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Checkpoints to Progression: Qualitative Analysis of the Personal and Contextual Factors that Influence Selection of Upper Extremity Reconstruction among Patients with Tetraplegia

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Abstract

Purpose—Patients with tetraplegia consistently rank better use of the upper extremity as their top functional priority. Multiple case series have demonstrated that Upper Extremity Reconstruction (UER) is well-tolerated and can produce substantial functional improvements for appropriate candidates; however, UER remains critically underutilized. The mechanisms that drive differences in provider practice and referral patterns have been studied, but comprehensive examination of the patient factors that influence UER decisions has not been performed for American patients.

Methods—Nineteen patients with C4-C8 cervical spinal injuries were selected using purposive sampling: 9 patients had undergone UER, 10 had not undergone UER. Semi-structured interviews were conducted and transcripts evaluated using grounded theory methodology.

Results—Our study yielded a conceptual model that describes the characteristics common to all patients who undergo UER. Patients who selected reconstruction proceeded stepwise through a shared sequence of steps: 1) functional dissatisfaction 2) awareness of UER and 3) acceptance of surgery. Patients' ability to meet these criteria was determined by three checkpoints: how well they coped, their access to information, and the acceptability of surgery. Extremely positive or negative coping prevented patients from moving from the Coping to the Information Checkpoint; thus, they remained unaware of UER and did not undergo surgery. A lack of knowledge regarding reconstruction was the strongest barrier to surgery among our participants.

Conclusions—We built a conceptual model that outlines how patients’ personal and contextual factors drive their progression to UER. Moving from functional dissatisfaction to understanding that they were candidates for UER was a substantial barrier for participants, particularly those with very high and very low coping skills.

Clinical Relevance—To improve utilization for all patients, interventions are needed to increase UER awareness. Standardizing introduction to UER during the rehabilitation process or improving e-content may represent key awareness access points.

Keywords

qualitative; spinal cord injury; surgery; tendon transfer; tetraplegia

Tetraplegia is a devastating outcome after cervical spinal cord injury (SCI). The functional losses individuals experience often result in profound caregiver dependence, financial hardship, and deep emotional distress.^{1–10} Persons with tetraplegia also stress the medical system. Patients are at increased risk for numerous medical conditions ranging from urinary tract infections to life threatening cardio-respiratory disease.^{9,11–13} Depending on cervical level and age at injury, the lifetime direct cost associated with tetraplegia ranges from 2.1 to 5.4 million dollars.¹⁴ Given such broad impact, interventions that foster patients’ independence are important at both the individual and societal level.

Although patients with tetraplegia experience deficits in multiple functional categories, they consistently rank hand and arm function as most important to their quality of life, making upper extremity reconstruction (UER) an appealing option.^{15–17} Even small gains in grasp or wrist extension can translate into substantial independence for tetraplegia patients.^{18–23} In fact, numerous studies demonstrate that UER has low complication rates and excellent long-term patient satisfaction.^{24–29} Yet, for all this potential benefit, only 10–14% of eligible U.S. patients ever undergo reconstruction.^{30,31,32}

This paradox between high potential benefit and low utilization likely stems from multiple variables, but investigation of these factors in the surgical literature is limited and sometimes contradictory. Qualitative research from New Zealand indicates that patients decline surgery when they lack social support or when they cannot tolerate the prospect of increased dependency during the immediate post-operative phase when immobilization may be required.^{33,34} Some survey data from the U.S suggest that patients question the benefits of UER, are deterred by pessimistic first impressions of reconstruction, or harbor concerns about the length of their recovery.^{35–37} However, a conflicting survey found that 80% of respondents would be willing to tolerate 2–3 months of increased dependence to ultimately improve function.³⁸

We sought to clarify and expand on this work by investigating the context surrounding UER barriers. Using the International Classification of Functioning’s (ICF) biopsychosocial model of health as our guiding framework, we performed a qualitative evaluation of why more patients do not select UER.³⁹ (Figure 1) Our study explores the features that distinguish patients who undergo surgery from those who do not. We then analyze the personal and environmental factors that drive this division at critical “checkpoints” in

patients' progression toward surgery. We aim to provide a comprehensive understanding of patients' experiences and identify points on the pathway where intervention will be most impactful to improve UER utilization.

Materials & Methods

Study Design

This was a cross-sectional observational study. Semi-structured interviews were conducted from August-September 2016 using a standardized interview guide created *de novo* by the authors. Initial prompts were derived from a literature review and the senior author's clinical expertise. (Appendix 1) Informed consent was obtained prior to participation, and audio recording was conducted for all sessions. This study was approved by our institution's research review board.

Subjects

To recruit patients with C4-C8 cervical spinal injuries who had undergone UER, we searched patients' electronic medical records at our institution for tendon transfer, tenodesis, and opponenplasty using International Classification of Disease (ICD9) and CPT codes. Patients who had not undergone surgery were recruited via email lists from the Department of Physical Medicine and Rehabilitation (PM&R). The researchers conducted screening phone calls to ensure patients had disability in all four limbs and that their injury occurred at least one year prior to interview. We excluded patients who were under age 18 or who did not speak English. Purposive sampling, (deliberate sampling wherein participants are selected to meet criteria defined *a priori* rather than randomly), was used to enroll an equal number of patients in the "surgery" (SG) and "no surgery" (NSG) groups.⁴⁰

Data Collection

We conducted interviews at patients' homes, our research facility, and via telephone. Initially, two investigators (X₁ surgery resident; X₂ medical student) were present at all interviews and held regular debriefing sessions to evaluate question clarity, interview style, and overall consistency. Participants were encouraged to clarify interview questions as needed and were invited to suggest changes or new questions to better reflect their experience at the end of each session. After standardizing delivery of the interview topics during the first 5 interviews, a single investigator conducted the remaining 14. All interviews were recorded and then transcribed verbatim by a member of the research team, which provided a second opportunity to evaluate interview consistency. We employed iterative (transcripts were re-analyzed as new themes arose) and emerging (explanatory ideas were identified and explored in-depth) analysis throughout data collection to identify developing themes. We amended our interview guide after interviews 7 and 12 to better capture these themes.^{41–43} Interviews continued until conceptual saturation, at which point participants no longer generated new themes.

Data Analysis

We used grounded theory and constant comparative analysis to structure our analysis.^{44–46} Investigators began open coding by independently reading 4 patient transcripts line-by-line

to generate a broad list of themes. Redundant themes were eliminated and nested concepts were clustered into themes, codes, and sub-codes to generate a preliminary codebook. The initial 4 transcripts were recoded, discrepancies were reviewed, and the codebook amended. One primary investigator (X₁) coded all 19 transcripts. Following a training exercise to unify coding methodology, four research assistants were added to diversify perspective (ensuring all important themes were captured), and to expedite the coding process. Ten transcripts were double-coded. The primary investigator and second coder compared transcripts in one-on-one meetings, discrepancies were evaluated, and no persistent disagreements emerged. Unclear code definitions were revised and the codebook updated periodically. (Appendix 2) Step-by-step study procedures, training exercises, and investigator contributions/credentials are summarized in a flow diagram. (Appendix 3)

Results

The study sample included 9 patients in the surgery group (SG) and 10 patients in the no surgery group (NSG). Table 1 summarizes patient demographic data. Initial analysis revealed that all patients who chose UER met three minimum conditions: 1) they were dissatisfied with their function 2) they became aware that they were candidates for UER and 3) they decided that surgery was acceptable. We then directed the bulk of our analysis to understanding why SG patients met these conditions whereas NSG patients did not. We propose three checkpoints that channeled individuals to either the SG or the NSG: how patients cope/adapt post-injury; how they access and use information; and how surgery stands to impact their lives. Based on the ICF framework, we then split our explanation of these checkpoints into the 'personal' and 'contextual' domains. Finally, we synthesized our findings into a conceptual model (Figure 2). This section will explain our model by providing an overview of the Coping, Information, and Surgical Impact Checkpoints and a detailed account of the personal or contextual experiences that move patients toward or away from surgery at each.

Checkpoint 1: Coping & Adaptation

How patients cope with tetraplegia depends on many interrelated and evolving factors. Post-injury, patients face numerous tasks, beginning with how to manage their own emotions and identity and extending to how they negotiate relationships and integrate into their communities. Given this complexity, our analysis did not reveal a unique set of coping strategies that distinguished SG patients from NSG patients. In fact, at the individual-behavior level (for example patients' ability to maintain perspective), SG and NSG patients were often indistinguishable. What separated patients was whether the balance of their coping behaviors was positive or negative and to what degree.

Ultimately, a continuum emerged with patients at coping extremes less likely to progress to UER. Patients with consistently exceptional coping generally did not experience enough dissatisfaction to move into the information-seeking phase, and defaulted to the NSG. Conversely, patients with extreme difficulty coping, lost self-efficacy, and became isolated from the mechanisms that could connect them to surgery. SG patients had the 'goldilocks' experience: enough negative coping to be dissatisfied, but not to the point that they

disengaged, and enough positive coping to maintain self-efficacy without accepting their condition entirely. A detailed examination of positive/negative coping in the personal and contextual domains follows.

Personal Factors

Like patients in other studies of chronic conditions, our participants felt that their injury incited a “biographical disruption”.^{47–49} That is, because their identity was linked to physical ability, an abrupt functional loss damaged their sense of self. In this context, positive coping behaviors were those that helped patients accept a new identity. Although participants almost universally endorsed a period of mourning immediately following injury, those with robust coping skills could stay optimistic and maintain perspective. Patients who accepted their injury could start finding ways to maximize their remaining function, and viewed assistance as a necessary fact of their new lives rather than a personal failing.

Patients with poor coping made frequent comparisons to their pre-injured selves or non-injured peers. They felt that their increased needs made them a burden to their loved ones. Instead of focusing on function and setting goals, these patients concentrated on their barriers. Overall, highly positive coping helped patients rebuild an identity that they liked, but decreased their incentive to seek additional treatment. Patients with predominantly negative behaviors became overwhelmed with feelings of worthlessness, had an unfavorable self-concept, and lost agency. (Figure 3)

Contextual Factors

Contextual factors related to participants’ surroundings. Patients’ social support, physical environment, and financial resources influenced coping by combating or reinforcing isolation. Patients with few social connections felt abandoned, whereas those with affirmative relationships had greater ease resuming their pre-injury roles or forming new friendships. Although participants almost unanimously endorsed some version of the sentiment “you find out who your real friends are,” genuine friends helped patients stay connected. Dedicated companions assumed caregiver roles, navigated mobility challenges, and adapted their activities. In cases where friendships dissolved, patients reported that their friends viewed them as diseased or broken.

Patients used financial and social capital to augment function. Participants who could afford to modify their homes reported more independence in household and personal care tasks. Patients also used out-of-pocket funds to fill insurance gaps and pay for wheelchair-adapted vans or additional caregivers. Well-connected participants reported that their social network helped with home renovations, and transportation. Patients who could not afford additional care felt that their progress was unfairly limited or reported increased isolation, which further reinforced feelings of helplessness. (Figure 4)

Checkpoint 2: Information Access & Use—If the balance of patients’ personal and contextual coping behaviors produced dissatisfaction with their function, becoming aware of UER was the next major breakpoint. UER-aware patients were often unsure of how they first learned about surgery, but identified PM&R physicians or physical therapists as the likely

source. To reflect this, we included a direct provider-awareness connection in our model. Most NSG patients reported no or minimal awareness of UER. To understand why, we examined this Information Checkpoint using the same ‘personal’ and ‘contextual’ lenses we applied to Coping.

Personal Factors

Patients differed in their motivation to obtain tetraplegia-related information. Patients who believed ongoing research would yield better treatments remained actively engaged with medical information. Participants thought that by remaining up-to-date, they would be able benefit from medical advances sooner; however, they tended to focus on stem cell treatments and exoskeletons, with no one reporting regular research on UER. Patients also sought information for tetraplegic-specific issues such as wheelchair maintenance, home care, or insurance through online SCI forums, but were skeptical of medical advice unless it was provided by a member they trusted. Participants preferred medical information from their doctors or patients with whom they could talk directly, though actually connecting to fellow patients was challenging. Patients with few information-seeking behaviors thought the SCI materials were not particularly relevant, or lost interest over time. One participant found it too depressing. Several patients also noted limitations in their ability to process complex medical information or ask the right questions. (Figure 5)

Contextual Factors

Technology, particularly touchscreen devices and voice-recognition software improved patients’ information access; however, patients varied in their usage. Some patients reported poor internet access or difficulty obtaining adaptive devices; others with limited technological fluency found their devices difficult to use. Similarly, patients who received printed newsletters from hospitals indicated that this information was often inaccessible because they were physically unable to turn the pages. A minority stated that they simply did not know where to get UER information. Predictably, many of the contextual factors that supported good coping (such as strong social networks and financial resources) improved information access. (Figure 6)

Checkpoint 3: Surgical Impact—If patients successfully moved through the Information Checkpoint and became aware that they were candidates, the final roadblock to UER was Surgical Impact. Patients almost uniformly stated that improved grip strength was their biggest surgical priority, both because they wanted to be able to perform specific physical tasks, and for broader reasons like increased family participation. Patients wanted to understand operative mechanics, possible risks, and the function they could expect following surgery.

Personal Factors

Patients who elected to undergo UER weighted potential functional gains far above other aspects of the decision, even discounting possible complications. Although surgical patients generally agreed that their surgeon offered realistic pre-operative counseling, one patient felt the benefits were exaggerated. Patients who were hoping for a definitive cure (even if they recognized its unlikelihood) expressed more hesitation about surgery than those who felt

they had achieved their maximal functional gains. Several patients also communicated a preference for less invasive treatments; others thought immobilization would harm their rehabilitation progress. The few patients who declined surgery did not point to a specific surgical fact that deterred them, but indicated that they found the entire process to be intimidating. (Figure 7)

Contextual Factors

To determine the contextual impact, most patients weighed potential functional benefits against the impact their recovery would have on their families' lives and their external commitments. In general, patients reported that they would tolerate more immobilization and longer rehabilitation times if the benefits they stood to gain were great. Patients acknowledged that their caregivers' burden would increase during recovery, but many felt that increased care was a surmountable obstacle. Potential candidates found immobilization to be a stronger deterrent than rehabilitation. Students/employees suggested that the amount of time they would need off would be a large factor in their decision, though they were reluctant to commit to a prohibitive cutoff point. (Figure 8)

Discussion

UER can be transformative for patients with tetraplegia, but remains critically underutilized. Understanding how or why barriers to UER materialize is difficult because patients have diverse and complex experiences. Our qualitative examination is distinct in the amount of emphasis given to the personal and contextual factors that shape patients' decisions to pursue reconstruction. We offer a conceptual model to outline the patient experience, first identifying the three conditions necessary to choose UER: functional dissatisfaction, awareness of UER, and surgical acceptability. We further develop this idea through our detailed examination of how patients fulfill these conditions through Coping, Information, and Acceptability Checkpoints. Our model provides a novel framework to understand where barriers to UER exist, and what behaviors could be leveraged for interventions at each step.

Our findings echo those from other fields that report inadequate coping skills correlate with low self-efficacy to produce poor outcomes, as well as upper extremity research that indicates highly activated/engaged patients experience less pain and disability.^{50–54} Our conclusion that patients with extreme-negative coping behaviors do not progress to UER is therefore predictable. Potentially more surprising, is our finding that, in strict progression-to-UER terms, high coping is not advantageous. By demonstrating that exceptional coping can actually hinder progress, our study questions the traditional conclusion that self-efficacious patients do best. Instead, we propose that, in select cases, doing well (coping with injury) actually prevents patients from doing better or at least, improving hand function with UER.

Psychology literature has shown that patients with disabilities sometimes demonstrate a preference for their current state, and irrationally discount better treatments (status quo bias), but the paradox that patients could cope so well that they miss an opportunity to improve function is not well-characterized in the surgical literature.^{55–57} Furthermore, participants with excellent coping skills were not so much “choosing” their status quo, as lacking exposure to UER. The degree to which patients with tetraplegia prefer non-invasive

treatments overall is not completely understood, but warrants further investigation as several subjects expressed a generalized fear of surgery, and patients' preference for non-operative treatment is becoming increasingly recognized.⁵⁸⁻⁶⁰

This study has several limitations. We did not employ objective functional metrics to correlate patients' perceived function with actual function. It is also possible that by their willingness to participate, study subjects represented a more proactive cohort than exists in the general SCI population. Because it was difficult to identify patients who were aware of but declined surgery *a priori*, our understanding of surgical acceptability was less rich than other parts of the model. Our sample was also predominantly white and from a single geographic location, which may limit the transferability of these findings. Although smaller than most quantitative studies, our sample size is consistent with other qualitative studies in this population and reflects our aim to provide a more complete understanding of the patient experience than might be had from a statistical comparison between two samples. Additionally, participants were added until conceptual saturation was reached, thus increasing our sample size would not generate new themes. Finally, our model may suggest a more linear progression than actually occurs for most patients. The contextual factors that shape patients' decisions likely have impact at multiple stages and may change over time.

Ultimately, our study suggests that coping is not a good leverage point to maximize surgical uptake. Given the breadth of factors our interviews identified, attempts to improve coping will be challenging and likely to be inefficient. Coping-directed interventions would also continue to ignore high-performers. Promising interventions will likely be those that move more patients into the information-seeking phase and ensure available and accurate UER resources. Interventions that promote introduction to hand surgery at multiple standard points may improve utilization, but will require physician buy-in, particularly from PM&R doctors who do not always share surgeons' belief in the benefits of reconstruction.

Improving UER e-content has potential given patients' growing preference for electronic media. Focusing on patient-led forums may have particular merit considering the study by Wagner et al. that found patients trusted UER if they learned about it from a fellow patient, and aligns with participants' preference to speak with other surgical patients prior to reconstruction.³⁶ However, implementation must be thoughtful to overcome some patients' lower trust of online materials. Video-chatting could be an area of expansion. Ultimately, ensuring an opportunity for all eligible patients to make an informed decision about UER is important in supporting patients' function. Our model provides a framework for these crucial efforts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. International Classification of Function Psychosocial Model of Function

Figure 2. Path to Upper Extremity Reconstruction
Conceptual model of progression to UER.

General Emotional Outlook	
Optimism & Gratitude	Negativity & Anger
<p>“Well I try to always be an optimist. I try to find the good in every day, you know, every day is not good, but there’s something good in every day”</p> <p>“I don’t view it as over; it was a change. I’ve been kicked a couple times when I was down, but there are millions of people who have it different and have it worse. I am one of those people that are grateful for what they have. ...”</p>	<p>“It’s horrible. Don’t ever get in this position. It’s just devastating”</p> <p>“I don’t have as much, like a slice of my emotional pie is sort of taken up every morning from the get-go”</p> <p>“It’s frustrating sometimes...I get mad and I’ll take my reacher and smack it on my couch, or I’ll go in my bedroom and I’ll scream.”</p>
Self-Orientation	
Ability to Maintain Perspective, Acceptance, & Willingness to ask for Help	Unfavorable Comparison & Unwillingness to ask for help
<p>“I always say, you know, ‘don’t compare yourself to others for you’ll become vain and bitter.’ There’s always someone better than you, and there’s always somebody worse than you. So, I’m always like ‘if I could just get my hands back, life would be so much easier!’ And then I’ve got a friend who is a C3, who’s in a blow chair, and, I look at him and he’s saying, ‘man, if I could just have <i>your</i> arms, I would be so much better!’ So... Everybody’s got a cross to bear, right? Some are just more visible than others. This [gestures to chair] is a pretty visible one, but I don’t know what yours are, but I’m sure you got something...Everybody does”</p> <p>“I don’t feel like I’m having help...I have a choice as to how I can accomplish [tasks] and I chose one of my limited options...the necessity of the things that I need done for me causes me to look at [needing assistance] differently.”</p>	<p>“But, you know, the thing that hurts me is, you know, I seen the guy across the street walking his little granddaughter. I sat there and cried. Yeah, You know, to just to hold her, hold her hand and walk...”</p> <p>“I did everything...people compared me to, Superman. I was Superman....that’s what’s so sad right now, is my kids remember me as that, along with my friends and coworkers...nobody can believe this happened to [me.] Nobody. This guy’s a state champion, he’s an all-American. He drowned? He broke his neck. Disgusting.”</p> <p>“Oh yeah, I’m mad as hell! I don’t like people taking care of me. I wanna do it myself, and when I try to do something myself, and I can’t do it, that just...makes me more mad”</p>
Directivity	
Adaptivity & Future Orientation	Nostalgia & Retrospection
<p>“You can sit there and complain all you want, but that doesn’t help. Nobody likes or wants to be like this...but the only way to get past it is to roll yourself. You gotta be able to invest in yourself and know you’re going to go forward.”</p> <p>“Set yourself a goal every day...something as simple as...cooking for yourself or making yourself a cup of coffee. Don’t dwell about what you used to be able to do, look at things different and how you can do things different.”</p>	<p>“My feelings are probably down some. I mean you get nostalgia; you live in the past. Um, you look at all the things you used to do and can’t do no more. Obviously I didn’t need help getting dressed before and now I need help getting dressed. Um, so things like that take a toll.”</p> <p>“I used to be a lot...more sure of myself... I liked my exercise-level and my body-level and everything else. Now everything’s gone to hell in a handbasket. I don’t look at myself in the mirror.Uh, just...not good, not good at all.”</p>

Figure 3. Personal Coping Domains

A comparison and positive and negative personal coping behaviors among participants

Connectivity vs. Isolation	
Social Support, Relationship Roles, & Independence	Social Isolation & Relationship Roles
<p>"My parents came every single day to the hospital after my injury and all through rehab, so...when you have that kind of a base uh to grow on [you do well]."</p> <p>"I had, just a wonderful support system of friends who would go 'wow, you're doing better!' and obviously, we like to hear those things. So my ego got massaged nicely by my family and friends and it was very, very motivational to me"</p> <p>"Having a wife as a caregiver, it's not necessarily a standard husband-wife relationship, but, I was injured when we met... since it's always somewhat been part of our relationship, it doesn't define it as much as it could've, or it does for some"</p>	<p>"It's almost they [friends] either are there for you, consistent or they abandon you and want nothing more because they don't know how to accept what is happening."</p> <p>"Hard to be a father... I mean, even to get my boy to ride a bicycle, is, you know, it's hard..."</p> <p>"My relationship with my wife is more like a caregiver thing. It's extremely sad, 'cause we lost our intimacy...I'll stand up sometimes and give her a hug, but, it's uh been a...very, very hard thing... You go through all these feelings like 'gee whiz!...we took a vow 'til death do us part...this is way beyond. 5 and 6 years of this?...' So you almost feel guilty"</p>
Maintaining relationships & Community Connection	
Positive Friend Behavior	Negative Friend Behavior
<p>I remember when I had the catheter, we would go somewhere and me I couldn't do it myself. I had to have someone do it. I have a couple buddies, a core of us, I go to their house and I say, 'I got to go to the bathroom, you have to help me do this.' There were no issues...I said, 'if this is weird, let me know.' They had no issues with it."</p> <p>"Has it been different? Yeah. Some of my friends live in older farm houses. They weren't designed for wheelchairs. We do what we can, or they come and meet me at my place where it is easier to get around. But we still do what we did before. Again, like the saying, 'if it is something that you can't deal with or if it affects you that much, step up or step out.'"</p>	<p>"[regarding going to social events] I don't know if I could really ask this buddy of mine, could he get me out of the car...and then would I be stable enough to walk and sit down in the chair? And somebody would have to help me get out of the chair. If I had to go to the bathroom, I could probably get in there, I could probably get my pants down and sit down if it was handicapped and there was a right-hand rail, which is a lot of 'ifs'. I probably couldn't get my pants up though, because at that point I would probably have a diaper on...So, without being able to grip with both hands It's extremely debilitating."</p>
Resources	
High Social/Financial Capital	Low Social/Financial Capital
<p>"I always need someone to drive me. One of my best friend's dads, a year before my injury, started a company that transports people with wheelchairs. So, when I got hurt, I was like, 'oh, if my parents can't take me, I will call him.' He won't ever charge me. He will take me right away, and usually you need to set up an appointment."</p> <p>"it's not only the highly-trained medical professionals that are necessary for me...there are a lot of folks that have just turned wrenches or have done just much simpler things that have been similarly empowering or necessary."</p> <p>"Socioeconomically I was advantaged, so I had the space to heal and work on my physical issues and not have to worry about how, you know I was going to pay bills or eat."</p>	<p>"A lotta money, man, when you get injured. I can't believe how much money this stuff is now, you get ripped off. They rip you off, man. People always rip you off, 'cause you're handicapped. Everything costs so much more. If something breaks on [the wheelchair]...you have to pay for it. Things go wrong and you just get by with what it is, you know? Cause you can't afford the guy to come over to your house for \$75"</p> <p>"Yea, I lost my house with my family."</p> <p>"I'm definitely more of their kid than I would be at thirty though, if I wasn't hurt...I work enough and make enough money that I can contribute to our household somewhat, but not enough that me being independent is a reasonable option at this point."</p>

Figure 4. Contextual Coping Domains

A comparison and positive and negative contextual coping influences among participants

Awareness of Upper Extremity Reconstruction	
Aware	Not aware
<p>"I don't remember if it was meeting with [hand surgeon] or a doctor, a PMNR because [PM& R physician] opened me up to a lot of things."</p> <p>"I was like, '[PM&R doctor], 'we've gotta do something about lefty here.' I'm like, 'look at it!' and that's how I got [hand surgeon], was through [PM&R physician]."</p>	<p>When I was first injured, and I first heard about it, people were just saying, 'wait, on...you know, when you're newly injured, like, at least a year, maybe more, before really, um, looking into or thinking about it' Honestly, it's something that I hadn't thought about in years."</p>
Motivation, Interest Areas, Information Trustworthiness	Motivation, Information Processing
<p>"It is very important because...spinal cord is always evolving, as you are doing research. CareNet is the biggest one I use to stay up to date on research and my fields."</p> <p>"I really look for, look up regularly stem cells treatments... any news related to spinal cord injury like exoskeletons FES, those kinds of things."</p> <p>"That one forum CareCure...is really good 'cause a lot of the DME medical suppliers post on there, so like any new products are on there, a lot of do-it-yourself modification stuff is on there...I look at the equipment section a lot, talking about wheelchairs and hand cycles and other stuff. Any time I go on there's like over a hundred people on there at one time...so you can get answers about questions for like anything like pretty fast."</p>	<p>"When I was first injured, I was much more interested in, you know the newest research but, you know, I've settled into life it doesn't come up unless I'm having an issue."</p> <p>"There's a care forum for spinal cord injured people. I started reading that, and it just depressed me, so I stopped it. The horrendous issues that these people have...I couldn't read 'em anymore"</p> <p>"We needed a manual chair for me to go home in and the suggestion was just look online... It'd be like sending a woman from a tribal village in Ghana to Neiman Marcus to shop for her first pair of shoes...I mean, I get it, like...I know what the function of these things is, but when I'm coming into contact with it, it's entirely foreign. Having a spinal cord injury there's just sooooo, so much stuff to learn, and if somebody takes the approach of like 'well what would you like? it's unhelpful, because you don't even know what you don't know"</p>

Figure 5. Personal Information-Seeking Behaviors

A comparison and positive and information-seeking behaviors among participants

Information Access	
Accessible info	Inaccessible information
<p>“There wasn’t a whole lot out there, technologically, from the time from when I got hurt...now, it’s tenfold I mean it’s, it’s grown insanely.”</p> <p>“I use the computer, um, iPad, you know iPhone obviously, all of that is so much easier for somebody that doesn’t have fine motor skills.”</p> <p>We do have Dragon I can speak into the program and that helps... It made responses easier if they are going to be really long.”</p> <p>““I just got this at my last fundraiser, 1500 dollars for this equipment, for me to be able to use my computer, you know, and then you get in touch with the real world.”</p> <p>“And I make friends at the hospital so they sometimes hear something or read something and they tell me about it and I look into it.”</p>	<p>“There’s the disability network...pretty much handed me a bunch of booklets and said here you go, and how are you supposed to read something when you can’t hold anything, or flip pages or anything like that, you know?”</p> <p>“[doctors] got to give me, like, cases where they let me talk to [other patients] and let them tell me how it was for them and how long it took for them. I didn’t really get a chance to talk to anyone.”</p> <p>“I would like to get a little more information on that [hand surgery]. Sure. I just don’t know where to go, I guess. And I wish there was something more I could find out...where to go, who to talk to.”</p> <p>“There is a lot of research that is quackery...People get really excited when they see something on the news and send it to me and like yea I have been looking into it. It is 5 years away from doing anything”</p>

Figure 6. Information Context

A comparison and positive and negative information access influences among participants

Surgical Acceptability	
Most Desirable Function	
“Grasp. Fingers. Any fingers. Incredible. I know fine motor is asking a lot, but it would be nice. To be able to write, even rudimentary writing. Grasp would be huge. Being able to feed myself.”	
Personal Acceptability	
Positives Gains & Realistic Preoperative Counseling	Potential Limitations & Exaggerated Preoperative Counseling
<p>“When I met the doctors, they gave me more than I ever wanted to know, so I never had a thought in my head that something could go wrong... I was going to put my trust in their hands to help me.”</p> <p>“I knew what I was expecting when I went in for surgery. I knew he would not get my hands perfectly straight because of the damage done to my spine.”</p> <p>“I wanted more at the time and it [surgery] was giving me more, unlike I was hanging on the hope [for a cure.] Hope was going for it. Not like we are going to wait five years; there wasn't anything around the corner. My mind was, ‘I want it now, I want it better now’</p>	<p>“I was actually basically led to believe there was more benefits than there were risks. And very little risks were ok... You're going to be all right. “</p> <p>“I would worry about...theoretically, is it reversible? What happens if they come up with some magical robot spinal cord...can they reverse? Will I have lost function there, 'cause now my hands are now rewired?</p> <p>“You know I think I told them that, you know I don't want to do any complicated surgeries. You know, I just wanted to do therapies and see what, where that would take me and if things didn't really work, there was no progress then I would think about that surgery.”</p>

Figure 7. Personal Surgical Acceptability

Comparison of the personal factors that influence acceptability of UER.

Contextual Acceptability	
Favorable Risk/Benefit & Supportive Context	Functional losses & Immobilization Concerns
<p>“Because if there’s a lot to get back, that, that’s worth a lot of immobilization”</p> <p>“I knew I had the help if I needed it. I have four daughters, a son and many friends in homecare that I could reach. To stick to it, to expand. So, that wasn’t an issue.”</p> <p>“So, I was like, okay, I can deal with that [immobilization]. No problem with it. I can be myself with it. I got a whole village of people who don’t mind feeding me. Lots of little kids don’t mind feeding [me]”</p>	<p>“The [surgery] will be more of burden on her [wife] than on me, right? Because she’s gonna have to deal with me being in hospital, and then with the recovery, and if it limits my ability to function, then unfortunately, it will fall on her.”</p> <p>“So [recovery time] that’s a pretty big, and like how long? ‘Cause, I’m in school, and I’m always like working at a job or doing something so it’s kind of important to stay active.”</p> <p>“The thing that intimidates me is the length of time your arm would be in a cast. The rehab I am fine with, but the cast does intimidate me because it does decrease my independence”</p>

Figure 8. Contextual Acceptability Domains

Environmental Factors that Influence acceptability of UER

Table 1**Patient Demographic Data**

Demographic	SG	NSG	Total
Sex			
Male	5	10	15
Female	4	0	4
Age at injury			
18-25	4	5	9
26-35	1	1	2
36-45	3	1	4
46-55	1	1	2
56-65	0	2	2
Ethnicity			
Caucasian	8	9	17
African American	1	0	1
Hispanic	0	1	1
Cause of Injury			
MVA	6	2	8
Diving	1	4	5
Other sport	0	2	2
Fall	1	1	2
Other traumatic cause	1	1	2
Level of Injury			
C4	3	2	5
C5	1	7	8
C6	4	1	5
C7	1	0	1
C8	0	0	0
AISA Grade			
A	4	4	8
B	2	4	6
C	3	0	3
D	0	2	2
Living situation			
Independent	4	3	7
Spouse/Partner	1	5	6
Parents	2	2	4
Assisted Living Facility	2	0	2
Educational Level			
Secondary School	6	1	7

Demographic	SG	NSG	Total
Vocational Training	1	1	2
Undergraduate Studies	2	5	7
Graduate Studies	0	3	3

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