

# “Being a patient the rest of my life” – The Influence of Patient Engagement on Recovery after Traumatic Brachial Plexus Injury

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## INTRODUCTION

Assessment of outcomes after adult traumatic brachial plexus injury (BPI) has historically focused on surgeon-graded measures of muscle recovery. Increasing attention is being directed to patient-reported outcomes and the patient experience after BPI. Our objective was to better understand the recovery course after surgical reconstruction for BPI, with a particular emphasis on identifying common points of frustration for patients and potential points for interventions.

## METHODS

We conducted semi-structured qualitative interviews with 15 BPI patients recruited from a single site’s patient population. Participants were ≥16 years old and 6+ months post-surgical reconstruction. Interviews were conducted by a trained interviewer and a designated field note-taker, neither of whom were associated with the participants’ clinical care. The interview guide invited patients to discuss their BPI experience and any impact it had on their social interactions, career path, self-perception, future plans, and life in general, from the initial injury to their interview date. Inductive and deductive thematic analysis was used for the qualitative data to identify themes and knowledge gaps.

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**“If you choose to go this path—spell it out so I feel like I’m quarterbacking this. Even though I’m not, let me feel like I’m quarterbacking this.”**

**“I can’t say that we were ever given an option.”**

**“After a certain point just talking to a few people on there [I] just made a decision that I’m just gonna basically kind take control of everything and not...just act like I’m just along for the ride; [I’ll] actually participate.”**

**“How am I gonna get better? What are we gonna do to fix this? Or, if it’s never gonna get better, then you better commit to it, put it on paper, so I’ll get on with my life and figure out how to get the disability.”**

**“...then [the hand surgeon] wanted to consult with his group of people and read it before we just jumped head into it. [...] he gave me a choice. And I said, “Yeah, let’s do that.” [...] But I felt very comfortable and trusted him because I knew that this was gonna be it.”**

**“...if the doctor cares enough that the patient needs to care enough too.”**

**“You’re just [kind of] stuck just always being a patient...which is something I’m definitely afraid of; being a patient the rest of my life.”**

## RESULTS

Patients described highly variable degrees of engagement during the course of their treatment. Many expressed frustrations related to waiting: waiting to find out what happened to them, waiting to see a new surgeon, waiting to see if the most recent surgery had any effect, or simply waiting to see if they would regain the functional ability to participate in the parts of their lives that may have been put on hold. Patients who described feeling as though they were included in the decision-making process regarding functional priorities and treatment options, seemed to be more likely to be actively engaged in and more compliant with their treatment plans. While more engaged patients still discussed waiting, they seemed to better comprehend the need for time to allow their bodies to recover and expressed less anger about their capabilities and quality of life during the recovery process.

## CONCLUSION

Patients who feel engaged in the decision-making process were more likely to be compliant with their post-op orders and long-term care, particularly in their utilization of physical therapy, pain management, and mental health services. When coordinating multidisciplinary care, measures to encourage patients to feel agency over their outcome can bolster treatment outcomes. Based on our findings, we believe that these steps will help patients develop the self-management tools necessary to navigate the lengthy recovery process after surgical reconstruction for BPI.