

Expectations and limitations due to brachial plexus injury: a qualitative study

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Published online: 1 May 2015
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Abstract

Purpose This study described physical and psychosocial limitations associated with adult brachial plexus injuries (BPI) and patients' expectations of BPI surgery.

Methods During in-person interviews, preoperative patients were asked about expectations of surgery and preoperative and postoperative patients were asked about limitations due to BPI. Postoperative patients also rated improvement in condition after surgery. Data were analyzed with qualitative and quantitative techniques.

Results Ten preoperative and 13 postoperative patients were interviewed; mean age was 37 years, 19 were men, all were employed/students, and most injuries were due to trauma. Preoperative patients cited several main expectations, including pain-related issues, and improvement in arm movement, self-care, family interactions, and global life function. Work-related expectations were tailored to employment type. Preoperative and postoperative patients reported that pain, altered sensation, difficulty managing self-care, becoming physically and financially dependent, and disability in work/school

were major issues. All patients reported making major compensations, particularly using the uninjured arm. Most reported multiple mental health effects, were distressed with long recovery times, were self-conscious about appearance, and avoided public situations. Additional stresses were finding and paying for BPI surgery. Some reported BPI impacted overall physical health, life priorities, and decision-making processes. Four postoperative patients reported hardly any improvement, four reported some/a good deal, and five reported a great deal of improvement.

Conclusions BPI is a life-altering event affecting physical function, mental well-being, financial situation, relationships, self-image, and plans for the future. This study contributes to clinical practice by highlighting topics to address to provide comprehensive BPI patient-centered care.

Keywords Disability · Expectations · Qualitative · Brachial plexus injury

Introduction

Adult brachial plexus injuries (BPI) are devastating events due to trauma or as a result of treatments for other medical conditions [2, 4, 6, 13]. Improvements in microsurgical techniques have made nerve repair and reconstruction possible for selected BPI patients [4]. These treatments and their rehabilitation regimens are complex and costly [9, 14].

The goal of BPI surgery is to improve quality of life and restore as much function as possible [2]. However, success of surgery currently is often measured by physicians according to physical examination and physician-derived scales that focus on motor function [2, 5, 12, 13]. While these measures provide valuable information, they may miss aspects of the experience that are most important to patients, such as appearance and

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emotional well-being [2, 7, 16]. In addition, although there are valid patient-reported scales for disorders of the upper extremity, they may not capture the complex and severe physical and psychosocial impact of BPI [2, 7, 9, 11, 17, 18]. These issues are particularly relevant for patients shortly after surgery because psychological well-being and its impact on rehabilitation during this time period are critical to what ultimately will be the outcome of surgery.

This study is the first phase of a trajectory of work to develop and validate a BPI-specific patient-reported scale that addresses the preoperative and postoperative physical and psychological impact of BPI, as well as change in condition over time. The current report provided details from this first phase which was a qualitative study involving in-depth interviews with preoperative and postoperative patients to ascertain their expectations of surgery and their experiences with BPI, particularly the impact of BPI on quality of life and functional status.

Materials and Methods

This study was approved by the IRB at the Hospital for Special Surgery, and all patients provided written informed consent and HIPAA authorization.

Preoperative Patients Preoperative patients were included if they were 18 years old or older and scheduled to undergo reconstructive surgery within the next several days for recently sustained partial or complete BPI. Consecutive patients were enrolled at the time of a routine preoperative visit with their surgeons or when they returned to the hospital for preoperative testing. Patients were interviewed in person by a single investigator experienced in qualitative research and were asked these open-ended questions about their expectations: “What do you expect as a result of your surgery? After you have recuperated from your surgery, what do you expect will be different?” Patients were encouraged to cite as many expectations as they wished and their verbatim responses were recorded in field notes. We emphasized that we were asking about what they expected, not what they hoped for. Enrollment continued until data saturation, defined as when no new expectations were volunteered. Patients also were asked about how the injury impacted their lives with these open-ended questions: “What bothers you the most about your arm? What valued activities can’t you do as well now because of your arm? What accommodations have you had to make because of your arm?”

Postoperative Patients Postoperative patients were included if they had undergone reconstructive surgery for a partial or complete BPI within the prior 9–24 months. The short-term

postoperative period was selected because rehabilitation is still in progress, many patients are not yet resigned to permanent disability, and patients can still attribute limitations and difficulties in their lives exclusively to BPI. Consecutive patients were enrolled at the time of routine follow-up visits with their surgeons and were interviewed in person by the same investigator with these open-ended questions: “What would you say is the outcome or result of your surgery? What is better now? What is still the same? What is worse? What bothers you the most now about your arm?” Patients were encouraged to report any activities or emotions they wished; enrollment continued until data saturation and their responses were recorded verbatim in field notes.

All patients were asked to rate their overall current condition using the following adaptation of a valid single item seven-point measure of well-being: “If you were to spend the rest of your life with your arm condition just the way it has been in the last 24 h, how would you feel?” with response options of “delighted,” “pleased,” “mostly satisfied,” “mixed—about equally satisfied and dissatisfied,” “mostly dissatisfied,” “unhappy,” or “terrible” [1]. Because this question is framed by a specific time period, it is more tangible than a general abstract question about satisfaction. Demographic information was obtained from patients and information about level of BPI (C5-6, C5-6-7, C7-T1, complete, upper trunk) was obtained from medical records.

Data Analysis Demographic and clinical characteristics were described with means and frequencies. All open-ended responses were reviewed with standard qualitative techniques using grounded theory, a methodology in which verbatim responses are sequentially aggregated into larger themes through an iterative process. Specifically, during the initial open coding phase all verbatim responses were analyzed line by line to identify unique concepts. Concepts were then aggregated into categories based on similarities to each or based on specific phenomena [3, 21]. The entire process was driven by patients’ perspectives and not by investigators’ a priori hypotheses. Codes were then assigned to categories and the verbatim responses were then reviewed again to determine the prevalence of categories. Although the formal analysis took place after all data had been acquired, as the interviews progressed the investigators noted when no new perspectives were being volunteered, i.e., data saturation, at which point no new patients were enrolled. The qualitative analysis was corroborated by two investigators (corroboration), one was a methodologist with expertise in qualitative research and the other was an orthopedic surgeon with expertise in upper extremity surgery. Each investigator conducted the qualitative analysis independently to discern concepts and categories and then through consensus arrived at the final set of categories.

Results

Ten preoperative and 13 postoperative patients were enrolled from April 1, 2013, to March 18, 2014; no patients refused to participate. The mean age was 37 ± 14 years (range 19–63), 19 were men, and all were working or were full-time students at the time of the injury.

Among preoperative patients, four had complete and six had partial plexopathy, and the mode of injury was from a motorcycle accident (six), recreational vehicle accident (three), or as a consequence of cervical spine surgery (one). The mean time from injury to enrollment was 7 ± 3 months and from enrollment to subsequent surgery was 12 ± 13 days. In response to the question about how they would feel if they had their current condition for the rest of their life, two reported mixed (equally satisfied and dissatisfied), one mostly dissatisfied, three unhappy, and four terrible.

Among postoperative patients, six had complete and seven had partial plexopathy, and the mode of injury was from a motorcycle accident (five), motor vehicle accident (six), oncologic radiation therapy (one), or prolonged malposition during critical care for a bowel perforation (one). The mean time from injury to enrollment was 33 ± 37 months, and the mean time from surgery to enrollment was 14 ± 4 months (range 10–22 months). In response to the question about how they would feel if they had their current condition for the rest of their life, three reported pleased, two mostly satisfied, three mixed, two mostly dissatisfied, one unhappy, and two terrible.

Preoperative Patients' Expectations

Preoperative patients cited pain-related issues as major expectations, including decrease in pain severity and better response to pain medications (Table 1). Improvement in function was another major expectation with most patients citing major activities related to gross movement of the arm, self-care, family interactions and, to a lesser extent, discretionary activities, such as sports. All patients had expectations related to work which were tailored to the type of employment, for example, using a telephone and computer for office workers (i.e., lawyer, financial analyst) and regaining range of motion and strength for manual laborers (i.e., mechanics). Some patients spoke in general terms with expectations of restored global function and noted the need to shift their focus from enjoyable activities to accomplishing basic activities of daily living.

Patients reported they learned about BPI surgery and derived their expectations mostly from their own internet research, including hospital websites and blogs with other patients. Some patients were concerned about having overly ambitious expectations and wanted to avoid disappointment (“I know things could get worse.”). In some instances, patients were cautious (“After speaking with my surgeon I now know I will not be back to normal.”).

Table 1 Preoperative patients' expectations of surgery

Category	Concept
Pain	“I expect the pain to go away.”
	“I expect strong medication to relieve pain will work... even a reduction in the strength of pain would be a relief.”
	“I sleep sitting up, and then only for 3 h because of the pain. I expect to be able to sleep, to lie on my side.”
Movement	“I expect to get movement again in my arm. I do not expect 100 %; that is unrealistic. But I expect 90 %.”
	“If I had to say what I expect, it is for my arm to move more, to be able to bend my elbow.”
	“I am right handed, I can't do anything. I expect to have my arm back a little. I know it can never be 100 %; I was told there is no guarantee, but maybe 80 %.”
	“I expect to see a little movement in my right arm. Now it is a wet noodle. If I could bend my elbow... they are telling me I might be able to do that.”
Self-care	“Normal activities of daily living. I expect to do things unassisted, like dress and bathe; now I need help with shampoo, drying myself, washing my back.”
	“It is hard to get dressed in the morning, buttoning my pants is hard.”
Interaction with family	“My girlfriend is pregnant and I expect to hold my baby like a normal person would.”
	“I expect to hold my daughter again with both arms.”
Work	“I expect to return to work.”
	“I expect to get back to work. I worked since I was 13 years old, I hate to be home.”
Sports	“I expect to play softball again.”
Global function	“I expect to get my life back.”

Preoperative Patients' Symptoms, Physical Limitations, and Mental Health Effects

Preoperative patients reported both continuous and intermittent severe pain that varied in quality (Table 2). They also cited limitations in managing essential activities, such as eating and self-care, and becoming dependent on others for these activities. All patients cited devastating effects on work with the inability to continue current employment or attend school. Many had become financially dependent on others because of work disability. Some patients reported they were unable to participate in sports and mourned the loss of their preinjury physique and fitness. All patients reported they had made major compensations, mostly to rely on the uninjured arm. Patients also reported they were self-conscious in front of others about their disability and appearance, and purposefully avoided social and professional public situations.

All patients cited effects of BPI on their mental health with a spectrum of depressive, anxiety, and anger symptoms (Table 3); some patients had considered suicide. Patients

Table 2 Preoperative patients' symptoms and physical limitations

Category	Concept
Pain	<p>“The pain is beyond anything I can describe, shooting, numbing, stabbing. I cannot think about anything else but pain.”</p> <p>“I get spurts of pain every 20 to 30 min, lasting 3 to 7 s, then it stops.”</p>
Essential activities	<p>“Using a knife is difficult and I bend toward the table instead of lifting the fork.”</p> <p>“My life is very different. It is hard to get dressed in the morning.”</p> <p>“My wife, son and daughter help a lot...to the point where if they see I can't do it, they ask 'can I help?' They tell me 'ask us' but it kills me to have to ask, I was never that way.”</p>
Work	<p>“I can't work right now. It is not a steady business. I do a lot of physical work myself. It is specialized work; I need to be there. I have not done anything at work in a year.”</p> <p>“I went from working 18 h a day to sitting on a couch.”</p> <p>“I used to work in my father's restaurant—I can't do anything now. I am not working.”</p> <p>“I can fix anything...but now I sold my shop and rent the expensive equipment.”</p> <p>“I get tired sooner because of the pain and have to leave earlier. I work as a financial analyst, so I work on the computer.”</p> <p>“I can't work. I can't even tie my shoe laces.”</p>
Financial dependence	<p>“My wife was a stay-at-home mom. Now she has to go out to look for work and I can't take care of the kids, not all three of them, by myself. We are struggling a lot financially.”</p> <p>“I live with my mother now. I am single and I used to have my own apartment.”</p> <p>“I don't have many people to help me. I moved in with my sister. For 4 months I have been in my sister's apartment watching TV. She has helped me a lot.”</p> <p>“Our lifestyle had not changed because my wife has a successful career.”</p>
Interaction with family	<p>“I cannot play with my children because it hurts...I have to stop. My son likes to hold on to my neck, but I can't do that. All I can do is play computer games.”</p> <p>“I can't do things with my sons, like play tennis, golf and ride bikes.”</p>
Sports	<p>“I am a huge weight lifter, I could bench 400 lb and dead lift 600 lb. I played competitive softball 3 times a week...now I ride the bike for aerobics instead.”</p> <p>“I used to train at the gym. I was a boxer. I was real good; I was going to compete as a boxer and then this happened. I don't work out any more.”</p>
Compensations	<p>“I use my right hand to lift my left arm to the correct position when I am cooking. Once my arm is there, I can then use my hand.”</p> <p>“I have to learn to do everything with my left hand. Writing takes forever. I cooked only two meals since the accident. I changed my daughter's diaper for the first time this week.”</p> <p>“I have always done everything with my right hand. It is unbearable to switch to the left.”</p>
Function in public	<p>“I can't go to court; I can't put on a suit and tie everyday. I cannot conduct myself as before. We have a saying 'you have to be on your feet', you have to affect presence and emote. I won't be able to adjust my clothing properly if I use the bathroom.”</p> <p>“I don't want to be around people because it shows that the left side is bony, there is no muscle definition. At the store they look at me funny when I hold the groceries in my right arm and have to lean forward to help my left hand get the change.”</p> <p>“When I have to sign for the credit card, people look at me because I can't write.”</p>
Appearance in public	<p>“I don't feel like myself. I don't want to talk about it with people. I avoid people because I don't want to tell them what happened. It brings back the accident.”</p> <p>“It doesn't look nice...when my friends come to the house I always put on a tee shirt or something so that it is not a topic to discuss. I don't like talking about it.”</p> <p>“I don't go out much. If people ask me what happened and I know them, I will tell them. Otherwise I don't bother.”</p>

reported they received emotional support from their social network (“We have a hot line at work.”; “My wife is key to the situation.”) and some had professional counseling and treatment; however, success of treatment varied among patients. The injury also precipitated loss of relationships (“I separated from my wife right after this happened. She is not

the type to get through things like this.”). A few patients spoke openly about their determination to think positively and move forward with their lives (“I stay upbeat. I can't go back and change things. I have to deal with it.”; “I am a very positive person. Nothing bothers me. I am church going, I know God will take care of me.”).

Table 3 Preoperative patients' mental health effects

Category	Concept
Emotions	<p>"It is devastating; in between thoughts my life changed."</p> <p>"It changed my whole life. It turned my life upside down. It changed everything. I battled depression in the beginning. I was in a funk. I asked myself 'why me?' I live a good life, why did this happen to me? It was stressful."</p> <p>"When I don't sleep it affects my mood and energy level, I get cranky at times."</p> <p>"In the beginning I was not depressed, I was angry, irritable with everyone."</p> <p>"I get down and tired a lot. It's because of the pain - I can't sleep, I am always tired, that's why I am down."</p> <p>"This is both a physical and mental injury. You can't let it get you down. You really have to motivate yourself. I don't want anyone to feel sorry for me."</p> <p>"It is mentally stressful, but I am not depressed yet. I was minutes away from them taking me off the respirator and life support because of the brain damage. I beat that. Now there is basically the pain. I figure I must be here for a reason, so I can't give up yet."</p>
Emotional dependence	<p>"I have 4 older and 2 younger siblings...my nieces and nephews come to me; they tell me things they don't tell their parents. I am the cool guy in the family."</p> <p>"I try to help myself. I focus on activities; I read...my family helps."</p> <p>"My wife has modified her routine...she has been by my side every step of the way."</p> <p>"Hunting is a group activity...we were six, now I am close with one friend and his son. This friend has stayed by my side; he is the brother I never had."</p>

Some patients viewed their injury as a way to teach others ("I want my son to see me struggle and to see my pain. This way he will stay out of trouble. I want him to learn there are consequences. I don't want him to do anything stupid...It wasn't my fault...But I don't want him to take unnecessary chances."). Some patients commented about remembering the accident ("I don't know what happened and I don't want to know."; "I wasn't lucky like some people—I wasn't knocked out, I remember the whole thing; I relive the whole thing."), and others commented that their accident was unforeseeable ("I don't know what happened. I just went to get gas. It is ironic.").

An additional source of stress was finding and paying for surgery ("My doctors told me there was nothing else that could be done; so I took matters into my own hands."; "I found out about this surgery myself. My regular doctors didn't know what I had, they didn't know about this surgery...that's why it took so long to get here, that and all the trouble with insurance.").

Postoperative Patients' Symptoms, Physical Limitations, and Mental Health Effects

Most postoperative patients still had pain, but generally, it was improved (Table 4). Sensation was a new topic and most commented that they had abnormal feeling in their arm and hand. Return of movement was reported by most patients; however, function with respect to fulfilling essential activities was still notably impaired. Maintaining work and school continued to be major challenges and some patients relied on others for help ("I do studies on-line now. I need extended time on tests or my mother has to do it. I can't type yet, I can't use a mouse."). Loss of ability to compete in desired sports also was noted and some patients had switched to other sports. Patients also continued to compensate with the uninjured arm for many daily activities. They also compensated by using special devices, like new cooking utensils, sports equipment, and workplace tools.

Patients reported multiple emotions that persisted after surgery (Table 5). These included depressive symptoms, frustration, anger, guilt, anxiety, and remorse at losing enjoyable discretionary activities. For some patients, the emotional reaction was debilitating and required psychiatric care. There also were strong feelings about the time required to heal with most patients commenting they were distressed with the recovery time even though many reported they had been advised about this ("The recuperation is long, but not longer than expected because my surgeon told me; everything is on schedule."). A few patients were so frustrated with the time to heal that they claimed amputation might be better; however, none were actively seeking this drastic intervention ("It is frustrating. I would rather have it gone. It is in my way. I always have to worry about it. I don't want to do this for the rest of my life. If it is not going to get any better, I would rather they take it off."). Some patients noted the irony that they recuperated from life-threatening injuries also incurred during the accident, but it is the non life-threatening BPI that will cause them life-long disability. Most patients coped with their emotions by keeping busy, by drawing on their own inner strength ("I had the mindset that disability would not overcome me"), and by relying on their social network. Some patients, however, were ambivalent about depending on others for help ("In the last few months I have become a little bothered. I go to the store and people offer to help me, to pack my groceries. I appreciate their offer but I don't want to rely on others for help. My daughter's boyfriend is very handy, I ask him for certain things; he is a God send. But at the same time I don't want to ask for help."). For the most part, patients were still disheartened by the appearance of their arm even though there were improvements. Appearance continued to limit their willingness to participate in social activities.

Table 4 Postoperative patients' symptoms and physical limitations

Category	Concept
Pain	"I still have some pain, but it is not an issue."
	"The pain is less; the pain is good, good enough for me."
	"The pain is better; I no longer have those shooting, lancing pains."
	"The pain is not as excruciating, but it is still there."
	"The pain is increased in my hand but it is acceptable because I gained function."
Sensation	"I feel pins and needles and the nerve pain is unbearable. Medicines help for a while."
	"Before I had only a small area of sensation, now I can feel below the elbow."
	"I still do not have sensation in parts of my hand or my forearm. I burned myself the other day and I did not know it."
	"I was so hypersensitive in the beginning, even the hospital gown on my skin was painful. The tingling is better."
	"I have some feeling in my forearm, it is not regular feeling but I can recognize that it is there."
Movement	"I have to wear a glove if it is less the 65°, even indoors, the hand hurts otherwise."
	"I still can't feel my thumb and first finger, so that is still a small issue."
	"The pain is still there, the same sensibility is still missing."
	"Before surgery I could only grab things, now I can lift my arm all the way up."
	"I can now move my arm away from my body a little, but it is still limited."
Essential activities	"I can move my biceps only just some, it is not full range of motion, but it is some."
	"Before surgery my arm was non-functional, I could move my hand only. Now I can bend my elbow and move my arm away from the rest of my body. It is not complete, but it is much better."
	"I have some movement back; I can do some 'therapy' activities like pinch, but these activities do not correspond to my daily activities."
	"I can move it some now, but I don't feel normal. My hand can't move, I can't bend my elbow; but surgery did not make it worse."
	"Now I can put on clothes easier, use deodorant, shave, shower and tend to hygiene."
Work/school	"I can tie my shoes and dress myself now."
	"It helped strengthen my arm. I can lift it now. I can use it more for functions around the house."
	"It is still hard for me to drive."
	"I can't throw a ball with my children or skip a rock at the beach. I want to do these things but I can accept that I can't. What I can't accept is not being able to eat at the table. This reminds me of all the horror I have been through. It is the day-to-day activities that bring it all back."
	"I am 110 % less active. I was a science teacher. I was always on my feet. I also took care of my 3 children by myself; I managed my home by myself. Now I am dependent on my boyfriend."
Sports	"I can't go to school; I would have to take off too many days."
	"My major was architecture, but now because of my arm I switched to international business."
	"I was in college at the time of the injury. My goal became just to finish college and get a job. I had limited options and could only have a desk job. I got a job as an insurance manager."
	"I am a chiropractor and acupuncturist. I am still not working. I bought special needles and am trying to go back to being an acupuncturist. Things don't look good for me right now as a chiropractor. My main goal is to return to work and not be disabled."
	"I can't be in the military anymore. I have a best friend who is a computer genius. I am partnering with him to start a new business."
Sports	"I still work. I am a car mechanic. It takes more effort and I use my left arm now and I get limbs involved. I get really tired really fast sometimes and have to stop, but I still try to do it. I have no choice. I can't do anything else. This is all I know. If I had to start over again and learn something else it would be more frustration for me. I have to put my mind to it and keep doing it."
	"I still can't play sports. I am not competitive. Sports is a big part of my life; I lost it."
	"I fasten my arm with a strap and play soccer for recreation; I can't play for college anymore."

Finally, some postoperative patients took a global view of their situation and commented that the injury had ramifications for their long-term overall physical health, life

priorities, and decision-making processes. Many also stated that because they were still early in the recuperation process, they anticipated additional improvement in their condition.

Table 5 Postoperative patients' mental health effects

Category	Concept
Compensations	<p>"I learned to do a lot of things with my left arm and hand, and now there has been an evolution to my right arm and hand as things have gotten better."</p> <p>"I got a new bike rack so that I can lift my bike myself. I got a new cutting board for cooking; cooking is my passion. The board has spikes. I also got new food processors."</p>
Emotions	<p>"I get anxious and sometimes depressed. I cry."</p> <p>"I think of it often and sometimes feel guilty."</p> <p>"You have a feel-bad-for-yourself phase because it is really a big deal."</p> <p>"It was my fault. I get frustrated. There are so many things I cannot do. I have constant anger, irritation, and frustration. I stew in myself for a little while then I go on."</p> <p>"I just have to deal with it. I get a down feeling—it comes and goes. I look at other people's situations and I realize I can still deal with this."</p> <p>"I have a grudge against the damage that was done by the radiation. I had a 3 % chance of this happening. I have a very, very bad grudge. The surgery gave me my life back."</p> <p>"It destroyed my life. It is a loss; one has to go through a grieving process. I am a different person because of my mood, my pain, not having physical function. I have been diagnosed with PTSD from the accident—I have nightmares, panic attacks, and depression."</p>
Time to recuperate	<p>"Things are moving along according to plan, but the catch 22 is that it is so slow. I was told it would take long, but I didn't expect it to be this long. It didn't register that it would take so long."</p> <p>"I am frustrated; I thought I would have biceps function by now. I would tell other people to be patient, it takes longer than you think."</p> <p>"I don't have patience. They told me it would be a long time; but it is really long."</p>
Coping	<p>"My wife and my church help me through this."</p> <p>"My friends know and they help me."</p> <p>"I was under the care of a psychiatrist for 1 year and was treated with medication, which helped."</p> <p>"It affected my mood quite a bit. I took medications, I had a psychiatrist... I thought about suicide, but never tried anything. What helped was staying busy."</p> <p>"I keep busy to get away from my thoughts. This helps a lot."</p> <p>"I had good support from my family, friends, and physical therapist. My family was the most helpful because they did not let me feel sorry for myself; they kept telling me I can do it with one hand. Once you get past that you are OK."</p>
Appearance in public	<p>"People comment all the time. I appreciate their concern. Their curiosity doesn't bother me, but it is frustrating when they offer advice. They don't know what it is like."</p> <p>"I would rather not be with people because they ask about it and it brings back memories."</p> <p>"My arm looks like a Holocaust survivor. I wear hoodies and long sleeves all the time. I have contractures too. My appearance has a big effect on my confidence. I lack an arm."</p> <p>"Social settings are annoying. I have to move my hand a lot, rub my hand. It feels better if I do that. But what does the guy next to me think of me? So I don't go out much."</p> <p>"I do not need the sling anymore. I hated the sling because of the appearance. People would ask me what happened or would make bad jokes. It made me mad. So I appearance-wise it is better."</p> <p>"I camouflage it pretty well. I learned how to do this."</p>
Global view	<p>"I used to be an avid gym goer; now I have gained 60 lb and my health has deteriorated."</p> <p>"This slowed the pace of my life. I am more mature, the accident had an impact; I appreciate everything more. I slowed down making decisions so that I will have better conclusions."</p> <p>"I wish my arm was back to the way it was...I don't expect the way it was, but someday better than it is now."</p>

Discussion

Patients reported devastating effects of BPI on their physical and mental well-being. In most cases, the impact was life altering, affecting basic activities of daily living and self-care, and rendering patients disabled for complex integrated functions, such as sustained employment. In addition, expectations

of surgery tended to be global in nature, primarily focusing on pain relief and restored arm movement.

The profile of limitations and expectations of BPI patients reflects both the severity and abruptness of the affliction. This is in stark contrast to the profile of patients undergoing other types of upper extremity surgery, such as shoulder surgery, which tends to reflect nuanced activities that are being

gradually lost due to chronic conditions [15]. As such, broad assessments of pain severity and ability to perform essential activities may be the appropriate indicators for change in preoperative and immediate postoperative BPI patients.

We found variations in symptoms and disabilities for both preoperative and postoperative groups. This may be attributed to several factors. For preoperative patients, this may be due to variation in the time between the injury and surgery. Some patients who had lived with BPI longer may have come to acknowledge their new reality and already had some success in making accommodations. It may be these patients viewed surgery as a way to optimize their situation while those with very recent injuries viewed surgery as a way to be restored to their preinjury state. Variations in symptoms and disabilities for postoperative patients also may have been due to variation in the time between injury and surgery as well as to variation in the type of surgery performed. In addition to being tailored to the degree and location of the injury, in some cases, surgery was planned to be a staged process and was still in progress. We preferentially included only short-term postoperative patients, and they were aware that additional improvement was likely. This was reflected by those patients who reported they were better because of surgery, but they would not be pleased if they had to spend the rest of their lives in their current condition.

Only a few other studies attempted to measure patient-reported effects of BPI. In one study, researchers queried 32 patients a mean of 7 years postoperatively using a physician-derived survey and found adverse impacts on leisure activities, health, financial situation, and employment [4]. Another study of 25 patients a mean of 3 years postoperatively used existing patient-reported scales to measure effects of BPI, and found marked disability in emotional well-being and physical function [10]. Our study confirms these effects and, by using qualitative techniques, provides new information about how patients begin to compensate for BPI. In another study, other investigators also used qualitative techniques to assess BPI by interviewing 12 patients at least 1 year postoperatively or post injury for nonsurgical patients [7]. This study reported patients had emotional effects including anger, frustration, depression, mourning, less energy, and decreased self-efficacy and self-esteem. Patients also had major changes in education, employment, and outlook on life, felt social discomfort and unattractiveness, and regretted their increased reliance on others for daily activities and finances. Satisfaction with outcome of surgery varied and was associated with pain, dysfunction, and work disability [8]. The findings of our study support the results of this study and provide additional details about the devastating effects of BPI on all aspects of life. Several other qualitative studies have been conducted focusing on neonatal brachial plexus palsy; these studies reported profound effects on child and adolescent emotional, social, and physical function as well as body image, finances, and family dynamics [19, 20].

This study has several limitations. First, it was conducted in a subspecialty BPI center and may not be representative of patients treated in other settings. Second, patients were a heterogeneous group with respect to the degree of plexus injury. Third, patients were interviewed at the time of a clinical visit and their responses may have been influenced by the most recent information they received from surgeons and staff.

This qualitative study demonstrated that BPI patients have diverse expectations and limitations that center mainly on pain and essential activities of daily living. This study contributes to the management of BPI patients by highlighting topics to address to provide comprehensive patient-centered care. This study also provides a foundation to develop a BPI-specific patient-reported scale.

Acknowledgments This work was supported by an internal institutional grant from Richard Menschel for personnel funding and research registry support.

Conflicts of Interest Carol A Mancuso declares that she has no conflict of interest.

Steve K Lee declares that he has no conflict of interest.

Christopher J Dy declares that he has no conflict of interest.

Zoe A Landers declares that she has no conflict of interest.

Zina Model declares that she has no conflict of interest.

Scott W Wolfe declares that he has no conflict of interest.

The study was supported by a grant from Richard Menschel for personnel funding and research registry support.

Statement of Human and Animal Rights This study was approved by the Institutional Review Board at the Hospital for Special Surgery. This study included only human; there were no animals.

Statement of Informed Consent All patients provided written informed consent.

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