

A Qualitative Study of the Adult Patient's Experience after
Complete Avulsion Traumatic Brachial Plexus Injury:
Subjective Outcomes and Implications for Patient Educations

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March 15, 2013

ABSTRACT

Background: Complete avulsion traumatic brachial plexus injuries are severe, debilitating type of nerve injury. Current treatments provide incomplete functional recovery, which may or may not be useful to patients. Patient satisfaction has become an important outcome metric in plastic and reconstructive surgery. The aims of this study are to determine patient-reported outcomes, satisfaction, and the degree to which patients' expectations were met, in order to reveal the adult patient's experience and perspective and highlight areas in which preoperative or initial patient education can be improved.

Methods: Patients who were seen at the University of Michigan for complete avulsion brachial plexus injuries were recruited. Ten patients participated, 5 of whom had reconstructive surgery. We used four questionnaires (MHQ, SF-36, BCOPE, and SWAP-BPI) and qualitative interviews to investigate their subjective outcomes, experience, and satisfaction.

Results: This injury effects mental and emotional health, social behavior and relationship, physical functioning, return to work, body-image, and quality of life. There were significant negative correlations between the use of certain coping strategies and overall mental health. Negative body image caused social discomfort and interfered with relationships. Pain was experienced by 80% of participants. Both surgical and non-surgical patients were happy with their decisions about medical treatment for their injuries. Six patients were not initially treated at large, urban medical centers and were not informed about reconstructive surgery.

Conclusions: Complete avulsion brachial plexus injuries are rare and are not common knowledge for the lay population. It is imperative that people suffering from these injuries be told about treatment options or referred to medical centers that offer them right away. Likewise, it is important that physicians discuss not only functional recovery with patients, but also quality of life and psychological health issues. This will help patients create realistic expectations and make the best decisions about their care.

An undergraduate senior thesis submitted in partial fulfillment of the requirements for the degree
of Honors Bachelor of Science in Interdisciplinary Physics

University of Michigan

2013

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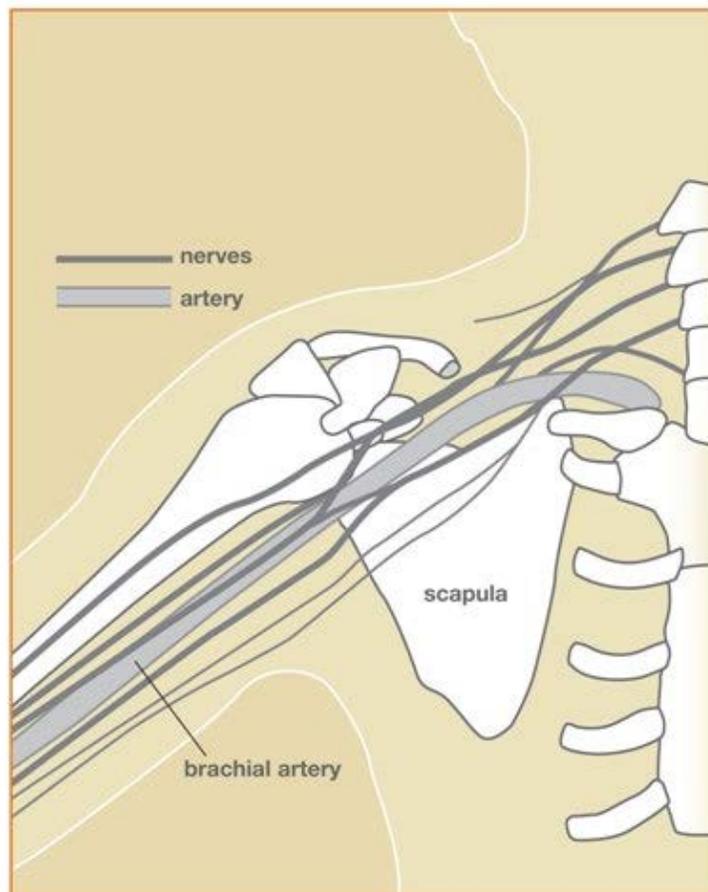
ACKNOWLEDGEMENTS

I would like to thank Dr. Kevin Chung for taking me on as a research assistant and teaching me about patient-oriented research and academic medicine since the summer of 2009. The experience and skills I have gained working with him have enriched my undergraduate career and will undoubtedly be valuable in medical school. His ongoing mentorship has contributed to my development as a clinical researcher and as a person. I would also like to thank Melissa Shauver, Dr. Chung's research coordinator, for her guidance and support throughout this project. Her willingness to answer my questions and proofread rough drafts has been immensely helpful. I would like to thank Esther Liu for her help transcribing interviews and Kate Chang for her advice about statistical analysis. Finally, I would like to thank Professor Jean Krisch for encouraging me to pursue an honors degree and for lending me a non-medical perspective on my thesis.

INTRODUCTION AND BACKGROUND:

The brachial plexus, which is a network of nerves that originates the spinal cord near the neck and shoulder, innervates the shoulder, arm, wrist, and hand. Figure 1 depicts the basic anatomy of the brachial plexus. There are five nerve roots, which come out of the spinal cord at the C5, C6, C7, C8, and T1 vertebrae. Stretching, severing, crushing, or avulsing any of the nerves damages the brachial plexus and disrupts some or all of the neural messaging that goes to and from the limb, including that which provides sensation and muscle control. The various types of nerve injuries and differences between them are shown in Figure 2.

Figure 1. Basic anatomy of the brachial plexus. (www.assh.org)

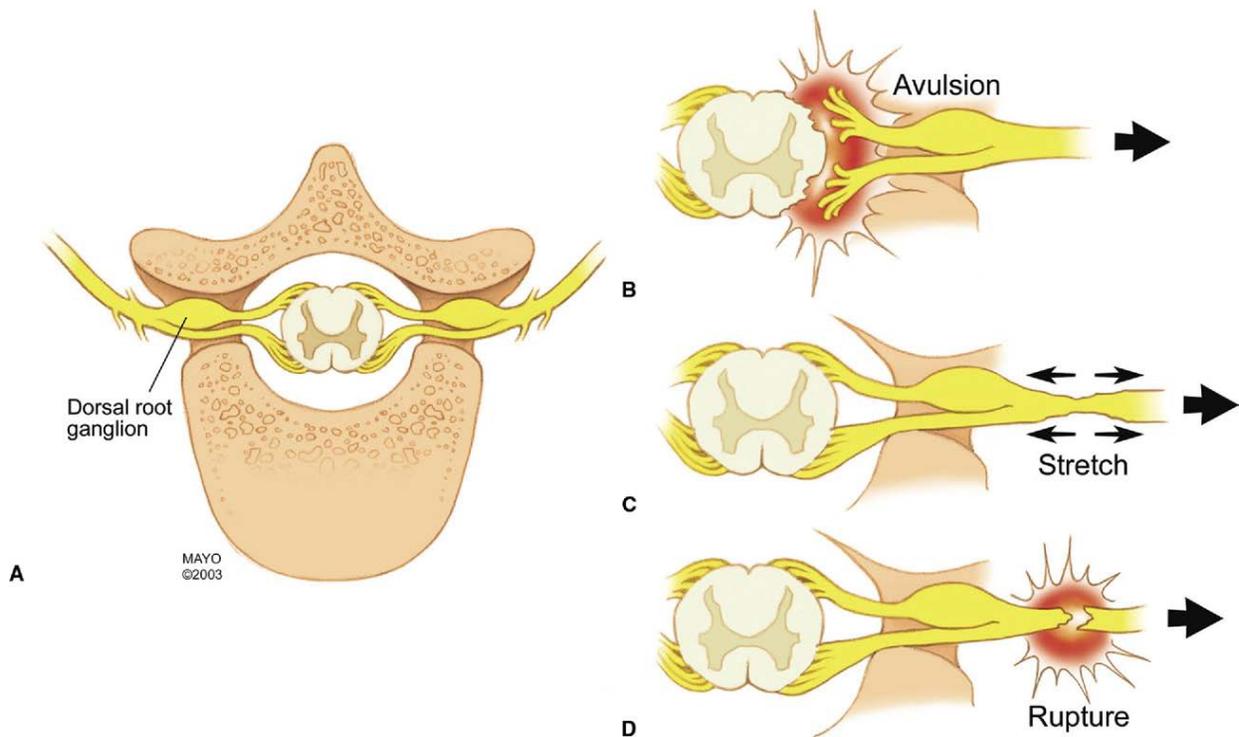


Brachial plexus injuries (BPIs) can be congenital or caused by trauma, such as a fall or motor vehicle accident. The most serious and debilitating type of traumatic BPI is a complete avulsion injury, in which all five nerve roots are torn out of the spinal cord and all arm, wrist, and hand, as well as some shoulder function, is lost. Without any treatment, a person with this type of injury will be left with a “flail arm,” over which he/she has no control. Traumatic BPI is

a devastating event with lifelong effects. It robs people of their upper extremity function, makes simple tasks challenging or infeasible, and is often accompanied by chronic pain.

The most common causes of BPIs, including total avulsion injuries, are motorcycle, motor vehicle, and snowmobile accidents.¹⁻³ BPIs occur in 1.3% of all polytrauma patients and 5% of those involved in motorcycle or winter sports accidents.^{4,5} As extreme sports become more popular and resuscitation techniques improve, more people survive these accidents with BPIs.³ BPIs most often afflict young men around 25 years old, who are embarking on their most productive years of life. Complete avulsion BPIs are associated with low rates of return to work, chronic pain that may be unresponsive to medication, and loss of independence.⁶ Patients also experience psychological, emotional, and social difficulties.^{3,6} BPIs are accompanied by a considerable socioeconomic consequence in the form of direct costs (i.e. surgical repair and physical rehabilitation, and productivity loss, as well as a marked decrease in quality of life (QOL)).⁷

Figure 2. Different types of nerve injuries near the spinal cord.⁸



Chronic pain is common after avulsion BPIs and is responsible for a large portion of the disability.⁹ In one study, 54 (84%) of 64 patients with complete brachial plexus palsies reported pain.⁹ It can be localized to one part, such as the hand, or radiate up or down the entire limb. For some, the pain is constant with periods that are better or worse, for others the pain occurs

randomly, or seems to be exacerbated by cold or changing weather. Pain itself, which tends to be unresponsive to medication, is disabling and disruptive to social activities and employment.¹⁰

Apart from the physical limitations of BPI, patients' social lives, career, and emotional health often suffer also. In a study of 32 patients with BPIs, most felt that their injury affected their personal lives and 22 encountered "at least some discrimination on the basis of their injury," which in many cases limited employment opportunities or career advancement.⁴ Only 54% of the previously employed subjects were able to return to work.⁴ Wellington found that appearance and body image after BPI greatly impacted people's social lives.⁶

Management and reconstructive options for this complete avulsion BPIs have improved markedly over the past 60 years. Shoulder fusion, elbow bone block, and finger tenodesis were the standard treatment after World War II. Unfortunately, this approach yielded few good outcomes and was replaced by combined transhumeral amputation and shoulder fusion, the gold standard of the 1960s. When performed within 24 months of injury, most patients experienced good and fair outcomes.³ More recent advances in microsurgery and improved understanding of nerve injuries and repair have brought about "reliable restoration of elbow flexion and shoulder abduction, in addition to useful prehension of the hand in some cases."³

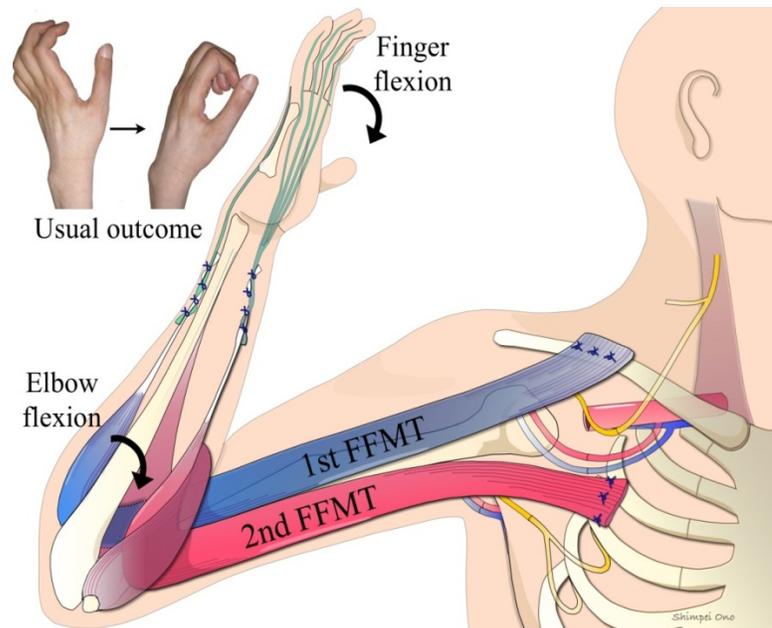
CURRENT TREATMENT OPTIONS AND OUTCOME MEASURES

Today, the surgical options for complete brachial plexus avulsion injuries include nerve transfer, muscle transfer, tendon transfer, arthrodesis, and amputation. Although there have been some experiments with implanting nerves into the spinal cord after total avulsion BPI, the results so far are limited and do not justify the risks and costs of the procedure.⁹ The double functioning free muscle transfer (FFMT), such as the procedure described by Doi et al., remains the gold standard for restoring elbow and hand function to patients with complete avulsion BPIs.^{3,8,11} Figure 3 shows the expected outcomes of these procedures. Many factors can affect the objective and subjective outcomes of these operations; personality, social support system, and education level, although less obvious type and severity of the BPI can have an equal role in determining a patient's outcome.¹²

Most BPI patients acquired their injuries in a type of major trauma, like motor vehicle accidents which account for about 70% of all BPIs.²⁻⁴ As a result, many suffer concomitant injuries, including scapula, clavicle, extremity, or rib fractures, spinal injury, brain injury, coma, and damage to internal organs.^{3,5,8} Ideally, when signs point to avulsion injury, exploration and reconstruction should be performed at 3-6 weeks.⁸ In cases of polytrauma however, a full examination is often prevented by the presence of multiple fractures or comatose state so that the patient's BPI may not be diagnosed until he/she receives primary treatment or comes out of the coma.^{5,8} This can limit a patient's options for surgical repair because the window for nerve reconstruction after injury is just 6 months.⁸ The optimal time for surgery is based on our understanding of "irreversible changes" that occur in the motor end plate.⁸ The success rate and

outcomes of surgical intervention are lower when operation is delayed (9-12 months) or late (>12 month).⁸

Figure 3. Double FFMT, or Doi procedures. (Image courtesy of Dr. Shimpei Ono)



Apart from the obvious physical limitations and pain associated with BPIs, patients experience psychological distress, poor self-esteem and body image, difficulties establishing or maintaining personal relationships, and discrimination due to the appearance of their arms.^{4,6} Personality as well as one's outlook and coping strategies influence subjective outcomes, including patient satisfaction and perception of functional improvements.¹² These physical and psychosocial factors make life more challenging and are difficult to adapt to even with the best surgical outcomes.

Defining a “good” outcome and figuring out how to measure it are difficult tasks. Quantitative methods alone are “often inadequate for exploring emotional or complex issues such as how patients make decisions or their feelings about outcomes.”¹³ The main goals of reconstructive surgery, according to physicians, are to restore motor function, in particular elbow flexion, and protective sensation. Other areas such as shoulder abduction and stability, and intrinsic hand function are considered lower priorities.^{8,12,14} When assessing the quality of healthcare, physicians often use traditional measures such as postoperative infections and motor function, whereas patients' main concerns may be restoring their ability to live independently, alleviating pain, or cosmesis.^{1,12} Even if a result is measurable or clinically notable, it may not translate into practical use or have a satisfactory aesthetic for patients.^{2,4,12,14} Patients often have different opinions than their health care providers of what constitutes a good outcome.² For instance, gaining 20 degrees of elbow flexion, a noticeable improvement to a clinician, may not enable a patient to return to school or work, do daily activities they once enjoyed, or live

independently. If elbow flexion or another motor function is the sole parameter being considered, a patient can have a “good” result without being satisfied overall.¹² To accurately measure outcomes we must define treatment objectives according to both the physician and the patient.¹²

Qualitative research can provide insight into how patients feel and why. Patients’ satisfaction with the treatment process and results and whether or not they feel there have been substantial improvements are ultimately the most important outcomes. Their lives are the ones being affected by the injury and medical intervention and thus their opinions should carry the most weight. A major determinant of patient satisfaction are the patients’ expectations for their care.¹ To a great extent, these are based on patient education and preoperative information provided by their physician. Preoperative information can reduce anxiety, increase patients’ “perceived levels of comfort and confidence,” and lead to higher levels of patient satisfaction.¹⁵ Patients often determine the success of their treatment and rehabilitation based on “the impact it has on their lifestyle,” meaning how it limits or impedes their daily activities and livelihoods.⁷ Information and patient education are especially important for patients with complete avulsion BPIs, because the injury is rare and quite complex, the possible gains from surgical intervention are small compared to the function that was lost, and BPI has a huge impact on nearly all aspects of life.⁶

Patient satisfaction as an outcome metric has been gaining popularity in plastic and reconstructive surgery.¹³ There is little known about the experience and satisfaction of complete avulsion BPI patients and whether the functional gains achieved by current therapeutic modalities translate into practical utility.⁷ As Bengston et al. pointed out, “injury factors” such as the mechanism and severity of a BPI affect a patient’s outcome and in order to extrapolate the results of surgical intervention, research must consider patients with similar types of BPIs, such as total avulsion injuries.¹² Wellington found that semi-structured interviews “yielded a wealth of descriptive subjective experiences” about quality of life after BPI from patients.⁶ Other studies have used surveys to address patient satisfaction and quality of life, but none have used qualitative interviews to understand the expectations, hopes for treatment, and the effects of preoperative information on expectations and satisfaction in patients with complete avulsion BPIs. Moreover, patients who elect conservative managements such as physical therapy are frequently omitted from studies and there is no control group against which outcomes of surgical reconstruction can be measured.

STUDY AIMS

In this study, we used questionnaires and a qualitative interview to determine the patient-reported outcomes, satisfaction, and the degree to which patients’ expectations were met; highlight areas in which the patients’ expectations for or assessment of outcomes differ from those of their physicians’; and, compare the results of non-surgically managed patients to those who have undergone reconstructive surgery. We hope to elucidate the adult patient’s experience with complete BPI and treatment so that doctors provide treating these injuries can provide better

preoperative education, including realistic, tangible expectations, and improve the experience for future patients.

MATERIALS AND METHODS:

Patient recruitment and exclusion process

164 patients with traumatic BPIs were seen by either Dr. Yang or Dr. Chung at the University of Michigan Health System. We screened these patients according to the inclusion criteria listed in Table 1. 22 were eligible for the study and were contacted via mail. Patients who underwent no surgery were intended to serve as a control group against which the results of surgical patients could be compared. The consent form is shown in Appendix 2.

We obtained information about the nature and date of the injury and treatment from subjects' medical records.

Questionnaires

Currently, there are no standard questionnaires for assessing the outcomes or satisfaction of patients suffering from BPIs. Hill et al. identified 103 different measures used to assess activity after traumatic BPI in a systematic review of questionnaires.⁷ None of those that were specific to BPI had been clinimetrically evaluated in this population.⁷ The DASH (Disability of the Arm, Shoulder, and Hand) and the ABILHAND, were the only questionnaires to attribute greater than half their scores to UE activity. However, the DASH measures both symptoms and function, and therefore an improved outcome may not be correlated with improved UE activity, and the ABILHAND, developed for individuals with rheumatoid arthritis who underwent wrist fusion, may not be applicable to BPI patients who have no or minimal use of their hand.⁷ Wellington identified five themes from interviews of patients with traumatic BPIs: employment, past, current, future; pain experiences; body image, self-worth, and external relationships; sexuality, emotions, and internal relationships; and, future goals and plans.⁶ Choi et al. also identified return to work as an important measure for BPI patients.⁴ We selected questionnaires to cover these and other aspects of the experience.

We chose to use four questionnaires to gather information about basic physical and mental health, hand and arm function, coping strategies, and satisfaction with appearance; the Short Form 36 (SF-36), the Michigan Hand Outcomes Questionnaire (MHQ), a modified version of the Swap With Appearance (SWAP) scale adapted for brachial plexus patients, the SWAP-BPI, and the brief COPE (BCOPE). We used the SF-36 to assess the general physical and mental

| Table 1. Inclusion Criteria |
|---|
| Brachial plexus injury is a complete (C5-T1) avulsion sustained in trauma |
| Normal arm and hand function prior to injury |
| At least 18 years of age |
| Minimum of one year having passed since the injury or surgery |
| Patient has no other upper extremity nerve palsies, neuropathies, or congenital abnormalities affecting the brachial plexus region, arm or hand |

health. The MHQ, whose validity and reliability have been demonstrated in patients with carpal tunnel syndrome and rheumatoid arthritis, was used to measure pain, satisfaction with hand function, activities of daily life, work performance, aesthetics, and overall hand function.¹⁶ The original SWAP was developed to measure the subjective view and social aspects of body image in burn patients with good validity and psychometric properties.^{17,18} It has since been successfully adapted for patients with scleroderma, who also suffer from disfigurement.¹⁷ To the best of our knowledge the SWAP has not been used with BPI patients, however, burn and BPI patient groups undergo similar changes in aesthetic that influences self-esteem and often social interactions. The SWAP-BPI differs from its parent scale in that it focuses on the upper extremity and body-image after BPI instead of burn. The SWAP-BPI is shown in Appendix 3. The BCOPE has also been successfully used as a psychometric evaluation in burn patients, who must cope with complex issues during recovery.¹⁹ Galvin and Godfrey recommend the BCOPE for use in spinal cord injury patients, who like those with BPIs, suffer sudden, often permanent “physical and lifestyle changes.”²⁰ Anderson et al found that certain coping mechanisms employed by adults with spinal cord injuries, who were injured in adolescences, are associated with higher life satisfaction.²¹ We included the BCOPE because the use of different coping strategies may correspond to higher or lower patient satisfaction, emotional health, and quality of life.

Interview

A research assistant conducted the one-on-one interviews with study subjects, following an interview guide, which is in shown in Appendix 4. The interviews were audio recorded and labeled with study identification numbers, not patient identifiers, to protect the privacy of study subjects. A person not involved with other parts of this study then transcribed the recordings. The Human Institutional Review Board of the University of Michigan approved all aspects of this protocol

Data and Statistical Analyses

For the sake of comparison, we divided subject results into two groups: surgical and non-surgical. The latter group includes all patients who did not undergo surgical intervention for their BPI as well as the one patient who had amputation and shoulder arthrodesis, because he also did not have reconstructive surgery.

Every patient completed all four questionnaires, which were scored as follows. SF-36 results were scored according to the SF-36v2 scoring guide, which provides raw and norm-based scores for 8 health domains (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health) as well as psychometrically-based physical component summary (PCS) and mental component summary (MCS) scores. We scored MHQ results using the excel scoring sheet provided by the official MHQ website.(<http://sitemaker.umich.edu/mhq/scoring>) SWAP-BPI results were treated qualitatively,

to see how patients felt about the appearance of their BPI lesions and how these feelings affect their social lives. We computed BCOPE scores using the scales provided by the developer, which summarize raw responses to the 28 items into scores for 14 different types of coping mechanisms. (<http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>)

Typical analysis of qualitative data involves transcription, open coding, creation of a codebook, focus coding, and data analysis.¹³ Because of the small sample size, we did one round of coding to identify common themes from the interview transcripts. We then analyzed the prevalence of codes in the surgical and non-surgical groups.

The relationships between patient characteristics, interview themes, and questionnaire scores were examined using *t*-test, chi-square, and linear regression analyses.

RESULTS:

Of the 22 patients contacted, 10 chose to participate. All participants were male. The average age was 37.7 years (range of 25 to 66 years). The most common types of trauma were motorcycle accidents (n=4), snowmobile accidents (n=2). Falling onto the shoulder, all-terrain vehicle (ATV) accident, football tackle, and motor vehicle accident were also reported. Five subjects had single or double muscle transfers, 1 underwent amputation and shoulder arthrodesis, and 4 elected not to have surgery. No patients underwent nerve transfer or DREZ operations. Patient demographics are shown in Table 2.

| Table 2. Patient Demographics and Injury Mechanisms | | | | | | | | |
|--|-----|----------------|---------------------|--|------------------------|-------------------------|----------------------------------|-----------------|
| Patient | Age | Marital Status | Trauma | Concomitant injuries | Dominant hand affected | Time Since Injury (yrs) | Surgical treatment | Time to Surgery |
| 1 | 31 | Married | Snowmobile accident | Clavicle, pneumothorax, vertebrae fractures; arterial injury | No | 6 | FFMT | 9 mos. |
| 2 | 35 | Married | ATV accident | Coma; lower extremity fractures; hemidiaphragm paralysis | No | 13 | - | - |
| 3 | 66 | Widowed | Motorcycle accident | Lower extremity, radius fractures | Yes | 8.5 | Amputation, shoulder arthrodesis | 4 yrs. |
| 4 | 48 | Single | Snowmobile accident | Coma; Rib, vertebrae, pelvis, clavicle, skull, fractures; punctured lung | Yes | 10.67 | FFMT | 2 yrs. |

| | | | | | | | | |
|--|----|----------|---------------------|--|-----|------|-------------|---------|
| 5 | 42 | Single | Motorcycle accident | Vertebrae, shoulder, lower extremity fractures | No | 7 | - | - |
| 6 | 51 | Divorced | Car accident | Clavicle, scapula, fractures | No | 2.33 | - | - |
| 7 | 25 | Single | Motorcycle accident | Coma; TBI; ARDS; rib, skull, vertebrae fractures | Yes | 4.33 | FFMT | 9 mos. |
| 8 | 26 | Single | Football tackle | None | Yes | 4.33 | Double FFMT | 9 mos |
| 9 | 27 | Single | Fell on shoulder | None | Yes | 24 | FFMT | 19 yrs. |
| 10 | 26 | Single | Motorcycle accident | Let dislocated; radius fracture | Yes | 2.5 | - | - |
| FFMT = functioning free muscle transfer, Double FFMT = both parts of Doi procedure | | | | | | | | |

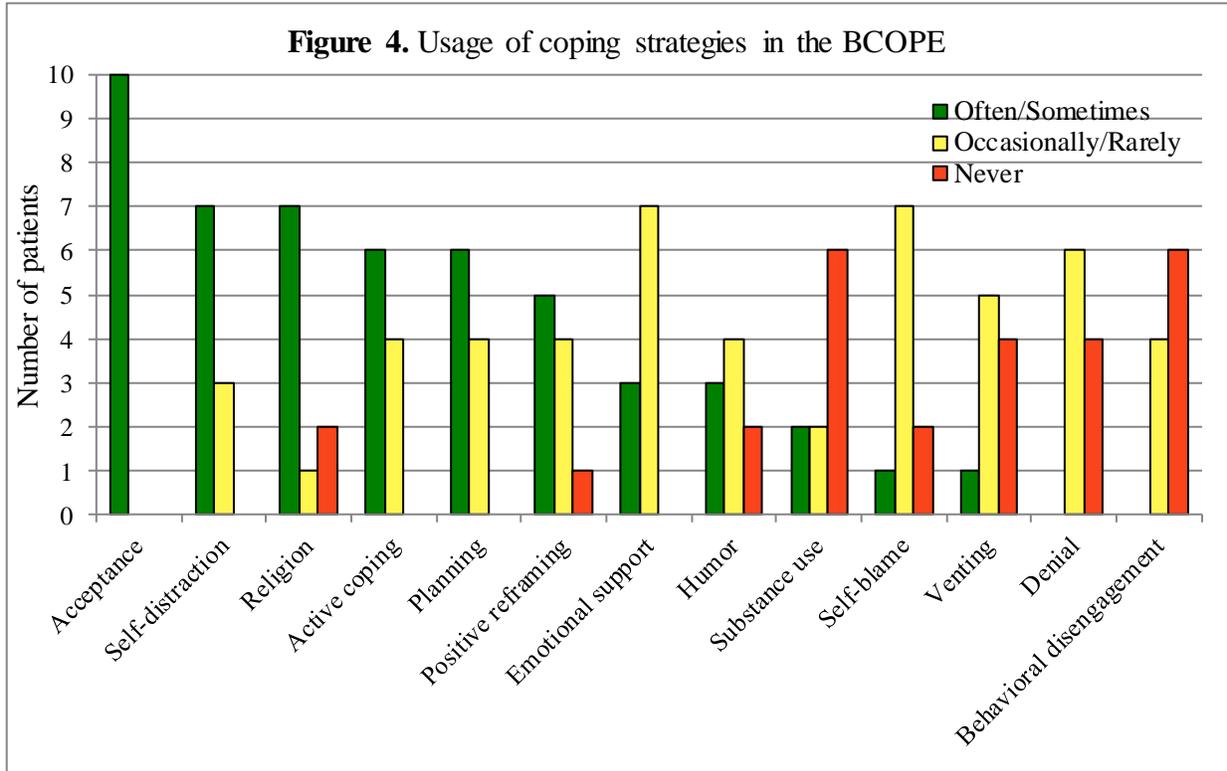
Table 3 compares the scores of participants whose non-dominant hands were injured to those whose dominant hands were injured. The differences between mean scores for other components were not significant. Participants whose dominant hands were injured were significantly more likely than people whose non-dominant hands were affected to feel well adapted ($p=0.053$). They were not significantly more or less likely to be satisfied with the outcome of their arms or experience changes in their social lives as a result of their BPIs ($p>0.10$).

| Table 3. Significant differences between the mean scores of patients whose dominant and non-dominant hands were injured ($p<0.05$) | | |
|---|---------------------|-------------------------|
| | Dominant Hand (n=6) | Non-dominant hand (n=4) |
| MHQ Pain of affected hand | 48.33 | 85.0 |
| SF-36 Pain | 46.67 | 26.75 |
| SWAP-BPI Interference with Relationships | 9.50 | 14.75 |
| SWAP-BPI Social Discomfort | 2.83 | 5.0 |

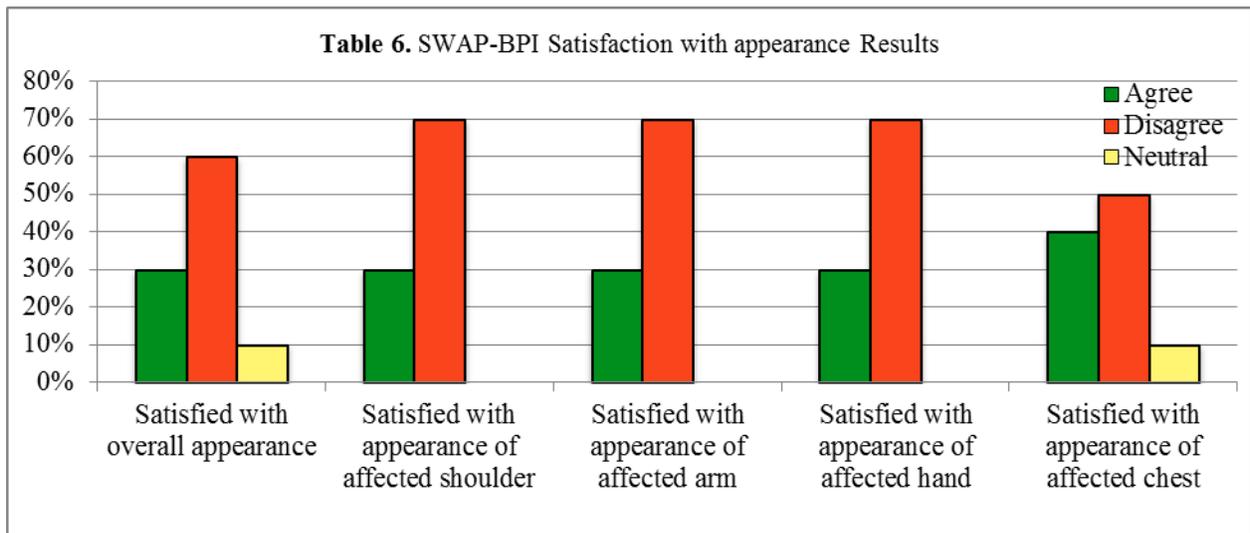
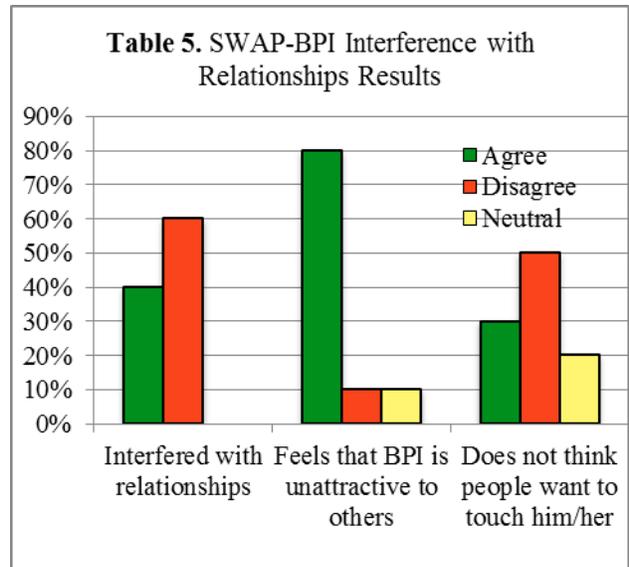
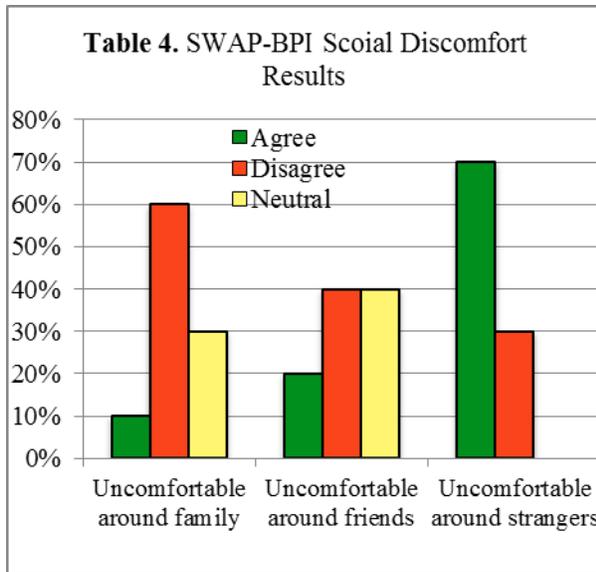
Questionnaire Results

Patients results were divided into two groups: surgical and non-surgical. The latter group includes the 4 patients who did not have any surgery as well as the 1 patient who had amputation and shoulder arthrodesis.

All patients reported using at least 3 coping strategies often. The mean usages of venting ($p=0.052$), positive reframing ($p=0.037$), and self-blame ($p=0.034$) were significantly higher in the surgical group. There were no coping strategies that the non-surgical group used significantly more. Both groups reported high use of acceptance, religion, self-distraction, active coping, and planning. The reported use of each type of coping strategy is shown in Figure 4.



We separated the results of the SWAP-BPI into three categories: social discomfort (items 1-3), satisfaction with appearance (items 4-8) and interference with relationships (items 9-11). The results are shown in Tables 4-6. All but one of the people who were dissatisfied with the appearances of their arm, hand, shoulder, and chest were also dissatisfied with their overall appearance. Three of the 8 subjects who felt their BPI lesion was unattractive to others also felt people do not want to touch them, and 4 of them also felt that it interfered with their relationships. Patients who were satisfied with the outcome of their arm had significantly lower scores for interference with relationships than those who were not satisfied ($p=0.025$). There were not significant differences between the scores of the surgical and non-surgical patient groups.



Mean MHQ scores from the surgical and non-surgical patient groups are shown in Table 7. There are no significant differences between the mean scores of these groups. There were significant differences between mean scores of patients' affected and non-affected hands, which are shown in Table 8.

| Table 7 Mean MHQ results of Surgical and Non-Surgical patient groups | | | | | |
|---|------------------------------|-----------------|-----------------------------|---------------------------------|-----------------------|
| Patient Group | Overall ADL of affected hand | Ability to work | Aesthetics of affected hand | Satisfaction with affected hand | Pain of affected hand |
| Surgical (n=5) | 13.93 | 42 | 21.25 | 5.83 | 63 |
| Non-surgical (n=5) | 23.57 | 35 | 40 | 1.67 | 63 |

ADL=activities of daily living
 All Scores are out of 100. Higher scores indicate better subjective opinion except for Pain scores. Higher pain scores indicate greater interference or disability due to pain.
 There were no significant (p -values ≤ 0.010) difference between the surgical and non-surgical groups.

| Table 8. Mean MHQ scores of the Affected and Non-affected hands | | | | | |
|--|----------------------|------------------------|---------------------|-------------------------|------------------------------------|
| Hand | Overall ADL of hand* | Overall hand function* | Aesthetics of hand* | Satisfaction with hand* | Function relative to pain of hand* |
| Affected | 18.75 | 4 | 30.63 | 3.75 | 63 |
| Non-affected | 66 | 95.5 | 96.25 | 93.75 | 14.5 |

ADL=activities of daily living
 All Scores are out of 100. Higher scores indicate better hand performance, except for the Pain scale, for which higher scores indicate more pain.
 *Difference in mean scores is significant ($p \leq 0.01$)

The mean raw scores of the surgical and non-surgical groups from the SF-36 are shown in Table 9. The raw scores for role limitations were especially low. This is also seen in the mean norm-based scores for role limitations due to physical health and emotional problems, which were 28 and 30, respectively. Both mean norm-based scores are 2 standard deviations below the norm.

| Table 9. Mean SF-36 raw scores of Surgical and Non-Surgical patient groups | | | | | | | |
|---|-----------------------------|--------------------------|---|--|----------------|--------------------|-------|
| Patient Group | Physical component summary* | Mental component summary | Role limitations due to physical health | Role limitations due to emotional problems | General Health | Social functioning | Pain |
| Surgical (n=5) | 42.20 | 42.08 | 0 | 6.66 | 80.60 | 72.50 | 43.80 |
| Non-surgical (n=5) | 32.70 | 48.92 | 0 | 33.32 | 75.20 | 65.00 | 33.60 |

Scores range from 0-100. Higher scores indicate better health or ability.
 *p-value ≤ 0.05

There were significant negative correlations between SF-36 MCS scores and both SWAP-BPI social discomfort ($r = -0.623$, $p = 0.054$) and interference with relationships scores ($r = -0.556$, $p = 0.095$). SF-36 MCS also had negative associations with the use of self-distraction ($r = -0.682$, $p = 0.030$) and denial ($r = -0.589$, $p = 0.073$) to cope. There was not a significant difference in SF-36 social functioning scores between those who thought their BPI interfered with their relationships and those who did not.

RESULTS OF PATIENT INTERVIEWS

The patient interviews lasted between 22 minutes and 1 hour and 44 minutes, with an average length of 52 minutes. The biggest determinant of time was how talkative and willing to share each person was. Some seemed to feel quite comfortable and offered up examples and information from their lives, whereas others seemed to be less open and gave shorter answers. For this second category of interviewee, the interviewer tried to use additional probing questions so that people would flesh out their answers and give more explanation.

Patient Education

Six patients were diagnosed within the first month after their injury, and only 3 were told about reconstructive surgery in that time. One patient who was first seen at a small, rural medical center and spent six weeks in a coma after his injury was never diagnosed or even given a reason for the state of his arm. He finally diagnosed himself after requesting his medical records and researching his symptoms on the Internet. Five participants were initially treated at similar (i.e. small, rural) hospitals and one by traditional African healers. These patients were significantly less likely to be diagnosed within the first month ($p=0.091$) and 5 of the 6 were often not informed about reconstructive surgery at these smaller institutions. One patient said that he was told “there’s nothing they [the doctors] can do for it.”

One patient felt that he was never given an adequate explanation of the injury and why his arm could not be totally “fixed.” He said that he knew of people whose arms had been severed by farming equipment and reattached, and therefore wanted to know why function could not be restored to his arm, which had never been severed. Other patients said that they understood the injury, but when asked to explain it said that their shoulder was “knocked out of place” or “all [that] it is, is ripped.”

All patients who chose surgery said that their doctors discussed the recovery process and what to expect in terms of function, but only one said that they were also told what to expect in terms of non-functional outcomes, such as appearance.

Medical Decision Making

The main factors in the decision to have the FFMT in the surgical group were getting function back ($n=4$), having insurance ($n=3$), and feeling that it was important to try the surgery and take that step towards having a more functional arm ($n=2$). All patients in this group reported that they were happy with their decision, none had any doubts about it, and 3 wished that they had known more in the beginning or asked their physicians more questions before the surgery. One wished that he had known the importance of time and had sought treatment “as soon as I got out of the hospital.” Another, whose outcome failed to meet his expectations, wished he would have known “if this type of surgery would have a negative side... meaning it might work, or it might not work,” as well as what to do if the surgery does not “work.”

One patient, who had a FFMT and is happy with that choice, had initially made up his mind not to have the surgery. He felt having it would be “betraying God” and would eliminate his future eligibility for any newer, more promising treatments that are developed. He was able to calm the latter concern by researching BPI treatments, including experimental ones like spinal reinsertion, and determining for himself that FFMT would likely remain the gold standard for years to come.

Those in the non-surgical group reported the following reasons for choosing not to have FFMT: the surgery may not work (n=4), having just recuperated from the initial injury they do not want to go through another recovery period (n=4), FFMT will not provide any useful function (n=5), it is too costly (n=2), they do not want to have the surgery in case a better procedure that provides more function is developed in the future (n=2), they have been doing fine living with a flail arm and do not feel the need to change it (n=1), the FFMT will not restore sensation to their arm (n=1), and they did have good “chemistry” with the surgeon (n=1). 3 of the 5 non-surgical patients were not told about reconstructive surgery initially. In one case, the patient lived with the BPI for 11 years before hearing about FFMT. Four of the 5 reported being happy with their decision, 3 still had doubts or wondered how their life would be different if they had had the FFMT, and 3 wished that they had known more or asked more questions about the surgery before they made their decisions. They felt they should have asked what “it” is and why doctors cannot “fix it.” A patient mentioned that “when the doctor did try to explain it to [him], [he] had a hard time understanding,” due to the use of what the patient considered to be technical language. One participant also regretted rejecting the surgery without taking “the time to research it” himself. He said that once he heard the probability that the operation might fail, he said no.

The patient who chose amputation did so because he felt his arm had become “a hazard and hindrance.” Instead of “having it as a piece of meat, [he] decided to go ahead and have it amputated.” He felt assured in his decision because it seemed “obvious” to him that he would not get any usable function back from current operations, like FFMT.

Quality of Life

All patients reported that they live “one-handed,” meaning they use their non-injured hands to complete tasks and are unable to perform tasks using two-hands. Eight experience frequent, chronic pain. Three of these patients reported that their pain is affected by cold weather or changes in weather. Nine patients said they could take care of themselves on a daily basis, 8 feel well-adapted to life with a BPI, 6 still participate in the same leisure activities as before the injury (although often with some modifications), and 3 have returned to the same or new work. Most (80%) patients previously held physically demanding jobs, such as construction work, 1 held a management position, and 1 was a student.

Six reported that they disliked having to ask for help and 5 that they asked for help as a last resort. One participant said that only if he “totally can’t do it,” will he ask someone. Reasons for not asking for help varied; some felt it was important to learn to figure out a way to do things with one arm, while others felt embarrassed asking for assistance because they were very physically able and independent prior to the injury. One patient admitted that there are times when he is “just feeling really lazy, which I think we all do at times...[and I] kind of use it as an excuse” to have someone do things for him.

Only one patient said that his outlook on life did not change as a result of his injury. Five said they were “pissed off” in the beginning and 6 that they do not let it “get” to them now. Many made statements like “I’ve learned to deal with it” or “it’s part of my daily routine.” Five said they are more careful now, respect life more, or appreciate how quickly things can change. Only one said that he lost the drive to do better and has “given up.” Many patients brought up emotional changes. Three said that they experienced depression after their injury. One experienced a period of time after his injury when he did not want to leave the house or see people. He eventually got past this and resumed his regular social activities.

Half of the subjects said that their social lives were unchanged by their injuries. Of the patients whose social lives changed after their injuries, only two said it changed for the better. One of these two said that he found out who his “real friends” were, stopped hanging out anyone who was not, and made a group of new friends that he says are “nicer” and “friendlier.” The second told us that he had actually “gained a lot of friends because of [his] injury.” The other participants whose social lives were changed by their BPIs reported a decrease in the size of their friend group and/or amount of socialization. Two patients experienced discrimination; one was called names, like “one-armed bandit,” and the other felt that employers turned him down when he applied to jobs he was otherwise qualified for.

Eight felt that the people around them understand what they go through; although some feel that the experience cannot be fully understood by those without a BPI. “That was one painful part of it,” said a patient, “the fact that I was the only one knowing the exact state of feeling that I’m having towards the situation.”

Three patients said that most people they meet do not notice their arm, because they keep their hands in their pockets. Four participants disliked wearing a sling, because it is uncomfortable, does not help them in any way, or draws attention to their disability. One said that it caused people to ask questions, and he was “tired of telling everybody what happened.”

Advice

When we asked patients what advice they would give to someone with a similar injury knowing everything that they currently know, they gave answers about making the decision to have surgery, what to expect from life, and how to live with a BPI. Their answers are shown in Table 10. A patient who had FFMT said that there are “going to be things you get back...little

improvements that you never knew you even wanted back.” Another said he would “advise anybody to at least have it [FFMT]. If it doesn’t work now, you might as well at least try it because something good might come out of it and better.” The need to stay positive was a common theme throughout many of their pieces of advice. One patient put the need to adapt and move forward very bluntly, “Either you adapt or you give up...either you deal with [it] and move on or you might as well just take a 25 cent bullet and get it over with.”

Satisfaction

Those who were satisfied with the outcome of their arms had significantly higher MHQ satisfaction with aesthetics scores ($p=0.052$). Aside from this there were not significant differences in the questionnaire scores between patients who were and were not satisfied with their outcomes. Four subjects were not satisfied with their outcome; two from the surgical group and two from the non-surgical group. A non-surgical patient said, “I still have a glimmer of hope that someday they’ll be able to fix it, but I’m satisfied for right now”

| Table 10. Advice from patients for others with BPIs |
|--|
| Don’t give up (n=8) |
| Everything is going to be a challenge (n=5) |
| Expect frustration, difficulty, and/or depression (n=6) |
| Expect what your doctors tell you will happen (n=3) |
| Adapt and learn to live one-handed (n=4) |
| Get treatment as soon as possible (n=2) |
| Be proactive and do your research (n=5) |
| Explore every treatment option (n=7) |
| Do what is right for you treatment-wise (n=3) |
| Have the surgery (n=3) |

Everyone that had surgery noticed improvements in the strength or function of their arms. One said that his shoulder stability was the “biggest improvement.” He can “actually support [himself] on [his] shoulders...even being intimate.” Another said that his elbow flexion is useful for carrying grocery bags, which he can hook on his arm with his elbow bent. Two of the non-surgical patients saw improvements, of which one was the amputee. Six patients felt that the outcome of their arm met or exceeded their pre-treatment or initial expectations.

All surgical patients and 3 non-surgical patients were satisfied with the care they received for their BPIs. Six patients felt that their doctors’ prognosis and initial information was accurate. Seven felt that their physicians have a good understanding of what they go through and that they had good communication with their doctors. Only one patient reported a discrepancy in opinion between himself and the surgeon. He felt that the doctor “really liked what he saw” in follow-up appointments. He, however, was not “as excited” and said that the doctor was “seeing what I can do and I’m seeing what I can’t do still.”

DISCUSSION:

The devastating nature of complete avulsion brachial plexus injuries, costs of surgical reconstruction, and relatively small functional gains motivated us to try to reveal the patient’s experience and feelings. Many studies have documented the viability and functional gains of

muscle transfers. Doi et al. achieved good or excellent results in 96% of patients using double FFMT.¹¹ In another study, 79% of patients with single FFMT for elbow flexion achieved good or excellent elbow flexion strength.³ Whether or such functional recovery is useful to patients or enables them to do two-handed activities has not been studied. In this study, we found that all patients, regardless of surgical treatment, continue to live one-handed. The mean MHQ score for activities of daily living for two-hands (37.5) was lower than that of either the right (54.5) or left (40.0) hands. In fact, three patients said that the MHQ did not feel relevant or applicable to them because they cannot do anything with two hands. Nevertheless, all patients who had FFMT operations were happy that they had chosen to have surgery and saw improvements in their arms.

Communication and Patient Education

Communication has become an important measure of the quality of healthcare, with good communication being defined as that which welcomes and fosters patient participation, question asking, and active decision-making about their own care.¹⁵ Unfortunately, patients often feel under-informed about their diagnoses and treatment, often times because they do not understand the complex or technical explanations from their healthcare providers.¹⁵ One of the participants in this study expressed exactly that, and others felt that they still had questions the need to be answered. Studies of patient education have found that written information is more easily absorbed and better remembered than verbal information.¹⁵ It can also prompt discussion and questions from the patient, which could be very useful to patients with BPIs who often are thinking about multiple injuries and may feel overwhelmed. One patient felt that no one had ever given him a satisfactory explanation of his injury and was frustrated by this. He “still [doesn’t] know exactly what’s wrong” or “why they [physicians] can’t fix it.”

Diagnosis of the BPI is the first step in educating patients. However, many patients go undiagnosed for some time due to concomitant injuries or because they are seen at a non-primary health center that is not equipped to diagnose them. Kaiser et al. recommends that BPI should be “considered in all patients after a motorcycle or car crash,” especially if they have common concomitant injuries of patients with BPI.⁵ Even once patients are correctly diagnosed, however, they can run into communication problems when they explore treatment options or want to understand exactly what a BPI is and what it means for them. As seen above, it is very important that patients get the opportunity and have the resources to ask any and all questions they have before they make a decision regarding their treatment.

Medical decision making:

Engaging patients in the medical decision making process has multiple benefits. It can help reduce spending on procedures that do not “add to the health [or quality of life] of individuals” and promote discussion to help patients make the right choice for their lives.²² Arora and McHorney found that while the majority prefers a “passive role,” certain characteristics are associated with wanting a more active role in deciding their care.²³ Being younger, female, or

college-educated, using active coping strategies, and placing higher value on health were all significant predictors of desiring an active role.²³ In this study we found that half of the patients were proactive about their treatment, meaning that they did their own research and/or sought out surgery consults on their own.

Half of the patients were not told about treatment options initially, including 3 of the 5 non-surgical patients, which may contribute to the sentiment that having the surgery would set them back in their recovery. 80% of the patients experienced concomitant injuries, so it is understandable that once they recover from these they would be hesitant to go through a major operation. However, the functional deficits of complete avulsion BPIs are lifelong and the results of surgery are best when it is performed sooner, so it is important that patients are informed about their options early and counseled about the long-term effects.²⁴ A patient who had FFMT surgery said that it was “discouraging to be set back in any way,” but is happy that he had the operation. Another, who was somewhat disappointed with his outcome, still offered to be a “guinea pig” for any experimental operations in the future. On the other hand, some non-surgical patients thoroughly explored the available treatment options, and decided that none were “worth it” to them. Making decisions about medical care is a very personal process. This can make it difficult to “balance advocacy for active participation with individual patient preferences.”²³ It is therefore important for physicians to encourage open communication and to try to learn patients’ preferences.²³

We believe it is especially important to help patients set realistic expectations for their recovery. In this study, 5 of the 6 participants who were satisfied with the outcome of their arm felt that their expectations had been met. We also found that 6 patients still hope for better treatments to be developed. Two brought up stem cell research and bionic arms, neither of which appear to be viable options for the foreseeable future. To prevent disappointment and to help patients make decisions based on practical options, physicians must talk thoroughly and realistically about what patients can expect both with and without surgery.

Coping strategies, social lives, and relationships

We found negative associations between the use of self-distraction and denial to cope and SF-36 MCS scores, which suggests that these coping strategies are not beneficial for patients with BPI. We did not find any significant correlations between the use of specific coping strategies and satisfaction with the outcome.

Participants who injured their dominant hands used active coping strategies significantly more than those who injured their non-dominant hands. In this study, 6 patients injured their dominant arms and all of them felt they were well adapted to life with a BPI. Of the 4 whose non-dominant arms were affected, 2 felt well adapted. We suspect that people who lose the use of their dominant hand are more likely to keep trying to adapt, because they were already forced to find new ways to go about their everyday lives. People who still have use of their dominant

hand may need more encouragement from friends and family or their physicians to learn to adapt.

That most patients reported feeling angry, depressed, or frustrated at one point or another is consistent with the results of other studies.^{4,6,25} Overall, however, it seemed as though emotional problems were worst in the beginning were somewhat lessened with time. This could be due to the shock of learning the diagnosis, because it implies functional limitations for the rest of your life. One patient's initial reaction was "that everything [he] lived for is gone" for the rest of his life, and "the term 'forever' is the hardest thing to deal with." After a few years, however, most patients felt adapted and hopeful. Only one patient reported giving up. Nevertheless, the emotional trauma of BPI is considerable, and it may be beneficial to patients to seek some sort of psychological support or therapy. Two patients said that they try not to share their emotional strife with their families because they do not want to make their loved ones sad. Another said that he felt lonely, because no one around him knew how he felt. He said he would advise others with BPIs to look into therapy if they thought it might be useful.

Over half the participants in one study felt that discrimination "had hindered their career development and/or job advancement to some degree."⁴ The fact that one patient in our study encountered such discrimination could be explained by the types of jobs held by participants before the injury. Of the 9 who were previously employed, 8 held physically intensive jobs, which they could not expect to go back to, such as hot tar roofing and construction. Many said that they were going back to school or living on federal disability payments. Only 30% were able to return to work or find a new job. This fraction is low compared to other studies.^{4,6}

Pain

Unlike emotional pain, physical pain did not get better over time for most patients. Some described instances when they stayed home or curled up in the fetal position because they were debilitated by pain. Pain can impede people's social and professional lives. We believe that physicians treating people with BPIs, should have ongoing discussions with patients about pain and what options are available for alleviating it.

Discrepancies

Shin et al. states that although the functional gains provided by surgery are rudimentary at best, "these results must still be regarded as an advance in these otherwise irreparable avulsion injuries."³ Surgical patients in our study all saw improvements in function, for which some found practical uses, including carrying groceries. Two of the 5, however, were dissatisfied with their outcome, which they felt did not meet their pre-operative expectations. Many studies have found that even when surgery yields measurable improvements, patients may still be unhappy with their arm function or aesthetic.^{2,4,12,14} Consequently, we were expecting to find discrepancies between surgeon and patient perceptions of patient outcomes. Only one participant, however, felt that he and his doctor viewed his outcome from incongruent perspectives.

Questionnaires

It is interesting that although there was not a difference between the mean pain scores of surgical and non-surgical patients for the MHQ, there is a difference in the mean pain scores on the SF-36. There was not a significant correlation between MHQ and SF-36 pain scores ($R^2 < 0.10$). This could indicate that these are not the ideal questionnaires to use for this patient population. Additionally, two patients told us that the MHQ did not seem to apply to them or was difficult to answer since they could not use one of their hands, or in the case of the patient who had his arm amputated, only had one hand.

The SWAP-BPI and BCOPE results did reveal some significant correlations between satisfaction with appearance or use coping strategies and SF-36 and MHQ scores. These findings agree with previous studies, which have found that BPIs affect body image, social life, and emotional health.^{4,6}

LIMITATIONS:

The primary limitation of this study is the small sample size. This, however, reflects the small population of patients who have this particular injury. Nevertheless, some analyses may not have had the power to detect statistical significance due to the small sample size. Although there was a range of ages, only two races and one gender were represented, making it difficult to generalize the results of this study to women or patients of other ethnic backgrounds.

Other potential limitations include the retrospective gathering of information about preoperative expectations and initial patient education and the lack of data about the pre-injury quality of life. For some patients it had been many years since they were originally diagnosed and told about their BPIs, and they may misremember parts of the experience. There may also be social desirability bias, because this study attempted to measure patients' feelings and thoughts. Respondents may have felt the need to give socially desirable answers or to withhold negative remarks about their treatment experience. Another limitation is that the outcomes measures used in this study have not been validated in this population.

CONCLUSION AND RECOMMENDATIONS:

Traumatic brachial plexus injuries are devastating events, whose lasting effects permeate all aspects of a person's life. Whether or not someone chooses surgery, they will be forced to adapt, relearn simple tasks, cope with negative self-image, and, more often than not, find a new job. We suggest that doctors provide patients with BPIs with a written pamphlet or handout that explains the nature of their injury, all currently available treatment options, which health centers offer these treatments, and practical expectations for life with a BPI, including typical experiences with pain, body-image, and return to work. Having something to refer back to can help patients absorb the information, spark questions, and ultimately enable patients to make informed decisions about their healthcare.¹⁵ We feel it is especially important for smaller and more rural

hospitals to offer written materials like these, because every patient deserves to know what his/her options are, regardless of where he/she is initially seen and whether or not that hospital offers reconstructive surgery.

The results of this study suggest that FFMT procedures do not enable patients to do two-handed activities or use their affected arms for many useful activities. Nevertheless, patients that choose to have the operation seem, in general, to be happy with their decision to do so whether or not they are satisfied with the outcome. MHQ, SF-36, BCOPE, and SWAP-BPI results also suggest that coping strategies and body image issues significantly impact the experience of patients following traumatic brachial plexus injury. Further studies are needed, however, to evaluate the reliability and validity of these questionnaires in the population of complete avulsion BPI patients. Due to the limitations of this study, we recommend that additional research be carried out to determine the utility of FFMTs for patients with complete avulsion brachial plexus injuries, as it the operation(s) have monetary and temporal costs.

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APPENDIX 1. Glossary of Terms and Abbreviations

BCOPE – Brief COPE. An instrument used to measure patients’ use of different coping strategies. It has 28 questions. Higher scores indicate greater use of coping strategies.

BPI – Brachial plexus injury.

Brachial plexus – The network of nerves that come of the spinal cord near the neck and shoulder provide sensory and muscle innervation to the shoulder, arm, wrist, and hand.

Complete/total avulsion – Avulsion of all 5 nerve roots of the brachial plexus (C5-T1)

Doi procedure/double FFMT – A two-part FFMT operation for people with complete avulsion brachial plexus injuries. The first gracilis muscle transfer restores elbow flexion, and the second finger/hand flexion. (See Figure 3.)

FFMT – Functioning free muscle transfer. A surgical procedure used to restore basic arm function to people with complete avulsion brachial plexus injuries. The gracilis muscle is taken from the leg and transferred to the affected arm to provide elbow flexion or basic hand function.

MCS – Mental component summary. A summary score of mental health using the results from 4 sections of the SF-36. Scores range from 0-100, with higher scores being better.

MHQ – Michigan Hand outcomes Questionnaire.

PCS – Physical component summary. A summary score of physical health and function using the results from 4 sections of the SF-36. Scores range from 0-100, with higher scores being better.

SF-36 – Short Form 36. A metric used to evaluate the overall physical and mental health of people with a variety of injuries, illnesses, and disorders. It provides scores for 8 different health domains: physical function, physical role, bodily pain, general health, mental health, emotion role, social function, and vitality. It has 36 questions. Higher scores indicate better physical and mental health or less hindrance due to physical and/or mental health problems.

SWAP-BPI – Satisfaction With Appearance scale after Brachial Plexus Injury. This is a modified version of the SWAP that measures satisfaction with appearance, interference with social life, and social discomfort as a result of the changes in appearance after traumatic brachial plexus injury. It has 11 questions. Higher scores indicate more interference with social life, social discomfort, and satisfaction with appearance. (See Appendix 3.)

UNIVERSITY OF MICHIGAN

CONSENT TO BE PART OF A RESEARCH STUDY

INFORMATION ABOUT THIS FORM

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits of participating in the study.

Please take time to review this information carefully. After you have finished, you should talk to the researchers about the study and ask them any questions you have. You may also wish to talk to others (for example, your friends, family, or other doctors) about your participation in this study. If you decide to take part in the study, you will be asked to sign this form. Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to you.

1. GENERAL INFORMATION ABOUT THIS STUDY AND THE RESEARCHERS

1.1 Study title: A Qualitative Study of Patient Experiences and Satisfaction with Treatment for Traumatic Brachial Plexus Injury (HUM00064705)

1.2 Company or agency sponsoring the study:

This study is not sponsored.

1.3 Names, degrees, and affiliations of the researchers conducting the study:

Kevin C. Chung, M.D., M.S., Section of Plastic Surgery, University of Michigan

2. PURPOSE OF THIS STUDY

2.1 Study purpose:

Patients who have had a traumatic brachial plexus injury (BPI) often undergo multiple reconstructive surgeries to improve the function of their arm. Some patients are very satisfied with the results of their treatment. Other times the outcomes of these operations may have little practical significance to patients even when they are clinically significant to physicians. In this case patients may feel that their results did not meet their expectations.

The first aim of this study is to figure out what patients' expectations are prior to BPI treatment and whether or not patients are satisfied with the outcomes of their treatment. The second purpose is to find out if there are differences in the expectations of patients and physicians and how physicians can improve the care and counseling they provide to patients with BPI.

3. INFORMATION ABOUT STUDY PARTICIPANTS (SUBJECTS)

Taking part in this study is completely **voluntary**. You do not have to participate if you don't want to. You may also leave the study at any time. If you leave the study before it is finished, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.

3.1 Who can take part in this study?

Adults who have sustained complete (C5-T1) traumatic brachial plexus injuries and who had normal arm function prior to this injury can participate. Patients must also be able to read, speak, and understand English. Patients who have undergone nerve transfer, muscle transfer, or no surgery at all will be included. Patients who are less than 18 years old, or who have other upper extremity nerve palsies, neuropathies, or congenital defects cannot be part of the study.

3.2 How many people (subjects) are expected to take part in this study?

20 subjects at the University of Michigan are expected to participate.

4. INFORMATION ABOUT STUDY PARTICIPATION

4.1 What will happen to me in this study?

You will be asked to complete four questionnaires about your physical health, quality of life, and arm function. You will also be asked to participate in a one-on-one interview at the University of Michigan North Campus Research Complex. When you come in for the interview, you will have time to complete the questionnaires.

In addition, we will collect data about your BPI and treatment from your medical record. (e.g. how much time passed between your injury and first operation, what the physicians' opinions and expectations were, etc.)

4.2 How much of my time will be needed to take part in this study?

Each subject will be asked to complete **4 questionnaires** and **1 interview** in person. Each questionnaire should take up to **10 minutes** to complete. The interview should be about **30 minutes**. The entire visit is expected to last about **1 hour 15 minutes**.

4.3 When will my participation in the study be over?

In addition to the time above, we will collect information from your medical records. The entire study is expected to last about **1 year**.

5. INFORMATION ABOUT RISKS AND BENEFITS

5.1 What risks will I face by taking part in the study? What will the researchers do to protect me against these risks?

The known or expected risks are:

- Possible psychological stress from talking about your injury and treatment

The researchers will try to minimize these risks by:

- Conducting the interview in a comfortable environment and asking you to let us know if you ever feel uncomfortable.

As with any research study, there may be additional risks that are unknown or unexpected.

5.2 What happens if I get hurt, become sick, or have other problems as a result of this research?

The researchers have taken steps to minimize the risks of this study. Even so, you may still have problems or side effects, even when the researchers are careful to avoid them. Please tell the researchers listed in Section 10 about any injuries, side effects, or other problems that you have during this study. You should also tell your regular doctors.

5.3 If I take part in this study, can I also participate in other studies?

Being in more than one research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. You should not take part in more than one study without approval from the researchers involved in each study.

5.4 How could I benefit if I take part in this study? How could others benefit?

You may not receive any personal benefits from being in this study. However, there are possible benefits of the research for future patients, because the results of this study will help physicians provide better care and counsel.

5.5 Will the researchers tell me if they learn of new information that could change my willingness to stay in this study?

Yes, the researchers will tell you if they learn of important new information that may change your willingness to stay in this study. If new information is provided to you after you have joined the study, it is possible that you may be asked to sign a new consent form that includes the new information.

6. OTHER OPTIONS

6.1 If I decide not to take part in this study, what other options do I have?

This is a voluntary study that does not include any sort of treatment for participants. The alternative to participating is to not participate.

7. ENDING THE STUDY

7.1 If I want to stop participating in the study, what should I do?

You are free to leave the study at any time. If you leave the study before it is finished, there will be no penalty to you. You will not lose any benefits to which you may otherwise be entitled. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. If you decide to leave the study before it is finished, please tell one of the persons listed in Section 10 "Contact Information" (below).

7.2 Could there be any harm to me if I decide to leave the study before it is finished?

If you choose to leave the study early, no harm will come to you. However, if your data set is incomplete, it may be excluded from the study.

7.3 Could the researchers take me out of the study even if I want to continue to participate?

Yes. There are many reasons why the researchers may need to end your participation in the study. Some examples are:

- ✓ The researcher believes that it is not in your best interest to stay in the study.
- ✓ You become ineligible to participate.
- ✓ Your condition changes and you need treatment that is not allowed while you are taking part in the study.
- ✓ You do not follow instructions from the researchers.
- ✓ The study is suspended or canceled.

8. FINANCIAL INFORMATION

8.1 Who will pay for the costs of the study? Will I or my health plan be billed for any costs of the study?

There are no costs or billing for this study.

By signing this form, you do not give up your right to seek payment if you are harmed as a result of being in this study.

8.2 Will I be paid or given anything for taking part in this study?

You will receive a \$100 check for completing the 4 questionnaires and the interview.

8.3 Who could profit or financially benefit from the study results?

No one will profit or financially benefit from the study results.

9. CONFIDENTIALITY OF SUBJECT RECORDS AND AUTHORIZATION TO RELEASE YOUR PROTECTED HEALTH INFORMATION

The information below describes how your privacy and the confidentiality of your research records will be protected in this study.

9.1 How will the researchers protect my privacy?

Research records will be kept in a separate research file that does not include names, registration numbers, or other information that is likely to allow someone other than the researchers to link the information to you.

9.2 What information about me could be seen by the researchers or by other people? Why? Who might see it?

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to take part in the study. Information about you may be obtained from any hospital, doctor, and other health care provider involved in your care, including:

- Hospital/doctor's office records, including test results (X-rays, blood tests, urine tests, etc.)
- Alcohol/substance abuse treatment records
- All records relating to your brachial plexus injury, the treatment you have received, and your response to the treatment
- Billing information

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.

- The researchers may need the information to check your test results or look for side effects.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- Study sponsors or funders, or safety monitors or committees, may need the information to:
 - Make sure the study is done safely and properly
 - Learn more about side effects
 - Analyze the results of the study
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- Information about your study participation may be included in your regular UMHS medical record.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, social security number, payment amount, and related information for tax reporting purposes.
- Federal or State law may require the study team to give information to government agencies. For example, to prevent harm to you or others, or for public health reasons.

The results of this study could be published in an article or presented at a scientific meeting, but would not include any information that would let others know who you are.

9.3 What happens to information about me after the study is over or if I cancel my permission?

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed, even after you have canceled your permission or the study is over.

Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities (This information would not include your name, social security number, or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System's privacy policies. For more information about these policies, ask for a copy of the University of Michigan "Notice of Privacy Practices". This information is also available on the web at

<http://www.uofmhealth.org/patient+and+visitor+guide/hipaa>. Note that once your information has been shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

9.4 When does my permission expire?

Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by writing to the researchers listed in Section 10 "Contact Information" (below).

10. CONTACT INFORMATION

10.1 Who can I contact about this study?

Please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Talk about study-related costs to you or your health plan
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Kevin C. Chung, M.D., M.S.

Telephone: (734) 936-5885

Mailing Address:

2130 Taubman Center, SPC 5340
1500 East Medical Center Drive
Ann Arbor, MI 48109

Research Assistant: Lauren Franzblau

Telephone: (734) 763-1828

Mailing Address:

North Campus Research Complex
2800 Plymouth Road, Bldg. 90
ATTN: [Lauren Franzblau, Bldg. 10, Rm. A127]
Ann Arbor, MI 48109-2800

You may also express a concern about a study by contacting the Institutional Review Board listed below.

University of Michigan Medical School Institutional Review Board (IRBMED)

2800 Plymouth Road

Building 200, Room 2086

Ann Arbor, MI 48109-2800

Telephone: 734-763-4768 (For International Studies: US Country Code: 001)

Fax: 734-763-1234

e-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy or concerned about a study you may contact the University of Michigan Health System Compliance Help Line at 1-866-990-0111.

When you call or write about a concern, please provide as much information as possible, including the name of the researcher, the IRBMED number (at the top of this form), and details about the problem. This will help University officials to look into your

concern. When reporting a concern, you do not have to give your name unless you want to.

11. RECORD OF INFORMATION PROVIDED

11.1 What documents will be given to me?

Your signature in the next section means that you have received copies of all of the following documents:

- This "Consent to be Part of a Research Study" document. (*Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.*)

12. SIGNATURES

Research Subject:

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with Lauren Franzblau. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study.

Name (print legal name): _____

Signature of Subject: _____

Date of signature: _____

Patient ID: _____

Date of Birth
(mm/dd/yyyy): _____

Principal Investigator (or Designee):

I have given this research subject (or his/her legally authorized representative, if applicable) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

Name: _____

Title: _____

Signature: _____

Date of Signature: _____

APPENDIX 3. SWAP-BPI

Satisfaction With Appearance after Brachial Plexus Injury (SWAP-BPI) Scale

In each of the following statements, circle the most correct response for you. The response choices are:

- 1 – strongly disagree
- 2 – disagree
- 3 – somewhat disagree
- 4 – neutral
- 5 – somewhat agree
- 6 – agree
- 7 – strongly agree

| | | | | | | | | |
|----|---|---|---|---|---|---|---|---|
| 1. | Because of changes in my appearance caused by my brachial plexus injury, I am uncomfortable in the presence of my family. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|---|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|--|---|---|---|---|---|---|---|
| 2. | Because of changes in my appearance caused by my brachial plexus injury, I am uncomfortable in the presence of my friends. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|--|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|---|---|---|---|---|---|---|---|
| 3. | Because of changes in my appearance caused by my brachial plexus injury, I am uncomfortable in the presence of strangers. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|---|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|--|---|---|---|---|---|---|---|
| 4. | I am satisfied with my overall appearance. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|--|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|--|---|---|---|---|---|---|---|
| 5. | I am satisfied with the appearance of my affected shoulder(s). | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|--|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|---|---|---|---|---|---|---|---|
| 6. | I am satisfied with the appearance of my affected arm(s). | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|---|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|--|---|---|---|---|---|---|---|
| 7. | I am satisfied with the appearance of my affected hand(s). | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|--|---|---|---|---|---|---|---|

| | | | | | | | | |
|----|---|---|---|---|---|---|---|---|
| 8. | I am satisfied with the appearance of my chest. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|---|---|---|---|---|---|---|---|

| | | | | | | | | |
|-----|---|---|---|---|---|---|---|---|
| 12. | Changes in my appearance have interfered with my relationships. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|-----|---|---|---|---|---|---|---|---|

In each of the following statements, circle the most correct response for you. The response choices are:

- 1 – strongly disagree
- 2 – disagree
- 3 – somewhat disagree
- 4 – neutral
- 5 – somewhat agree
- 6 – agree
- 7 – strongly agree

13. I feel that my brachial plexus injury lesion is unattractive to others. 1 2 3 4 5 6 7

14. I don't think people would want to touch me. 1 2 3 4 5 6 7

Note. This survey has been adapted from Lawrence, J. W. et al. (1998). Development and Validation of the Satisfaction With Appearance Scale: Assessing Body Image Among Burn-Injured Patients. *Psychological Assessment*, 10, 64-70.

Note. Items 1-3 and 12-14 adapted from "A Burn Specific Health Scale" by B. Blades, N. Mellis, and A. M. Munster, 1982, *Journal of Trauma*, 22, p. 872-875. Copyright 1982 by Andrew M. Munster. Adapted with permission

APPENDIX 4. Interview Guide

BPI Interview Question Guide

Before interview, have patients complete all questionnaires.

General Questions and Background Info:

1. What did you think of the questionnaires you took?
2. Do you have any questions about them?

Aim 1: To determine patients' main concerns, hopes, and expectations associated with them, as well as how these hopes affected the patients' choice to undergo surgery.

Now I'm going to ask you about the decisions you made about your treatment. We are interested in why you chose surgery/did not choose surgery.

1. Could you tell me about your injury?
2. Before you choose a treatment, what were your main concerns about your arm?
3. What were the most important outcomes in your mind? What were the least important?
4. What treatment options were discussed with you?
5. How did you decide to have (or not have) the surgery?
6. How did your doctors discuss the recovery process with you?
7. What were you told to expect? What was the prognosis for your arm?
8. What did you expect in terms of non-functional outcomes? Such as body-image, appearance, returning to work, or social life?

Aim 2: To determine patient satisfaction with surgical treatment.

Now I'm going to ask you to think about your life before your injury. We are interested in the impact that your injury has had on your life.

Functional/Physical:

1. Tell me about your overall health before the injury.
2. How would you describe your everyday energy level before/after your injury?
3. After your treatment, what changes do you notice in your physical functioning?
4. How does it affect your daily activities?
5. What is the greatest limitation resulting from BPI?

Social/Personal:

1. Has your outlook on life changed? In what way?
2. Could you tell me about your social life? How has your injury affected the way you socialize or who you socialize with?
3. What do you do when you need assistance?

4. Who helps you?
5. How do you feel asking for help?
6. Do you feel like the people around you understand what you are going through?
7. Have you thought about joining a group for people with brachial plexus injuries?

Were expectations met?

1. What improvements have you noticed as a result of surgery/treatment?
2. Has anything gotten worse or not changed?
3. How do these changes impact your socialization and work?
4. How has your outcome compared to your pre-treatment expectations?
5. What parts of your treatment are you satisfied with?
6. What parts are you dissatisfied with?
7. Are you happy with your choice of treatment? Do you wish you had pursued one of the other options?
8. If you could advise someone like you, who has a similar injury, knowing everything that you know now, what advice would you give them? What should they expect?

Aim 3: To determine where there are discrepancies in the expectations of patients and physicians, and to help physicians communicate reasonable expectations for surgical and functional outcomes to patients.

1. How do you think your opinion of your outcome compares to your doctors'? Were your doctors satisfied with the results?
2. How does your outcome compare to your expectations?
3. How do the expectations or prognosis from your doctor compare to your actual results?
4. Do you feel that your doctors have a good understanding of what you are going through?
5. How did the information your doctors gave you before treatment compare to your actual experience?
6. Do you wish you had known anything else before treatment? If so, what?
7. What other questions would you have asked your doctors?

Wrap up

Now we are done with the interview questions.

1. Overall, are you satisfied with the results of your surgery?
2. Is there anything else you would like to talk about?

Thank you very much for your time!