,2}. Patients are usually young adults who sustained trauma, such as from a motor vehicle accident or sports injury^{1,3,4}. Severe motor and sensory dysfunction and variable degrees of neuropathic pain are hallmarks of the condition. Furthermore, the sudden nature of the injury can lead to a realm of psychological challenges, such as emotional distress, loss of independence, and depression, that can overwhelm patients and potentially hamper recovery. Capturing these psychological elements within a BPI disease-

specific context is necessary in order to thoroughly understand disability and recovery from this complex condition. For BPI, outcomes historically have been reported on the basis of surgeon-graded muscle function; more recent efforts have incorporated functional and generic psychological questionnaires¹⁻¹⁰. However, these outcomes do not simultaneously include broad perspectives of, and attention to, multiple physical and emotional aspects of life impacted by BPI over time. In addition, a BPI-specific questionnaire is needed to standardize outcome reporting among clinicians and

Disclosure: This work was supported by the J.W. Kieckhefer Foundation, the Howard J. Golden Family Research Fund, and a Richard Menschel institutional award; these groups did not have roles in the investigation. The **Disclosure of Potential Conflicts of Interest** forms are provided with the online version of the article (<http://links.lww.com/JBJS/E605>).

TABLE 1 Patient Demographic and Clinical Characteristics

Characteristic	Phase 1		Phase 2	
	Preop., N = 10	Postop., N = 13	Preop., N = 23	Postop., N = 27
Age* (yr)	38 ± 14 (24-63)	36 ± 15 (19-59)	41 ± 15 (23-71)	40 ± 16 (20-84)
Male (no. [%])	10 (100%)	9 (69%)	20 (87%)	24 (89%)
Working (no. [%])				
No, not because of injury	0 (0%)	1 (8%)	2 (9%)	1 (4%)
No, because of injury	9 (90%)	8 (61%)	11 (48%)	13 (48%)
Yes, with accommodations	1 (10%)	4 (31%)	8 (35%)	9 (33%)
Yes, without accommodations	0 (0%)	0 (0%)	2 (9%)	4 (15%)
Injury on dominant side (no. [%])	7 (70%)	6 (46%)	8 (35%)	18 (67%)
How injury occurred (no. [%])				
Motorcycle	6 (60%)	5 (39%)	9 (39%)	9 (33%)
Motor vehicle	0 (0%)	6 (46%)	7 (30%)	5 (19%)
Recreational vehicle	3 (30%)	0 (0%)	2 (9%)	6 (22%)
Other†	1 (10%)	2 (15%)	5 (22%)	7 (26%)
Complete plexopathy (no. [%])	4 (40%)	6 (46%)	13 (57%)	12 (44%)
Time between:				
Injury and first interview‡ (mo)	7 (3-14)	33 (14-153)	5 (3-7)	73 (13-195)
First interview and surgery‡ (days)	12 (1-38)	—	21 (2-81)	—
Surgery and first interview‡ (mo)	—	14 (10-22)	—	58 (9-142)
First and second interviews‡ (days)	—	—	3 (1-9)	4 (2-11)
DASH score§	52 ± 19	41 ± 28	49 ± 17	34 ± 20
RAND-36 physical health composite score#	33 ± 9	39 ± 10	35 ± 9	41 ± 10
RAND-36 mental health composite score#	48 ± 14	47 ± 16	46 ± 13	50 ± 12
If rest of life like past 24 hr (no. [%])				
Delighted	0 (0%)	0 (0%)	0 (0%)	1 (4%)
Pleased	0 (0%)	3 (23%)	0 (0%)	4 (15%)
Mostly satisfied	0 (0%)	2 (15%)	2 (9%)	4 (15%)
Mixed	2 (20%)	3 (23%)	0 (0%)	8 (30%)
Mostly dissatisfied	1 (10%)	2 (15%)	3 (13%)	5 (19%)
Unhappy	3 (30%)	1 (8%)	7 (30%)	4 (15%)
Terrible	4 (40%)	2 (15%)	11 (48%)	1 (4%)

*The values are given as the mean and the standard deviation, with the range in parentheses. †Other surgery, radiation therapy, malposition while not conscious, sports injury, work injury, or knife wound. ‡The values are given as the mean, with the range in parentheses. §DASH = Disabilities of the Arm, Shoulder and Hand. Possible score ranges from 0 to 100, with a higher score indicating worse status. The values are given as the mean and the standard deviation. #Possible score ranges from 0 to 100, with a higher score indicating better status. The values are given as the mean and the standard deviation.

researchers. We know of no uniform and widely accepted patient-reported questionnaires for documenting and comparing BPI outcomes according to clinical characteristics, such as nerve root levels involved, and results of novel surgical techniques, such as nerve transfers and grafting. In addition, there appear to be no existing questionnaires that simultaneously address the unique collection of physical and psychological symptoms that affect patients with BPI.

The objective of the current study was to develop and test a BPI-specific questionnaire that addresses the physical and psychological impact of BPI and also addresses patients' ex-

pectations for improvement from surgery and their assessment of actual improvement received. We hypothesized that patients would cite limitations and expectations with respect to multiple aspects of physical and mental well-being.

Materials and Methods

Patients with BPI who were undergoing, or who had undergone, surgical reconstruction were enrolled in this multiple-phase study during routine office visits and provided written informed consent. This study was approved by the institutional review board at the Hospital for Special Surgery.

TABLE II Weighted Kappa Values for Each Item of the BPI Questionnaire*

Questionnaire Item	Preop., N = 23	Postop., N = 27
Throbbing pain	0.77	0.72
Stabbing pain	0.69	0.72
Tingling	0.58	0.69
Numbness	0.67	0.71
Heaviness	0.52	0.52
Bathing and hygiene	0.74	0.71
Dressing	0.81	0.79
Eating	0.66	0.58
Dependence on opposite arm and hand	0.69	0.61
Activities with family and friends	0.61	0.53
Dependent on others for tasks	0.67	0.60
Dependent on others financially	0.83	0.74
Dependent on others emotionally	0.71	0.54
Decreased recreation or sports	0.56	0.62
Self-conscious about appearance	0.75	0.54
Self-conscious about disabilities	0.69	0.58
Difficulty coping	0.53	0.53
Deterioration in overall health	0.80	0.65
Better if amputation	0.72	0.75
Effect on employment/school	0.92	0.94
Effect on future career plans	0.87	0.96
Sad mood	0.58	0.65
Stress	0.68	0.54
Self-esteem	0.67	0.55
Anger	0.59	0.54
Guilt	0.73	0.72
Frustration with limitations	0.54	0.58
Frustration with time to heal	0.64	0.58
Altered life priorities	0.55	0.72
Paying for medical care	0.59	0.76
Extra fatigue	0.74	0.65
Relieve pain	0.73	0.54
Relieve numbness and tingling	0.81	0.64
Improve sleep	0.72	0.70
Move arm, elbow, hand	0.52	0.57
Manage personal care	0.69	0.59
Reduce need for pain medicine	0.87	0.81
Interact with family and friends	0.63	0.57
Return to work	0.64	0.71
Return to recreation or sports	0.52	0.58
Restore emotional well-being	0.50	0.52
Return to way was before injury	0.64	0.65
Improvement expected after 1 yr/as a result of surgery	0.50	0.69

*Measuring agreement between first and second administrations of the questionnaire for preoperative and postoperative patients in Phase 2. BPI = brachial plexus injury.

Preoperative
version

Impact of Brachial Plexus Injury Questionnaire

A brachial plexus injury can impact many aspects of life. There can be physical symptoms and effects on mental well-being. Please answer the following questions from the point of view of your **current** condition. For each item, please **circle** your response.

Please rate the severity of the following symptoms in your arm in the past week.

	None	A little	Moderate amount	A lot
Throbbing pain	1	2	3	4
Stabbing pain	1	2	3	4
Tingling	1	2	3	4
Numbness	1	2	3	4
Heaviness	1	2	3	4

How much difficulty did you have performing these activities in the past week?

	No difficulty	Some difficulty but I did it myself	A lot of difficulty but I did it myself	Someone had to help me	Someone had to do it for me
Bathing and hygiene	1	2	3	4	5
Dressing	1	2	3	4	5
Eating	1	2	3	4	5

Because of your brachial plexus injury, how much have you.....

	Not at all	A little	Some	A lot	Completely
Become dependent on the opposite arm and hand	1	2	3	4	5
Cut back on activities with family and friends	1	2	3	4	5
Become more dependent on others for tasks at home and outside the home	1	2	3	4	5
Become more dependent on others financially	1	2	3	4	5
Become more dependent on others emotionally	1	2	3	4	5
Decreased favorite recreational activities or sports	1	2	3	4	5
Avoided public situations because of being self conscious about appearance	1	2	3	4	5
Avoided public situations because of being self conscious about disabilities	1	2	3	4	5
Had difficulty coping with arm situation	1	2	3	4	5
Deteriorated in overall general health	1	2	3	4	5
Thought you would be better off if your arm were amputated	1	2	3	4	5

© 2017 Hospital for Special Surgery. All rights reserved. 1

Fig. 1-A

Figs. 1-A and 1-B Preoperative version of the Impact of Brachial Plexus Injury Questionnaire. (Reproduced with permission of Hospital for Special Surgery.)

Phase 1: Identifying Items for Draft Questionnaire

Phase 1 was based on a previously reported qualitative study of patients' physical and psychosocial limitations due to BPI and their expectations of improvement from surgery¹¹. In brief, patients were eligible if they were ≥ 18 years old, spoke English, and were scheduled for surgery (preoperative group) or had undergone surgery within the previous 9 to 24 months (postoperative group) for partial or complete BPI. Patients were interviewed in person by a single investigator (C.A.M.) who was experienced in qualitative research using standard questions and techniques. Patients were asked open-ended questions about what bothered them most about their arm, what activities they had curtailed, what accommodations they had made, and what their expectations were for improvement (preoperative group) or what

improvement had been achieved (postoperative group). Patients were encouraged to volunteer as many comments as they wished, and their responses were written down verbatim.

Patients also completed the Disabilities of the Arm, Shoulder and Hand (DASH), a 21-item questionnaire measuring symptoms and limitations due to upper-extremity dysfunction¹², and the RAND Health Survey (RAND-36), a 36-item questionnaire measuring general physical and mental health status¹³. Patients also answered a single question as a global assessment of the condition of the arm adapted from a validated measure of well-being, with 7 response options ranging from "delighted" to "terrible" (Table I)¹⁴.

Responses to the open-ended questions were assessed with standard qualitative techniques using grounded theory, a process by which responses are reviewed to identify unique

Preoperative version

These questions pertain to how your injury has affected your usual job/school and career plans.

Are you currently working/school?
 No, I am not working/school for reasons not related to my arm.
 Yes, I have the same job/school and made no accommodations to the way I work because of my arm.
 Yes, I have the same job/school but made accommodations to the way I work because of my arm.
 Yes, but I changed job/school because of my arm.
 No, I am not working/school because of my arm.

Since your injury, what has happened to your career plans?
 Not applicable, I am not working/school for reasons not related to my arm.
 I have the same plans.
 I have changed my plans because of my arm.

On a scale of 1 (not at all) to 10 (a lot), to what extent has your injury caused the following?

	Not at all									A lot
	1	2	3	4	5	6	7	8	9	10
Sad mood	1	2	3	4	5	6	7	8	9	10
Stress	1	2	3	4	5	6	7	8	9	10
Lower self-esteem	1	2	3	4	5	6	7	8	9	10
Anger	1	2	3	4	5	6	7	8	9	10
Guilt	1	2	3	4	5	6	7	8	9	10
Frustration with limitations	1	2	3	4	5	6	7	8	9	10
Frustration with time to heal	1	2	3	4	5	6	7	8	9	10
Altered life priorities	1	2	3	4	5	6	7	8	9	10
Anxiety from finding and paying for brachial plexus medical care	1	2	3	4	5	6	7	8	9	10
Extra fatigue because activities require more effort	1	2	3	4	5	6	7	8	9	10

How much improvement do you expect for your brachial plexus injury from surgery (or another treatment)?

	Back to normal or complete improvement	Not back to normal but...		No improvement	This expectation does not apply to me
	1	A lot of improvement	A moderate amount of improvement	4	5
Relieve pain	1	2	3	4	5
Relieve numbness or tingling	1	2	3	4	5
Improve ability to sleep	1	2	3	4	5
Move arm, elbow, hand	1	2	3	4	5
Manage own care (bathe, eat)	1	2	3	4	5
Reduce need for pain medicine	1	2	3	4	5
Interact with family and friends	1	2	3	4	5
Return to work	1	2	3	4	5
Return to recreational activities or sports	1	2	3	4	5
Restore emotional well-being	1	2	3	4	5
Return to the way I was before the injury	1	2	3	4	5
Amount of improvement expected after one year	1	2	3	4	5

2

© 2017 Hospital for Special Surgery. All rights reserved.

Fig. 1-B

concepts, which are then grouped into larger categories through an iterative process^{15,16}.

Phase 2: Assembling Draft Questionnaire and Establishing Test-Retest Reliability

Categories from Phase 1 became the items for the draft questionnaire and were phrased using patients' terminology. Response options also were worded according to patients' terms. Using the same items, 2 versions of the questionnaire were created, to query patients about their condition before surgery (preoperative version) or after surgery (postoperative version).

The draft versions were then tested among additional patients who were ≥ 18 years old, spoke English, and were either scheduled for surgery (completed the preoperative version) or had undergone surgery at least 9 months prior

(completed the postoperative version). To establish test-retest reliability, patients completed the same version of the questionnaire twice, several days apart. In most cases, the first administration occurred during an in-person interview and the second, during a telephone interview. To address external validity, patients also completed the DASH, the RAND-36, and the global "delighted-terrible" question at the time of the first interview.

A sample size of 50 meets rigorous criteria for repeatability testing¹⁷, and thus, we enrolled 50 patients in Phase 2.

Phase 3: Selecting Final Items, Scoring, and Validity

The weighted kappa statistic was used to measure agreement between the first and second administrations for each item. The

Postoperative
version

Impact of Brachial Plexus Injury Questionnaire

A brachial plexus injury can impact many aspects of life. There can be physical symptoms and effects on mental well-being. Please answer the following questions from the point of view of your **current** condition. For each item, please **circle** your response.

Please rate the severity of the following symptoms in your arm in the past week.

	None	A little	Moderate amount	A lot
Throbbing pain	1	2	3	4
Stabbing pain	1	2	3	4
Tingling	1	2	3	4
Numbness	1	2	3	4
Heaviness	1	2	3	4

How much difficulty did you have performing these activities in the past week?

	No difficulty	Some difficulty but I did it myself	A lot of difficulty but I did it myself	Someone had to help me	Someone had to do it for me
Bathing and hygiene	1	2	3	4	5
Dressing	1	2	3	4	5
Eating	1	2	3	4	5

Since your brachial plexus surgery (or other treatment) how much have you.....

	Not at all	A little	Some	A lot	Completely
Depended on the opposite arm and hand	1	2	3	4	5
Cut back on activities with family and friends	1	2	3	4	5
Depended on others for tasks at home and outside the home	1	2	3	4	5
Depended on others financially	1	2	3	4	5
Depended on others emotionally	1	2	3	4	5
Decreased favorite recreational activities or sports	1	2	3	4	5
Avoided public situations because of being self conscious about appearance	1	2	3	4	5
Avoided public situations because of being self conscious about disabilities	1	2	3	4	5
Had difficulty coping with arm situation	1	2	3	4	5
Deteriorated in overall general health	1	2	3	4	5
Thought you would be better off if your arm were amputated	1	2	3	4	5

© 2017 Hospital for Special Surgery. All rights reserved. 1

Fig. 2-A

Figs. 2-A and 2-B Postoperative version of the Impact of Brachial Plexus Injury Questionnaire. (Reproduced with permission of Hospital for Special Surgery.)

weighted kappa measures agreement above that due to chance, and ranges from 0 to 1 (with 1 indicating perfect agreement)¹⁸. An item was retained for the final questionnaire if the kappa value was ≥ 0.50 . A system was developed to generate scores for the subscales and domains (described below), and intraclass correlation coefficients (ICCs) were calculated to measure inpatient agreement in scores. For both kappa and ICC, a value of < 0.4 indicates slight/fair agreement; ≥ 0.4 to 0.6 , moderate; > 0.6 to 0.75 , good; and > 0.75 to 1 , excellent. External validity was assessed by comparing scores on the developed questionnaire with DASH and RAND-36 scores using Pearson correlations and with responses on the global assessment using Spearman correlations. Internal validity was assessed with Cronbach alpha correlations.

Results

Phase 1: Identifying Items for Draft Questionnaire

Ten preoperative and 13 postoperative patients were enrolled from April 2013 to March 2014. The mean age (and standard deviation) was 37 ± 14 years, 19 of the patients were male, all were working or were full-time students at the time of the BPI, but most were not working at enrollment because of the BPI (Table I). Most injuries were partial plexopathies and were due to motorcycle or motor vehicle accidents.

Both preoperative and postoperative patients volunteered that the BPI had dramatically impacted their lives in multiple ways¹¹, which included persistent pain, the inability to provide self-care, reliance on others for financial support,

These questions pertain to your job/school and career plans.										
Are you currently working/school? <input type="checkbox"/> No, I am not working/school for reasons not related to my arm. <input type="checkbox"/> Yes, I have the same job/school and made no accommodations to the way I work because of my arm. <input type="checkbox"/> Yes, I have the same job/school but made accommodations to the way I work because of my arm. <input type="checkbox"/> Yes, but I changed job/school because of my arm. <input type="checkbox"/> No, I am not working/school because of my arm.										
Since your injury, what has happened to your career plans? <input type="checkbox"/> Not applicable, I am not working/school for reasons not related to my arm. <input type="checkbox"/> I have the same plans. <input type="checkbox"/> I have changed my plans because of my arm.										
On a scale of 1 (not at all) to 10 (a lot), to what extent has your injury caused the following?										
	Not at all									A lot
Sad mood	1	2	3	4	5	6	7	8	9	10
Stress	1	2	3	4	5	6	7	8	9	10
Lower self-esteem	1	2	3	4	5	6	7	8	9	10
Anger	1	2	3	4	5	6	7	8	9	10
Guilt	1	2	3	4	5	6	7	8	9	10
Frustration with limitations	1	2	3	4	5	6	7	8	9	10
Frustration with time to heal	1	2	3	4	5	6	7	8	9	10
Altered life priorities	1	2	3	4	5	6	7	8	9	10
Anxiety from finding and paying for brachial plexus medical care	1	2	3	4	5	6	7	8	9	10
Extra fatigue because activities require more effort	1	2	3	4	5	6	7	8	9	10
How much improvement did you receive for your brachial plexus injury from surgery (or other treatment)?										
	Back to normal or complete improvement	Not back to normal but...			I did not have this expectation or this expectation did not apply to me					
		A lot of improvement	A moderate amount of improvement	No improvement						
Relieve pain	1	2	3	4	5					
Relieve numbness or tingling	1	2	3	4	5					
Improve ability to sleep	1	2	3	4	5					
Move arm, elbow, hand	1	2	3	4	5					
Manage own care (bathe, eat)	1	2	3	4	5					
Reduce need for pain medicine	1	2	3	4	5					
Interact with family and friends	1	2	3	4	5					
Return to work	1	2	3	4	5					
Return to recreational activities or sports	1	2	3	4	5					
Restore emotional well-being	1	2	3	4	5					
Return to the way I was before the injury	1	2	3	4	5					
Amount of improvement as a result of surgery	1	2	3	4	5					
© 2017 Hospital for Special Surgery. All rights reserved.										2

Fig. 2-B

career modifications, and deterioration in general health. Psychological effects included being self-conscious about appearance, anger, and lower self-esteem. Expectations for improvement included improving the ability to move the arm, interact with others, return to work, and decrease pain medications.

Phase 2: Assembling Draft Questionnaire and Test-Retest Reliability

The 43-item draft questionnaire addressed symptoms, limitations, emotions, and amount of improvement expected (or received). Likert response options were assigned for most items, except for the items regarding emotion,

**Impact of Brachial Plexus Injury Questionnaire
Scoring Instructions**

Symptoms Subscale score (5 items)

- Reassign responses as follows:
 - 0 = none
 - 1 = a little
 - 2 = moderate amount
 - 3 = a lot
- Sum all responses. The summed raw score for all 5 items ranges from 0 to 15.
- Transform the score to range from 0 to 100.
Transformed score = (raw score / 15) x 100.
- Report the transformed score. Higher score indicates worse symptoms.

Limitations Subscale score (16 items)

- Reassign responses for the first 3 items as follows:
 - 0 = no difficulty
 - 1 = some difficulty but I did it myself
 - 2 = a lot of difficulty but I did it myself
 - 3 = someone had to help me
 - 4 = someone had to do it for me
 Reassign responses for the next 11 items as follows:
 - 0 = not at all
 - 1 = a little
 - 2 = some
 - 3 = a lot
 - 4 = completely
 Assign the following to the item about current work/school:
 - = not working/school for reasons not related to arm
 - 0 = have the same job/school with no accommodations due to arm
 - 1 = have the same job/school with accommodations due to arm
 - 2 = changed job/school due to arm
 - 3 = not working/school due to arm
 Assign the following to the item about career plans:
 - = not working/school for reasons not related to arm
 - 0 = have the same plans
 - 1 = changed plans due to arm
- Sum all responses.
If working/school, the summed raw score for all 16 items ranges from 0 to 60.
If not working/school for reasons not related to arm, the summed raw score for all 16 items ranges from 0 to 56.
- Transform the score to range from 0 to 100.
If working/school, transformed score = (raw score / 60) x 100.
If not working/school, transformed score = (raw score / 56) x 100.
- Report the transformed score. Higher score indicates more limitations.

© 2017 Hospital for Special Surgery. All rights reserved.

Fig. 3-A

Figs. 3-A and 3-B Scoring instructions for the Impact of Brachial Plexus Injury Questionnaire. (Reproduced with permission of Hospital for Special Surgery.)

which were assigned responses according to a numerical rating scale.

Twenty-three preoperative and 27 postoperative patients were enrolled in Phase 2 (14 of these patients also participated in Phase 1) from August 2014 to February 2016. The mean age was 41 ± 15 years, 44 of the patients were male, most were working at the time of the BPI, but nearly half were not working because of the BPI at enrollment. Compared with the preoperative patients, the postoperative patients had better DASH ($p = 0.009$) and RAND-36 physical health scores ($p = 0.02$) and were more likely to be satisfied if no further clinical improvement was anticipated ($p < 0.0001$). For both groups, the amount of time between the first and second interviews was 3 to 4 days. The median time since surgery for the postoperative group was 3 years.

Phase 3: Selecting Final Items, Scoring, and Validity

Weighted kappa values ranged from 0.50 to 0.92 for the preoperative version and from 0.52 to 0.96 for the postoperative version (Table II), and thus, all 43 items and their formats were retained to form the final Impact of Brachial Plexus Injury Questionnaire (Figs. 1-A through 2-B).

The questionnaire was assembled according to 4 thematic subscales that parallel the clinical scenario, namely, symptoms, limitations, emotion, and improvement. The symptoms subscale has 5 items addressing the severity of pain, numbness, and tingling; the response options range from “none” to “a lot,” with numerical values on a 4-point Likert scale. The limitations subscale has 16 items: 3 items address difficulty with personal care, with responses on a 5-point scale ranging

Impact of Brachial Plexus Injury Questionnaire Scoring Instructions (continued)

Emotion Subscale score (10 items)

1. Reassign responses to range from 0 (not at all) to 9 (a lot)
2. Sum all responses. The summed raw score for all 10 items ranges from 0 to 90.
3. Transform the score to range from 0 to 100.
Transformed score = (raw score / 90) x 100.
4. Report the transformed score. Higher score indicates worse emotional well-being.

Improvement Expected Subscale score (preoperative) (12 items)

1. Reassign responses as follows:
 - 4 = back to normal or complete improvement
 - 3 = a lot of improvement
 - 2 = a moderate amount of improvement
 - 1 = no improvement
 - 0 = does not apply
2. Sum all responses. The summed raw score for all 12 items ranges from 0 to 48.
3. Transform the score to range from 0 to 100.
Transformed score = (raw score / 48) x 100.
4. Report the transformed score. Higher score indicates expecting more improvement.

Improvement Received Subscale score (postoperative) (12 items)

1. Reassign responses as follows:
 - 4 = back to normal or complete improvement
 - 3 = a lot of improvement
 - 2 = a moderate amount of improvement
 - 1 = no improvement
 - 0 = did not have this expectation or did not apply
2. Sum all responses. The summed raw score for all 12 items ranges from 0 to 48.
3. Transform the score to range from 0 to 100.
Transformed score = (raw score / 48) x 100.
4. Report the transformed score. Higher score indicates received more improvement.

Disability Domain score

1. Calculate mean score from Symptom, Limitations, and Emotion Subscale transformed scores.
(Symptoms score + Limitation score + Emotion score) / 3
2. Mean score ranges from 0 to 100. Higher score indicates more disability.

Improvement Domain score

Equivalent to either Improvement Expected Subscale score (preoperative) or Improvement Received Subscale score (postoperative).

© 2017 Hospital for Special Surgery. All rights reserved.

Fig. 3-B

from “no difficulty” to “someone had to do it for me”; 11 items address functional restrictions, with responses on a 5-point scale ranging from “not at all” to “completely”; and 2 items address work/school and career plans, with responses ranging from “no change” to “not able to work/attend school because of BPI.” The emotion subscale has 10 items addressing distress due to the BPI; responses according to a 10-point numerical rating range from “not at all” to “a lot.” The improvement expected (preoperative) and the improvement received (postoperative) subscales have 12 items addressing symptoms, movement, medications, employment, and emotions; responses range from “complete improvement” to “no improvement.”

A score can be generated for each subscale according to the scoring instructions (Figs. 3-A and 3-B); the nu-

merical values assigned for each of the patient responses are summed, and the score is normalized on a scale of 0 to 100. Given that symptoms, limitations, and emotional distress reflect disability, higher scores for those subscales reflect more of that attribute and, therefore, worse status¹⁹. An overall disability domain score also can be calculated as the mean of those subscales. This composite domain score is useful to gauge overall disability, while the subscale scores provide information on which attributes are causing the most disability. Similarly, for the improvement subscale, a higher score indicates more of that attribute, i.e., greater expectations for improvement (preoperative) or greater improvement received (postoperative)¹⁹. An improvement domain score can be reported as the “improvement expected” subscale score for preoperative patients or the

TABLE III Domain and Subscale Scores for Patients in Phase 2*

Domain and Subscale	Preop., N = 23				Postop., N = 27			
	Score†	No. with Min., Max. Score	Cronbach Alpha Coefficient	ICC	Score†	No. with Min., Max. Score	Cronbach Alpha Coefficient	ICC
Disability domain								
Symptoms subscale	58 ± 25 (20-100)	0, 3	0.61	0.85	49 ± 25 (13-100)	0, 1	0.77	0.87
Limitations subscale	41 ± 16 (11-77)	0, 0	0.82	0.96	34 ± 14 (7-63)	0, 1	0.83	0.88
Emotion subscale	44 ± 23 (0-88)	1, 0	0.88	0.88	31 ± 27 (0-97)	1, 0	0.94	0.92
Overall	48 ± 18 (11-88)	0, 0	0.91	0.95	38 ± 18 (8-82)	0, 0	0.64	0.94
Improvement domain								
Expected subscale (preop.)	69 ± 20 (21-100)	0, 1	0.86	0.90	—	—	—	—
Received subscale (postop.)	—	—	—	—	53 ± 20 (23-88)	0, 0	0.89	0.87
Overall	69 ± 20 (21-100)	0, 1	0.86	0.90	53 ± 20 (23-88)	0, 0	0.89	0.87

*Scores are from the first administration of questionnaire. Possible scores range from 0 to 100. For the disability domain, a higher value indicates a worse condition, and for the improvement domain, a higher value indicates greater improvement expected or received. The ICC (intraclass correlation coefficient) measures agreement between the first and second administrations of the questionnaire. †The values are given as the mean and the standard deviation, with the range in parentheses. The overall score for the disability domain is a composite score, reflecting the mean of scores calculated for the symptoms, limitations, and emotions subscales.

“improvement received” subscale score for postoperative patients.

Subscale and domain scores were calculated and were assessed for mean values and ranges for patients in Phase 2. Results from the first administration are summarized in Table III. For the preoperative version, scores for the subscales in the disability domain were normally distributed and spanned almost the entire possible range, with few patients having minimum (i.e., floor) or maximum (i.e., ceiling) scores. Cronbach alpha coefficients indicated good to excellent internal validity (0.61 to 0.91). Of the 3 disability subscales, the symptoms subscale reflected the greatest impact (had the highest mean score, 58 compared with 41 for limitations and 44 for emotion, with an overall domain score of 48). Scores for the improvement-expected subscale also were normally distributed but were shifted toward higher values (mean of 69), indicating greater expectations. Results for the second administration of the questionnaire were similar, as reflected by high ICC values (0.85 to 0.96).

For the postoperative version, all subscale scores from the first administration also were normally distributed and spanned almost the entire possible range, with few patients having minimum or maximum scores (Table III). Cronbach alpha coefficients indicated good to excellent internal validity

(0.64 to 0.94). The symptoms subscale score reflected the greatest impact (mean of 49 compared with 31 for emotion and 34 for limitations, with an overall domain score of 38), and scores for the improvement-received subscale also were normally distributed (mean of 53; interquartile range, 35 to 71). Results for the second questionnaire administration were similar, as reflected by high ICC values (0.87 to 0.94).

When mean scores were compared between the postoperative and preoperative groups, the overall disability domain score for the postoperative group was lower (38 compared with 48; $p = 0.05$), indicating less-severe symptoms, limitations, and emotional distress. The score for the amount of improvement also was lower in the postoperative group (53 compared with 69; $p = 0.01$); however, given the direction of scoring, this indicates that the actual improvement received (postoperative group) was less than the expected improvement (preoperative group).

The final analyses assessed external validity by comparing results from use of the questionnaire with outcomes using the standard scales. There were multiple associations between the various subscales and standard scales (Table IV). Worse symptoms and limitation subscale scores

TABLE IV Correlation Coefficients (and Corresponding P Values) from Comparisons Between Scores on the BPI Questionnaire and Standard Scales for Patients in Phase 2*

Domain and Subscale	Preop., N = 23				Postop., N = 27			
	DASH	RAND-36 Physical Health	RAND-36 Mental Health	Global Assessment	DASH	RAND-36 Physical Health	RAND-36 Mental Health	Global Assessment
Disability domain								
Symptoms subscale	0.45 (≤ 0.05)	-0.58 (≤ 0.005)	-0.16	0.30	0.57 (≤ 0.005)	-0.47 (≤ 0.01)	-0.34	0.34
Limitations subscale	0.63 (≤ 0.005)	-0.27	-0.53 (≤ 0.01)	0.50 (≤ 0.05)	0.74 (≤ 0.0001)	-0.41 (≤ 0.05)	-0.63 (≤ 0.005)	0.54 (≤ 0.005)
Emotion subscale	0.44 (≤ 0.05)	-0.08	-0.63 (≤ 0.005)	0.42 (≤ 0.05)	0.41 (≤ 0.05)	-0.34	-0.80 (≤ 0.0001)	0.30
Overall	0.60 (≤ 0.005)	-0.39	-0.51 (≤ 0.01)	0.47 (≤ 0.05)	0.67 (≤ 0.005)	-0.50 (≤ 0.01)	-0.72 (≤ 0.0001)	0.42 (≤ 0.05)
Improvement domain								
Expected subscale (preop.)	0.50 (≤ 0.01)	-0.56 (≤ 0.005)	-0.23	0.72 (≤ 0.0001)	—	—	—	—
Received subscale (postop.)	—	—	—	—	-0.41 (≤ 0.05)	0.43 (≤ 0.05)	0.35	-0.52 (≤ 0.005)
Overall	0.50 (≤ 0.01)	-0.56 (≤ 0.005)	-0.23	0.72 (≤ 0.0001)	-0.41 (≤ 0.05)	0.43 (≤ 0.05)	0.35	-0.52 (≤ 0.005)

*Based on first administration of BPI (brachial plexus injury) questionnaire. The subscales of the disability domain, DASH (Disabilities of the Arm, Shoulder and Hand), and global assessment are scored such that a higher score indicates worse status. The RAND-36 physical and mental health measures are scored such that a higher score indicates better status, and the subscales of the improvement domain are scored such that a higher score indicates more improvement expected (preoperative) or received (postoperative).

were associated with worse DASH and RAND-36 physical health scores (Fig. 4). A worse emotion subscale score was correlated with a worse RAND-36 mental health score. These associations existed for both preoperative and postoperative patients.

There similarly were correlations between the improvement subscales and the DASH, RAND-36 physical health, and global assessment scores. However, the direction of the association was different for preoperative and postoperative patients. Specifically, whereas a higher DASH score

(worse status) preoperatively was associated with a higher score for expected improvement, a higher DASH score postoperatively was associated with a lower score for received improvement (Fig. 5).

For most patients, our questionnaire took approximately 12 minutes to complete; the DASH, 10 minutes; the RAND-36, 6 minutes; and the transition from the disease-specific (DASH) to the more general (RAND-36) perspective, 5 minutes. There were no incomplete questionnaires, and no assistance in completing the questionnaires was required.

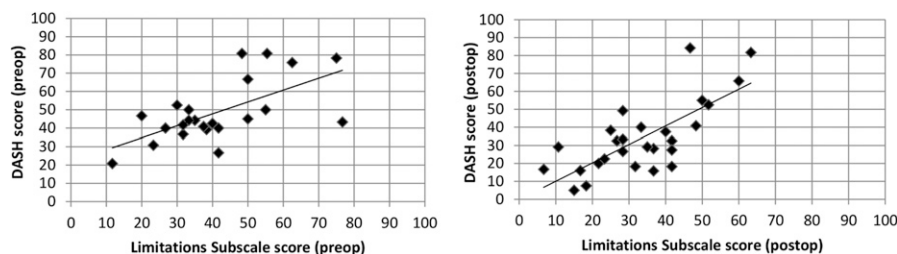


Fig. 4
Disabilities of the Arm, Shoulder and Hand (DASH) versus Impact of Brachial Plexus Injury Questionnaire limitations subscale scores preoperatively (Fig. 4-A) and postoperatively (Fig. 4-B).

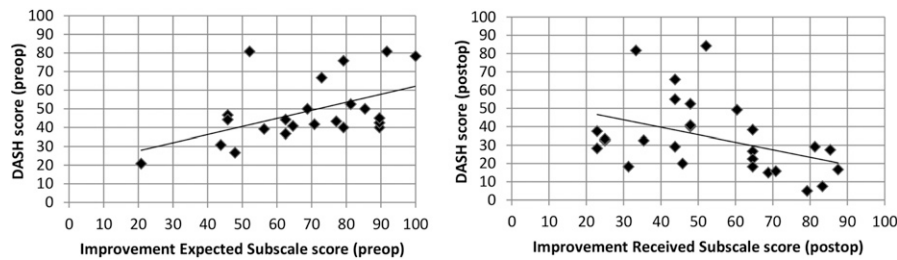


Fig. 5
Disabilities of the Arm, Shoulder and Hand (DASH) versus Impact of Brachial Plexus Injury Questionnaire preoperative improvement-expected (**Fig. 5-A**) and postoperative improvement-received (**Fig. 5-B**) subscale scores.

Discussion

We developed a questionnaire to measure physical and psychological disability from BPI and to assess improvement expected and received from surgery. The questionnaire items were derived from patients' input, and preoperative and postoperative versions were assembled. Each item was tested for repeatability, and each subscale was tested for repeatability and validity.

The questionnaire potentially can improve clinical care in several ways. First, the questionnaire provides a template from which patients can then discuss the spectrum of physical and emotional effects of BPI with their surgical team. This, in turn, offers providers the opportunity to comprehensively address patients' needs directly or through referral. Second, the questionnaire fosters discussion of realistic outcome expectations, which are necessary to maintain motivation and ensure long-term participation in rehabilitation. Third, the questionnaire provides a valid and standardized method for clinicians and researchers to document and compare patient-reported outcomes from specific or novel surgical interventions.

To facilitate the communication of results, we provide the option of calculating overall disability and improvement domain scores. The disability domain is composed of the symptoms, limitations, and emotion subscales. Although constituted by different numbers of items, each subscale is afforded equal weight in the domain score to reflect its relevance to the clinical scenario. The improvement domain is composed of the improvement subscale, tailored to the preoperative state (expected benefit) or postoperative state (actual benefit).

Our questionnaire contains 43 items with simple and varied response options based on patients' terminology to maximize ease of completion and participant attentiveness. Despite current trends to use short surveys, our goal was to capture as much of this complex condition as possible using a necessary and sufficient number of items. Our approach is consistent with perspectives of other investigators who have advocated for comprehensive measures of impairment from BPI^{2,8}.

Traditionally, BPI outcomes predominantly reflected surgeon-measured physical parameters (range of motion, strength, sensation)^{4,8,20}. However, to fully evaluate outcomes of treatment, assessments from patients' perspectives are essential, especially for complex injuries that affect every facet of life. The DASH is a widely used questionnaire that measures general

bilateral upper-extremity daily function^{5,7-9,12,20-22}. Several other upper-extremity questionnaires (none specific to BPI) and various general health questionnaires also have been used^{1,3,8,9,20,22}. Recently, a 31-item survey was developed for BPI to measure mechanical function of the affected limb for daily activities (e.g., put toothpaste on a toothbrush) and will be useful to track performance of these activities longitudinally⁶. Our questionnaire, in contrast, measures the impact of BPI on psychosocial life, activities of daily living, emotional aspects of recovery, and pain.

A strength of our questionnaire is that it was based on patient input and therefore captures information that might otherwise not be included in a physician-derived questionnaire, such as amputation, altered life priorities, emotional well-being, and cost of BPI⁷. Our methodology also permitted us to include a subscale addressing preoperative expectations for improvement and then to capture the amount of improvement actually received postoperatively. Measurement of expectations should be part of comprehensive assessments of BPI because patients usually do not know others with BPI, cannot witness outcomes in peers, and thus may not know realistic expectations²⁰. In our study, on the basis of group means, the preoperative patients had high improvement-expected scores (including expecting to be back to normal) and the postoperative patients had lower improvement-received scores. This finding provides evidence that preoperative expectations may be unrealistic. Consequently, surgeons should consider counseling patients on appropriate goals that will better align expectations with realistic surgical outcomes.

The issue of potentially unrealistic expectations also was uncovered through associations we found between expected improvement and preoperative function and between received improvement and postoperative function. For example, patients who had worse DASH scores preoperatively had higher improvement-expected scores. In contrast, patients who had worse DASH scores postoperatively had lower improvement-received scores. Thus, while it is understandable that patients with the worst preoperative status would have the most to expect, the salient question is whether such high expectations are realistic for these most-disabled patients. For postoperative patients, it is logical that those with worse function would report less improvement.

This study had several limitations. First, patients were enrolled from a tertiary center and may not represent patients in other settings. Second, although administered during interviews, the first administration of the questionnaire was in-person and the second, by telephone. Third, it would have been ideal to have the same patients complete both preoperative and postoperative versions of the questionnaire. However, this was not feasible given that the time to recuperate from BPI is prolonged. Fourth, although our collective sample size is one of the largest reported, it was not large enough for subanalyses to delineate the questionnaire's performance characteristics on the basis of demographic and clinical variables, such as the number of injured root levels. An ongoing longitudinal study with a larger sample size will address this and the responsiveness of the questionnaire.

In summary, we developed a questionnaire that measures the physical and psychological impact of BPI on preoperative and postoperative patients and that also captures the amount of improvement expected and received from surgery. Our questionnaire was constructed from patients' perspectives and includes items particularly important to them. Thus, our questionnaire fills a gap in the comprehensive assessment of patients with BPI by simultaneously addressing the spectrum of short-term and long-term physical and psychological consequences associated with this complex and life-altering condi-

tion and providing a valid and standardized method for clinicians to report outcomes. ■

Carol A. Mancuso, MD^{1,2}
Steve K. Lee, MD^{1,2}
Eliana B. Saltzman, BS³
Zina Model, BA⁴
Zoe A. Landers, MSW¹
Christopher J. Dy, MD, MPH⁵
Scott W. Wolfe, MD^{1,2}

¹Hospital for Special Surgery, New York, NY

²Weill Cornell Medical College, New York, NY

³Icahn School of Medicine at Mount Sinai, New York, NY

⁴Rutgers Robert Wood Johnson Medical School,
New Brunswick, New Jersey

⁵Washington University School of Medicine, St. Louis, Missouri

E-mail address for C.A. Mancuso: mancusoc@hss.edu

ORCID iD for C.A. Mancuso: [0000-0003-1800-570X](https://orcid.org/0000-0003-1800-570X)

References

- Hill BE, Williams G, Bialocerkowski AE. Clinimetric evaluation of questionnaires used to assess activity after traumatic brachial plexus injury in adults: a systematic review. *Arch Phys Med Rehabil*. 2011 Dec;92(12):2082-9.
- Choi PD, Novak CB, Mackinnon SE, Kline DG. Quality of life and functional outcome following brachial plexus injury. *J Hand Surg Am*. 1997 Jul;22(4):605-12.
- Ahmed-Labib M, Golan JD, Jacques L. Functional outcome of brachial plexus reconstruction after trauma. *Neurosurgery*. 2007 Nov;61(5):1016-22; discussion 1022-3.
- Dy CJ, Garg R, Lee SK, Tow P, Mancuso CA, Wolfe SW. A systematic review of outcomes reporting for brachial plexus reconstruction. *J Hand Surg Am*. 2015 Feb;40(2):308-13. Epub 2014 Dec 13.
- Mancuso CA, Lee SK, Dy CJ, Landers ZA, Model Z, Wolfe SW. Compensation by the uninjured arm after brachial plexus injury. *Hand (N Y)*. 2016 Dec;11(4):410-5. Epub 2016 Feb 3.
- Hill B, Pallant J, Williams G, Olver J, Ferris S, Bialocerkowski AE. Evaluation of internal construct validity and unidimensionality of the Brachial Assessment Tool, a patient-reported outcome measure for brachial plexus injury. *Arch Phys Med Rehabil*. 2016 Dec;97(12):2146-56. Epub 2016 Jul 29.
- Kretschmer T, Ihle S, Antoniadis G, Seidel JA, Heinen C, Börm W, Richter HP, König R. Patient satisfaction and disability after brachial plexus surgery. *Neurosurgery*. 2009 Oct;65(4)(Suppl):A189-96.
- Bengtson KA, Spinner RJ, Bishop AT, Kaufman KR, Coleman-Wood K, Kircher MF, Shin AY. Measuring outcomes in adult brachial plexus reconstruction. *Hand Clin*. 2008 Nov;24(4):401-15. vi.
- Novak CB, Anastakis DJ, Beaton DE, Mackinnon SE, Katz J. Validity of the Patient Specific Functional Scale in patients following upper extremity nerve injury. *Hand (N Y)*. 2013 Jun;8(2):132-8.
- Franzblau L, Chung KC. Psychosocial outcomes and coping after complete avulsion traumatic brachial plexus injury. *Disabil Rehabil*. 2015;37(2):135-43. Epub 2014 Apr 22.
- Mancuso CA, Lee SK, Dy CJ, Landers ZA, Model Z, Wolfe SW. Expectations and limitations due to brachial plexus injury: a qualitative study. *Hand (N Y)*. 2015 Dec;10(4):741-9. Epub 2015 May 1.
- Hudak PL, Amadio PC, Bombardier C; The Upper Extremity Collaborative Group (UECG). Development of an upper extremity outcome measure: the DASH (Disabilities of the Arm, Shoulder and Hand) [corrected]. *Am J Ind Med*. 1996 Jun;29(6):602-8. Erratum in: *Am J Ind Med*. 1996;30(3):372.
- Hays RD, Sherbourne CD, Mazel RM. The RAND 36-Item Health Survey 1.0. *Health Econ*. 1993 Oct;2(3):217-27.
- Andrews FM, Withey SB. Social indicators of well-being: Americans' perceptions of life quality. New York: Springer; 1976.
- Berkwits M, Inui TS. Making use of qualitative research techniques. *J Gen Intern Med*. 1998 Mar;13(3):195-9.
- Strauss AL, Corbin JM. Basics of qualitative research: techniques and procedures for developing grounded theory research. 2nd ed. Thousand Oaks: Sage Publications; 1998.
- Donner A, Eliasziw M. Sample size requirements for reliability studies. *Stat Med*. 1987 Jun;6(4):441-8.
- Kramer MS, Feinstein AR. Clinical biostatistics. LIV. The biostatistics of concordance. *Clin Pharmacol Ther*. 1981 Jan;29(1):111-23.
- Health Measures. Patient reported outcome measurement information system (PROMIS®) scoring. 2017. www.nihpromis.com/faqs. Accessed 2017 July 6.
- Dodakundi C, Doi K, Hattori Y, Sakamoto S, Fujihara Y, Takagi T, Fukuda M. Outcome of surgical reconstruction after traumatic total brachial plexus palsy. *J Bone Joint Surg Am*. 2013 Aug 21;95(16):1505-12.
- Novak CB, Anastakis DJ, Beaton DE, Mackinnon SE, Katz J. Biomedical and psychosocial factors associated with disability after peripheral nerve injury. *J Bone Joint Surg Am*. 2011 May 18;93(10):929-36.
- Franzblau LE, Shauver MJ, Chung KC. Patient satisfaction and self-reported outcomes after complete brachial plexus avulsion injury. *J Hand Surg Am*. 2014 May;39(5):948-55.e4. Epub 2014 Mar 5.