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Leveraging the Medical Context to Increase Upper Extremity Reconstruction among Patients with Tetraplegia: A Qualitative Analysis

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Abstract

Objectives—(1) To characterize patients' medical experiences from initial injury until they become candidates for Upper Extremity Reconstruction (UER). (2) To identify points in this medical context that may be most amenable to interventions designed to increase UER utilization.

Design—A qualitative cross-sectional study using grounded theory methodology and constant comparative analysis of data collected through semi-structured individual interviews.

Setting—Community

Participants—A sample of individuals with C4–C8 cervical spinal injuries (N=19) who sustained injuries at least one year prior to interview. Nine patients had undergone reconstruction, ten had not. The study sample was predominantly male (79%), white (89%), and ASIA Grade A-D were represented (Grade A: 42%; Grade B: 32%; Grade C 16%; Grade D 10%).

Interventions—none

Main Outcome Measures—Participant self-report of their medical experiences from the time of injury through the early recovery period.

Results—We identified three domains that formed patients' medical context prior to UER candidacy: (1) their ability to achieve and maintain health; (2) their relationship with health care providers; and (3) their expectations regarding clinicians' tetraplegia-specific expertise. Trust emerged as a major theme driving potential intervention targets. Patients transferred to referral centers had higher trust in tertiary providers relative to local physicians. In the outpatient setting,

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patients' trust correlated with the tetraplegia-specific expertise level they perceived the specialty to have (high for PM&R, intermediate for urology, low for primary care).

Conclusions—In appropriate candidates, UER produces substantial functional gains, but reconstruction remains underutilized in the tetraplegic population. By analyzing how patients achieve health and build trust in early recovery/injury, our study provides strategies to improve UER access. We propose that interventions targeting highly trusted points of care (transfer hospitals) and avoiding low-trust points (PCPs, home health) will be most effective. Urology may represent a novel entry point for UER interventions.

Keywords

qualitative; spinal cord injury; tendon transfer; tetraplegia

There are approximately 300,000 people living with spinal cord injury (SCI) in the United States, and tetraplegia now accounts for over half of all new neurologic injuries.¹ Patients with tetraplegia experience many functional losses, but impaired use of the upper extremity is particularly limiting.^{2–4} Studies of patients' priorities following injury consistently demonstrate that patients choose use of their arm and hand over improved bladder, lower extremity, or sexual function.^{5–7} In this context, interventions that can maximize or restore upper extremity function are highly valuable.

Upper Extremity Reconstruction (UER) is an effective way to improve function, but it remains critically underutilized. UER includes several procedures (fusion, tenodesis, and tendon transfer) that may be combined or performed individually to help patients regain use of their arm and hand.^{8–11} Estimates suggest that 65–75% of patients could improve with some form of UER; yet, only 10–14% of patients ever undergo reconstruction.^{12,13} Numerous case-series demonstrating excellent long-term patient satisfaction and low complication rates have done little to increase utilization.^{14–21} These persistently low operative rates suggest that establishing UER's effectiveness is not sufficient.²² If providers want to increase UER utilization, they must understand the broader patient context and apply this knowledge to interventions that match the patient experience.

Individuals' social, emotional, and medical contexts are well-established drivers of patients' medical decision-making.^{23–27} For decisions regarding UER, patients' medical contexts are particularly important because of their relation to operative timing. To be eligible for UER, patients must achieve maximal neurologic recovery (which generally occurs by one year following injury) and be medically stable.^{28–30} This lag between injury and eligibility has several implications. First, because tetraplegic patients have high complication rates following injury, maintaining health can be a substantial barrier to UER.^{31–33} Furthermore, during early recovery, patients have numerous interactions with providers that may build or erode their trust in the medical community long before they ever meet a hand surgeon.

Given this background, multiple analyses have tried to understand why patients do not select UER. However, by only looking at patients once they become UER candidates, researchers may miss the critical period when patients' opinions actually form. We propose that examining patients' experiences during early recovery may reveal a more effective entry

point for future interventions. We performed a qualitative analysis to determine what factors patients think influence their recovery, overall health, and their relationship with their health care team. We aim to better characterize patients' medical context from the time of their initial injury through the point they become candidates for UER. We then seek to identify points in the medical experience that can be leveraged to increase UER utilization.

Methods

Study Design

This was a qualitative cross-sectional study. Semi-structured interviews were conducted from August-September 2016 and used a standardized interview guide. The University Institutional Review Board approved this study. Written informed consent was obtained prior to participation. Subjects granted written permission to audio record all sessions.

Subjects

We used purposive sampling to include near equal numbers of patients who had undergone and not undergone surgery. We searched the electronic medical record to identify patients with C4-C8 cervical spinal injuries who had undergone UER using International Classification of Disease (ICD9) and Current Procedural Terminology (CPT) codes (Appendix 1). The Department of Physical Medicine and Rehabilitation (PM&R) supplied lists to identify patients who had not undergone surgery; patients were contacted by email and invited to join the study. Interested individuals were screened to confirm the presence of disability in all four limbs and initial injury dates at least one year prior to interview. We excluded patients who were under age 18 or non-English speaking.

Data Collection

Interviews took place in patients' homes, our research facility, and via telephone. At the study outset, two investigators CH, JM (characteristics discussed in Appendix 2) attended each interview. Caregivers attended interviews at participants' discretion, except in one case where facility policy mandated supervision. Member checking occurred throughout interview sessions. After establishing consistency through post-interview debriefing sessions and field notes, a single investigator attended each interview. We employed iterative (transcripts were re-analyzed every time a new theme arose) and emerging (explanatory ideas are identified and explored in depth) analysis throughout data collection to identify developing themes.³⁴ The interview guide was amended to expand questioning around emerging themes after interviews 7 and 12, as previously published³⁵ We continued recruitment until interviews demonstrated conceptual saturation, the point at which interviewing additional participants did not generate new themes. All interviews were audio recorded and transcribed verbatim.

Data Analysis

We used grounded theory to structure our analytic approach.^{36–38} Two primary investigators began analysis by independently open-coding four transcripts. The theme lists were then compared, redundant themes condensed, and related concepts were ordered into themes, codes, and sub-codes. Using the draft codebook, investigators re-coded the initial four

transcripts. All discrepancies were discussed and the codebook was amended to reflect changes. Definitions were added for each code and sub-code.³⁵ After completing training to unify methodology, an additional 4 reviewers joined the process. Ten transcripts were double-coded and reviewed in one-on-one meetings to ensure consistency, after which time a single investigator coded the remaining nine using NVIVO (QSR International Pty Ltd. Version 11, 2012). The codebook was updated periodically as new themes were identified.

Results

Consistent with national data, participants in our study were predominantly male (79%) and injured during the period from adolescence through middle age.¹ Our sample was mostly white (89%). Injury classification ranged from ASIA A-D (Grade A:42%; Grade B: 32%; Grade C: 16%; Grade D: 10%). Nine patients had undergone UER, 10 had not. (Table 1) From patients' statements, we identified three major components that formed their medical context prior to UER candidacy: (1) their ability to achieve and maintain health; (2) their relationship with health care providers; and (3) their expectations regarding clinicians' tetraplegia-specific expertise. A detailed examination of each follows.

Achieving and Maintaining Health

Initial Stabilization and Hospital Course—Most participants spoke about their immediate post-injury care in term of the procedures they received. Their experience of critical care and neurosurgery was largely limited to their physical recovery, and patients did not attach much emotional significance to this time. The few who had strong opinions perceived their eventual function to be highly shaped by the care they received immediately after injury. At the positive end, one patient reported that he “was blessed with a series of miracles” because his injury occurred close to the hospital and he was able to undergo rapid spinal decompression. Patients at the extreme-negative end felt that poor initial care or missed injuries resulted in irreparable harm that stunted their recovery. In these cases, patients did not place blame on a single person, but looked at their care process as a series of missed opportunities. (Figure 1)

Patients' perceptions of sub-standard care certainly undermined trust in their providers initially, but they differed in how much they allowed these perceptions to color their opinion of subsequent treatment. A few patients continued to have adversarial relationships with their care team (in reference to complying with his inpatient rehabilitation program, one patient reported that he needed to “behave myself like a good prisoner”). Conversely, many patients who were stabilized at a local hospital and later transferred to a tertiary center used the contrast provided by the “bad hospital” to restore or even strengthen trust in their tertiary providers. Their positive view of these providers was often enduring. Patients noted that they stayed in contact with their doctors by phone or email and reported driving long distances to continue care. One patient acknowledged that even many years after her injury, she traveled out-of-state to the hospital where she had gotten definitive care to evaluate her worsening hand function. (Figure 2)

Maintaining Health—After patients stabilized and completed inpatient rehabilitation, the bulk of their medical experience between injury and candidacy for UER centered on

maintaining health. To address their daily needs, most patients relied on a combination of professional and family-based care. Typically, even the most capable patients opted for some aid early in the day to expedite their morning routine. As expected, patients noted that assistance with hygiene or medical tasks such as bowel/bladder regimens helped them avoid complications or readmission. Less predictably, several also felt that the support they received with routine activities of daily living, such as dressing and household chores, was similarly crucial to their health. Without help, patients felt that they over-exerted themselves and the resulting fatigue left them vulnerable to illness. (Figure 3)

Ensuring high-quality home care was a substantial challenge for people who used professional caregivers. Several patients pointed to high turnover rates and relatively low pay for home health care providers as a hindrance. Others felt that the high demand for caregivers meant home health companies had low hiring standards. Participants adapted to this reality by cultivating friendships with their caregivers to improve retention and promote good care. Participants also spoke about the importance of developing good communication skills and patience; however, many had an acute sense that they needed to be vigilant and directive to protect themselves from negligent treatment. Nearly all patients felt that they had a deeper knowledge base than their caregivers and thus were responsible for training them. Consequently, most participants did not view home health providers as reliable sources of medical information. (Figure 4)

Finally, a minority of participants reported that they were unable to achieve stability owing to an ongoing cycle of complications and readmissions. One patient reported that during a long period of intubation for pneumonia, she lost the skills she had gained during occupational therapy. Other patients complained that bedrest restrictions for pressure injuries quickly undercut much of the hard-won strength they had built up in physical therapy. The threat of illness also forced patients to be hyper-vigilant to maintain their health: during one session, after the interviewer sneezed, a participant informed her that he would need to cancel the interview if the interviewer was sick. In several cases, complications or their sequelae persisted long after the first year following injury. As one patient put it:

“I have had so many extra health issues besides being paralyzed. That is the biggest thing with paralysis, it is never just paralysis. If I was just paralyzed, I really believe I would still be working, but I had so many external issues. My colitis got worse.... UTI's are a constant problem. Seems like I am always sick.”

Provider Qualities and Impact on Patient-Provider Relationship

Trust emerged as an important theme in patients' relationship with their providers. Most participants reported they had a positive, trusting relationship with their PM&R physician. This was important because they relied on these doctors for guidance in medical decision-making, referrals, and treatment. Like subjects in other studies assessing the tenets of patient-centered care, our participants valued clinicians with good bedside manner who exhibited personal investment in patients.^{39–41} Patients appreciated providers who accommodated their individual preferences (such as a desire to avoid medication) and provided services with few logistical hassles. Regarding tetraplegia-specific issues, patients appreciated physicians who respected their autonomy and treated them as complete humans.

This is possibly related to difficulties they encountered with these qualities when interacting with the general public. (Figure 5)

How physicians delivered information about paralysis and prognosis also had an impact on trust, but it was much less predictable than the one seen with provider qualities. One patient thought her neurosurgeon delivered news of her paralysis insensitively and continued to view him angrily years later. Some patients felt that their physicians were wrong in their assessments of recovery potential, whereas others felt that their doctors' conclusions that they would never walk again meant that their doctors lacked faith in them. All of these reactions served to weaken the bond between patients and providers. Alternatively, some patients who thought their doctors were wrong used their disbelief as a tool in recovery. In fact, defying their providers' predictions proved to be a deeply validating experience for patients and one that they drew from as a source of continued motivation. Moreover, if the provider then displayed excitement about their accomplishments, this strengthened the patient-physician bond. Regarding UER specifically, patients were also encouraged by their physicians' willingness to refer them to hand surgery; they viewed it as a sign that their physician believed in them. (Figure 6)

Provider Complement & Patient Expectations

To identify the key providers in patients' medical contexts we also asked patient to identify the providers they saw and the nature of their relationship. Most patients had a core of medical providers that included their PM&R physician, a primary care physician, and urologist. They saw additional specialists as indicated, including a hand surgeon for those who had undergone UER. No patients identified referral or introduction to hand surgery as part of their routine care. In the outpatient setting, participants had different standards for tetraplegia-specific expertise depending on provider specialty. Patients selected primary care physicians based on proximity and convenience. They accepted lower SCI familiarity because they felt their PM&R physician could fill in any SCI-specific gaps. Patients had higher standards for specialty physicians, particularly urologists. Several patients indicated that tetraplegia added increased complexity to their care; thus, they expected their urologists to understand tetraplegia-specific pathology. In addition to the gauging the accuracy of the advice their providers offered, patients also used physical and procedural cues to assess their providers' familiarity with tetraplegia. Patients were particularly attuned to inaccessible facilities or instances when clinic staff struggled to complete transfers smoothly. In these cases, patients assumed the staff had low tetraplegia knowledge. (Figure 7)

Discussion

Based on participant statements, it appears that influential mediators in patients' medical contexts do form in early injury/recovery. Trust emerged as an important theme in multiple domains. We found that patients' experiences during their initial hospitalization could strongly bias how much they trusted their physicians during subsequent interactions, which may directly impact their UER decision making. This relationship is illustrated by considering Ajzen's Theory of Planned Behavior.

According to Ajzen, individuals' beliefs regarding how significant people in their life will view their potential behavior (subjective norms) strongly predicts the individual's eventual actions. By establishing trusting relationships, physicians can elevate the importance of their subjective norms.⁴² In other words, patients who trust their doctors will base their decision to undergo hand surgery on how they believe their provider will react to that choice. This is particularly relevant in the context of Curtin *et al.*'s conclusion that PM&R physicians have significantly lower confidence in UER's effectiveness when compared to hand surgeons.⁴³ Taken together, these findings suggest physicians must remain cognizant of their own biases to avoid unduly influencing patients and that work to develop a shared understanding of UER's role among surgeons and PM&R doctors should continue.

A key step in this process may come from targeting referral hospitals. Among our most salient findings is the insight that patients have enhanced trust and longstanding loyalty to providers at referral hospitals. Although the longevity or extent of this halo effect remains undefined, it is reasonable to suggest that patients may be more receptive to future reconstruction if they learn about this possibility from trusted tertiary providers early in their course. It also suggests that long-term UER outreach from the referral center may have a role. A center-specific focus could also benefit the hand surgery-PM&R relationship. It is clear from Curtin's work that a shared concept of UER's benefits among these specialties does not always exist. This discord may be partially lessened by improved partnerships between surgeons and PM&R physicians. This kind of coordination is often difficult, but focusing on the hand surgeon-PM&R relationship across a few high-trust centers may help build collaboration efficiently.

The importance of targeting the correct providers for interventions was also echoed in patients' statements about their expectations of these professionals. Patients clearly tolerated different tetraplegia-specific expertise depending on their doctor's specialty. Participants were willing to accept primary care physicians with low SCI familiarity if they were nearby and available, but would drive hours to see their PM&R doctor. This suggests that efforts targeting generalists to increase UER utilization will be of limited use because patients do not use those providers for SCI-specific issues. Interventions aimed at home health providers will face similar problems as participants lacked confidence in the caregiver's knowledge base.

Urology, which was the other major specialty area in which patients needed regular care, may represent an unconventional access point. Patients felt their urologist should understand that tetraplegia made their care complex, which suggests that they expected their urologist to have some familiarity with SCI. Thus urologists (or perhaps their clinics) could be a source of targeted UER information, though PM&R physicians and hand surgeons would retain primary roles in referral and counseling, respectively. Examination of how to effectively add urology to the hand surgeon-PM&R physician dyad to improve systematic UER awareness is warranted.

Limitations—Our study has several limitations. Owing to its retrospective nature, patient reports of their initial experiences may be colored by events that happened later in their course. We did not independently verify cases where patients reported poor care, as our

relevant endpoint was perception. It is also difficult to determine whether the perception of poor care undermined what would have otherwise been a positive patient-provider relationship, or if patients' baseline skepticism cause them to characterize appropriate care as poor. Finally, our findings may not be transferable owing to the fact that our sample was predominantly white and from a single geographic area.

Conclusions

Current practice patterns have resulted in low UER awareness and substantial underutilization. Patients' medical contexts influence their willingness to undergo reconstruction; however, because most studies examining patients' UER decision-making begin after they become candidates, they may miss crucial aspects of how patients' beliefs form. Our qualitative analysis is notable for its focus on patients' experiences from the moment of injury through the point that they become eligible for UER. In understanding how patients' medical courses, preferences, and expectations shape their relationship with their health care team, we illuminate novel entry points for interventions to improve UER utilization.

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Abbreviations

CPT	Current Procedural Terminology
ICD9	International Classification of Disease (version 9)
PCP	Primary Care Physician
PM&R	Physical Medicine and Rehabilitation
SCI	Spinal Cord Injury
UER	Upper Extremity Reconstruction

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Appendix 1: Procedural Description Codes: CPT and ICD-9

Procedural Descriptions (CPT) Codes	Description
23395	Muscle transfer, any type for paralysis of shoulder or upper arm, single
23397	Muscle transfer, any type for paralysis of shoulder or upper arm, multiple
24301	Muscle or tendon transfer any type, upper arm or elbow, single
24305	Tendon lengthening upper arm or elbow, single
24320	Tenoplasty, with muscle transfer, with or without free graft/elbow to shoulder, single
25310	Tendon transplantation or transfer, flexor or extensor forearm and/or wrist single
25300	Tenodesis at wrist; flexors or fingers
25312	Tendon transplantation or transfer, flexor or extensor forearm and/or wrist with tendon grafts
25315	Flexor origin for cerebral palsy, forearm and wrist
25316	Flexor origin for cerebral palsy, forearm and wrist, with tendon transfer
25320	Capsulorhaphy or reconstruction, capsulectomy, wrist (includes synovectomy, resection of capsule, tendon insertions)
26471	Tenodesis for proximal interphalangeal joint stabilization
26480	Tendon transfer or transplant, carpometacarpal area or dorsum of wrist, single without free graft
26483	Tendon transfer or transplant, carpometacarpal area or dorsum of wrist, single with free tendon graft
26485	Tendon transfer or transplant, palmar, single without free graft
26489	Tendon transfer or transplant, palmar, single, with free graft
26490	Opponensplasty, sublimis tendon transfer type
26492	Opponensplasty, tendon transfer with graft
26496	Opponensplasty, other methods
26497	Tendon transfer to restore intrinsic function; ring and small finger
26498	Tendon transfer to restore intrinsic function, all four fingers
26820	Fusion in opposition, thumb, with autogenous graft

Procedural Descriptions (ICD-9) Codes	Description
8211	Tenotomy of hand
8371 (8251)	Advancement of tendon (hand)
8372 (8252)	Recession of tendon (hand)
8373 (8253)	Reattachment of tendon (hand)
8374 (8254)	Reattachment of muscle (hand)
8255	Other chg muscle/tendon length hand
8256	Other hand tendon transfer/tplnt
8257	Other hand tendon transposition
8258	Other hand muscle transfer/tplnt

Procedural Descriptions (ICD-9) Codes	Description
8259	Other hand muscle transposition
8272	Plstc operation hnd w/gft musc/fasc
8279	Plstc operation hnd w/oth gft/impl
8285	Other tenodesis of hand
8286	Other tenoplasty of hand
8375	Tendon transfer or transplantation
8376	Other tendon transposition
8341	Excision of tendon for graft
8381	Tendon graft

Appendix 2. Interviewer Characteristics, Interview Preparation, Study Introduction & Bias

Interviewer 1 CH: MD, female

Dr. H gained qualitative research experience through her undergraduate senior research project collaborating with Dr. Kathleen Morrow on Project LINK, a study examining the acceptability of vaginal microbicides to women. She completed a second qualitative project during medical school, assessing the effectiveness of a community-based bullying prevention workshop. She is a general surgery resident completing a 2 year research fellowship and is working toward a Masters in Health Services Research, which includes instruction in qualitative methodology. Dr. H became involved in this study as part of her T32 training grant under the mentorship of a senior hand surgeon with a special interest in upper extremity reconstruction for patients with tetraplegia.

Interviewer 2 JM: MA, male

JM is currently a second-year medical student. This is his first qualitative study. JM became involved in this study after being awarded a summer biomedical research training grant through his medical school. He received mentorship from the same senior hand surgeon

Interview Preparation

After generating an initial interview guide, questions were piloted for clarity using additional research staff. Interviewers conducted mock interviews in which the second interviewer played the participant to refine question order and language. Practice sessions were recorded.

Study Introduction & Bias

Several participants who had undergone reconstruction had a pre-existing relationship with this project's senior author; however he was not present for any interviews. Beyond initial screening phone calls, no participants had spoken with the interviewers prior to interview. Interviewers identified themselves to participants only as "researchers" and no additional

qualifications were discussed. Although participants were not asked to list the institutions where they received care, the majority reported some treatment at the University, and many continued to receive care there. Prior to the start of the interview, participants were informed of the interviewers' connection to hand surgery; however, all participants were told explicitly that the goal of the study was to learn about their experiences, not to recruit potential reconstruction candidates. Participants were told that they would be de-identified and their responses would have no bearing on their future medical care.

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"I was blessed with a series of miracles, some kids were right there, and they called an ambulance. My son, who works at the hospital, contacted [neurosurgeon]. [Neurosurgeon] came in, operated on me."

"Then they put me in an ambulance...and they were driving around and I was bouncing and my head's moving and I'm screaming, 'I'm in pain! Aaah! Don't! Stop!...I'm paralyzed. Stop!' They never four-pointed my head. They never put a c-collar on me...So they were supposed to follow protocol...I wish they would have, but they didn't, and we found out the reason they didn't was because they would get monies from the hospital to bring the patient...So they drove me 20 miles the other way to [medical center], which is this tiny, little, frickin' medical center, and they only had one neurosurgeon on staff there...Now they were supposed to pull over to the side of the road, check on air ambulance helicopter, survival flight to come get me, and fly me down to [large medical center] to one of the best neuro research spinal cord injury recovery programs in the world, where they've come up with this brand new situation where they would freeze the spinal cord to reduce the swelling. Those [expletives!]...I don't have any recourse against them either, you know? Who knows if they did any, you know, more injury to me...maybe they didn't, but what would have happened if I had gotten into that helicopter and landed [at large referral center]?"

"I did have an encapsulated ulnar nerve on my elbow on my right side. My right elbow—they didn't know my elbow was broken until I got down and started doing physical therapy, and then they're like, 'Oh, and you've had a broken elbow the whole time!' If they woulda' got it taken care of then I woulda' been a whole lot better off with my OT and whatnot, you know? But

having a broken elbow and having it heal the wrong way...it kinda hurt, you know, not getting into therapy for a month. It ruined everything"

Figure 1.
Initial Care

"A couple hours [after transfer] they knew right away that, the trach was too big and it was pushin' on my vocal cords. But [local hospital]? It took them June, July, almost two months to figure out that reason I wasn't able to talk was because the trach, and it took [tertiary specialist] a couple hours."

"[Tertiary Center] put me back together...[treated] another hole in my throat that [local hospital] didn't catch. So it was a blessing to go there...we didn't know what was next and they had already begun. Didn't know what I was supposed to be doing until I got to [tertiary center]."

Figure 2.
Trust in Tertiary Providers

“Cathing can be kinda difficult. I’ve tried doing cathing myself and it’s not easy, and I don’t think that I’ll ever get to the point where I can actually do it myself, um, just at least, not without, you know, seriously, like, getting contaminated. Yeah. There’d be some pretty serious UTIs after I started.”

“I have... a home-health-aid that comes in the morning for... usually about an hour, just helps me get dressed and stuff. I could do those things in the past, it just takes me a very long time...to like take a shower and get dressed and everything, it takes three hours, and I feel like with someone helping it takes an hour...When I was doing that myself I just didn’t sleep enough and...it wasn’t that healthy...I would be pretty, like more tired than I would if I just had someone help me. So it like was harder to like work, and do school... I like got sick more ‘cause I was tired”

Figure 3.
Home Health Care Assistance

"I mean then the home-healthcare like field it's very high turnover, 'cause it's like a pretty low-paying job. I think it's like nine or ten dollars an hour, so you get a lot of new people. A lot of times these agencies too will just throw people in...I had to learn how to be very patient because like, people are helping me, they may not understand the way I'm describing something, and kind of just have to be really patient, because it doesn't really help to get mad, because then, some people just get mad back at you... it escalates."

"[Caregivers] grow up and move out. I feel like this is a stepping stone: everyone is on their way through school and on their way up onto bigger and better...[I just] changed to a new company, um a week ago. So I took a few people from the other company that were good and were worth keeping around...I try to keep good people around, I found people to be reliable and to be close acquaintances or friends with."

"I've gotten into the habit of dictating a lot of things, so exactly how I want it done, and it'll frustrate people because they think I'm just, like, micromanaging them or, or something...I'm, not trying to be condescending or anything. It's like, um, some people need it, and so I just do for everybody to make it a habit."

Figure 4.
Ensuring Quality in Home Health Care

“[PM&R physician] has been very good in in terms of providing whatever resource I might ask for, which in this case has just been the physical therapy. If I want medication for pain, she would do that in a second. Um, she wants to hear...how I'm doing with my hands, and...she's encouraging.”

“[PM&R physician] gives you a sense of, 'you are still making your own choices.' He might steer you in his experience, but regardless of whether you want to make a good or bad decisions, you know, he still makes you feel that it is your decision. He is not one of the doctors that say, 'You are wrong I have been doing this.' He has experience, but everyone has the right to choose...He is still going to have the answers in his head, but you're on your own search of how you want to be treated and how you want your care. Obviously, some of us are a little bit angrier, some of have no clue and are a little bit lost, but he still makes you feel like you are little bit in charge. Like I said, he is one of those people to come in, make jokes, and greet you personally by shaking your hand and sees the person, not the chair.”

Figure 5.
Provider Qualities

“Dr. Numb-nuts up there at [city]? I wouldn’t recommend him to anybody. I don’t like him. He’s not a very good doctor and beside? He’s, he’s a jerk...he looked at me after I woke up from the coma and said, ‘You’re never gonna walk again.’ He’s lucky I couldn’t smack him or kick him... stupid.”

“When the doctor says this and that and you can prove them wrong, that just makes you feel like whatever a doctor tells you is stupid. They tell you what they know out of books, but God has the last say...It all goes back to God, because I am a miracle. I am one of his many blessing to pull me out of that accident. For the doctors to say the things they said about me, I just prayed on it. I didn’t listen to them; I constantly prayed on it. What those doctors said was lies and bullshit...I am not paralyzed from the neck down forever.”

“I don’t want them to give up on me like some PM&Rs have done. They just say, ‘Oh you can’t do this.’ I’m sorry, you have no idea what I put my mind to, I can do. Allow me that. Because I think they underestimate us...underestimate my ability, cause I’ve got it. Just ‘cause it’s not here [gestures to legs] doesn’t mean it’s not here [brain] to put with there [heart].”

“[regarding doctor checking physical strength] “I hooked him on my arm, he grabbed my arm. ‘Let’s see if you can give me any resistance?’ You know?...I pulled him right over my wheelchair, into my lap! He said, ‘Whoa whoa whoa!’ He said, ‘Yeah! I can’t believe it!’ And he tells everybody, ‘This guy’s unbelievable, cause [of what] he’s doing’”

Figure 6.
Impact of Prognosis

“When I was looking for a new PCP, I was looking for first available appointment...I was looking for somebody who was nearby, who is comfortable conducting business remotely, whether that be through [the university] portal or email. So my PCP, I...didn't look for somebody who was necessarily 'spinal cord' who had any, you know, special experience with spinal cord injuries. The doctor in PM&R was the doc I had on the floor when I was injured, so, you know, he's helpful for spinal cord-related things.”

“The most difficult thing is finding someone who understands the small sector of the population, people with spinal cord injuries. My urologist doesn't. I am trying to find a new urologist, because my urologist doesn't think outside. He only thinks of people who are normal and I have tons of special issues. He tries to prescribe medications he would for a normal person. He doesn't get that my immune system sucks and that I need more, so that's all...It helps to have someone who is familiar with spinal cord injuries.”

Figure 7.
Tetraplegia-specific expertise

Table 1

Patient Demographic Data

Demographic	Surgery Group	Non-Surgery Group	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
ASIA 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	Surgery Group	Non-Surgery Group	Total
Vocational Training	1	1	2
Undergraduate Studies	2	5	7
Graduate Studies	0	3	3

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