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The golden year: How functional recovery sets the stage for tendon transfer surgery among patients with tetraplegia—a qualitative analysis ☆☆☆



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ABSTRACT

Background: Tendon transfer surgery can effectively improve hand function for patients with tetraplegia but remains poorly utilized. Little is known regarding how patients' rehabilitation experiences influence their perception of function, identity, and coping to shape their reconstructive context.

Methods: We performed a cross-sectional qualitative analysis of 19 participants with C4–C7 cervical spinal injuries: 9 patients had undergone reconstruction; 10 had not. Semistructured interviews were conducted using an interview guide focusing on rehabilitation experience, the relationship between function and identity, and how patient experience evolved. Interview transcripts were analyzed using grounded theory.

Results: The study sample was predominantly male (79%), white (89%), and American Spinal Injury Association grades A–D (grade A: 42%; grade B: 32%; grade C: 16%; grade D: 10%). Recognizing rehabilitation's necessity, functional gains, and constructive patient–therapist relationships promoted engagement in therapy. Poor insurance coverage and financial constraints decreased rehabilitation access. Function affected identity through the degree to which it tied participants to a “patient” role. Early in recovery, patients' function, roles, and attitudes were fluid but solidified over time; how satisfied patients were with these final positions influenced how they coped.

Conclusion: The balance of patients' positive and negative coping has been found to influence patients' progression to surgery. This study describes how function and identity contribute to coping. Participants' function and identity evolved during a finite period we call “the golden year,” before reaching a fixed point around which they built their lives. The norms patients establish during this time may affect receptiveness to surgery.

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Introduction

After addressing immediate threats to life, maximizing function is often the next priority for trauma patients and their surgeons.

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Early postinjury, surgical decision making is highly algorithmic (eg, restoring blood flow in critical limb ischemia) and does not focus heavily on patients' external factors.^{1–4} However, as patients transition out of the hospital and their function-restoring surgical options become more elective, individual context becomes more important. This phenomenon is particularly evident when considering upper extremity reconstruction (UER) for patients with tetraplegia. UER, which includes fusion, tenodesis, and tendon transfers, is well tolerated and highly effective in appropriate candidates.^{5–12} Yet, despite a seemingly perfect match between patient preference (individuals with tetraplegia consistently rate better use of their hands as their top functional priority^{13–17}) and effective intervention, only 10% to 14% of eligible US patients undergo reconstruction.^{18–21}

Previous research examining why patients with tetraplegia do not undergo UER has largely focused on patient knowledge and

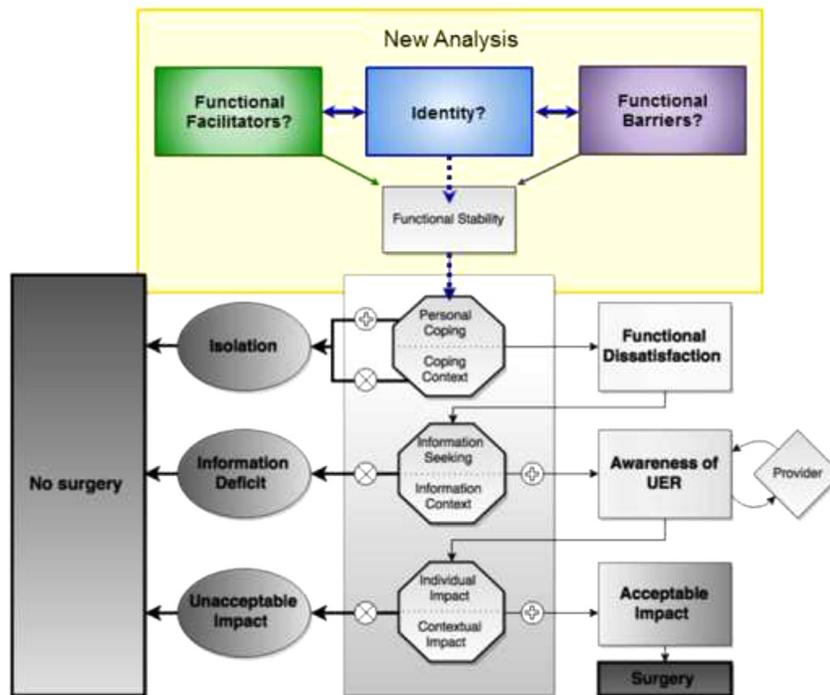


Figure 1. Original conceptual model and present study focus. Initial conceptual model (*in gray*) depicts participants' progression from the point of functional stability to surgery. The present analysis examines the barriers and facilitators of function, their relationship to identity, and how this may affect coping. UER, upper extremity reconstruction.

provider behavior. Several studies have reported that American patients with tetraplegia are often unaware of UER or have unfavorable impressions of reconstruction.^{22,23} Other work indicates that referring physicians have lower confidence in the benefits of UER than hand surgeons.²⁴ Emerging qualitative research indicates that patients' concerns regarding cost, increased caregiver dependency, and hope for a cure may all be deterrents.^{25–28} However, comparatively less is known regarding how American patients' larger social and functional contexts shape how receptive there are to surgery.^{25,29}

To address this gap, we conducted a multistage qualitative analysis to examine how American patients approach reconstruction. In our initial study we developed a conceptual model that described the minimum conditions (checkpoints) patients had to meet to progress from functional stability (the point at which no further neurologic recovery was expected) to surgery (Fig 1). We reported that the first checkpoint in each participant's pathway was functional dissatisfaction and that the balance of an individual's positive and negative coping behaviors strongly determined whether the individual moved forward. Participants who coped extremely well often did not display enough discontent to trigger a surgical referral, whereas participants who coped extremely poorly lost self-efficacy and became isolated from the mechanisms that could connect them to UER.³⁰ This analysis provided a framework to understand patients' decision making once they had achieved functional stability, but it largely ignored how patients actually improved their physical abilities. Moreover, by examining coping only from the point of functional stability onward, we likely missed aspects of how patients' experiences trying to regain function shape their identities and coping behaviors, thus setting the stage for their first steps toward surgery.

To better understand the interplay among function, identity, and coping, we performed a follow-up analysis to elucidate what elements of recovery patients believe are important to regaining function, the perceived barriers to physical improvement, and how

function contributes to patient identity. We then situate these findings in the context of our first analysis by exploring how the function/identity relationship relates to coping. Together these themes will help delineate how participants' experiences trying to regain function early in recovery can contribute to their surgical context.

Materials and Methods

Study design

This is a secondary analysis of a qualitative retrospective cohort study first performed from August to September 2016. The study was informed by consolidated criteria for reporting qualitative research (COREQ) methodology.^{31,32} Participants provided written informed consent for semistructured interviews and audio recordings. The University of Michigan Institutional Review Board approved this study.

Participants

Participants with C4–C7 cervical spine injuries were deliberately recruited to enroll equal numbers of surgical and nonsurgical participants (purposive sampling). Given the conservative sample size, no additional attempts were made to stratify enrollment based on demographic characteristics or injury patterns. Potential participants who had undergone tendon transfer, tenodesis, or opponenplasty were identified by using *International Classification of Diseases, Ninth Revision* and *Current Procedural Technology* codes to search the medical record. Nonsurgical participants were identified via a contact list from the University of Michigan Department of Physical Medicine and Rehabilitation. Non-English-speaking patients and those younger than age 18 were excluded from the study.

Data collection

A standardized interview guide was developed a priori and pilot tested by 2 interviewers (C.H., resident; J.M., medical student) before study initiation (Appendix 1). Consistent with the iterative and emerging principles of qualitative research (which dictate that preliminary analysis should be conducted as source data are accrued to identify important content areas that then guide future data collection), the interview guide was amended to include new themes after interviews 7 and 12.^{33–35} Participants were instructed to clarify prompts as needed during each interview and offered an opportunity to provide feedback about the quality and comfort of the session at the encounter's conclusion.

Interviews were conducted from September to August, 2016 and lasted between 45 to 120 minutes. Seventeen interviews were conducted in-person at patients' homes or our research center; 2 occurred by phone. Caregivers attended interviews at participants' discretion. All interviews were audio recorded and transcribed verbatim by a member of the research team. Interview delivery was evaluated a second time during transcription; any inconsistencies in interview style or content were reported back to the research team to further standardize each encounter. Interviews continued until no new themes were generated, at which point it was determined conceptual saturation had been achieved.

Analytic rationale

As reported in our initial analysis, participants did not identify a set functional point above which they deemed their abilities acceptable for daily living and below which they consistently opted for reconstruction. Although we did not employ any formal functional testing, both the surgical and nonsurgical groups included participants who reported varying abilities to feed themselves, write, or dress independently during the postinjury period. American Spinal Injury Association (ASIA) grades were also similar between groups. As such, rather than directly comparing surgical and nonsurgical patients, we aimed to define the barriers and facilitators to physical recovery that would ultimately lead to functional dissatisfaction (checkpoint 1). We then examined how function could potentially affect progression to surgery by analyzing the relationship among function, identity, and coping and how this evolves over time.

Data analysis

Grounded theory methodology and constant comparative analysis were used to analyze interview content.^{33,36} Codebook development started with open-coding using QSR Nvivo (Version 11) software (QSR International, Melbourne, Australia). In this process the investigators began by independently coding 4 transcripts to identify key concepts. Transcripts were then compared, and investigators combined important concepts into agreed on themes, codes, and subcodes to create a draft codebook. The 4 transcripts were recoded using the draft codebook, discrepancies were reviewed and resolved, definitions were edited, and the codebook revised. Because qualitative research values diverse outlooks, an additional 4 reviewers were trained in coding techniques and double-coded the first 10 transcripts to minimize researchers' chances of overlooking an important theme. All double-coded transcripts were reviewed during one-on-one meetings with a single investigator (C.H.). Changes were to the codebook were made to reflect previously unidentified concepts and disseminated to the group periodically (Appendix 2). Once there were no discrepancies and no new codes identified, the last 9 transcripts were then coded by the primary investigator (C.H.).

Results

The study sample included 19 individuals with C4–C7 cervical spinal injuries who sustained injuries at least 1 year before interview. Nine participants had undergone reconstruction; 10 had not. The study sample was predominantly male (79%) and white (89%), and ASIA grades A to D were represented. Participant demographic data are summarized in the [Table](#).

Functional facilitators

Rehabilitation emerged as a central theme in participants' perceptions of their functional recovery. All participants reported receiving both inpatient and outpatient rehabilitation, with varying amounts of physical (PT), occupational (OT), and hand therapy. Former athletes often genuinely enjoyed rehabilitation (particularly PT) and welcomed a forum where they could exert themselves. Other participants found rehabilitation to be arduous and painful; however, participants universally acknowledged therapy's importance, regardless of their personal enjoyment level.

As has been found by other researchers, participants in our study reported that motivation was also an important component

Table

Patient demographic data (previously published, *Journal of Hand Surgery*)

Demographic data	Surgery group	Nonsurgery group	Total
Gender			
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
Years from injury			
Mean (median)	9.8 (9)	10.9 (7)	10.2 (8)
Range	2–24	5–37	2–37
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
American Spinal Injury Association (ASIA) Impairment Scale 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
Vocational training	1	1	2
Undergraduate studies	2	5	7
Graduate studies	0	3	3

MVA, motor vehicle accident.



Figure 2. Functional facilitators.

in functional recovery.^{37–39} In the early postinjury period, small physical improvements created positive feedback loops that reinforced participants’ desire to engage in rehabilitation. This effect proved to be more durable in physical rather than in occupational therapy. Although participants largely accepted that their injury level would place a ceiling on their physical capabilities, many stayed motivated to attend PT because they believed it was necessary to maintain strength and prevent backsliding. Several participants cited becoming unable to transfer as evidence of the functional declines that resulted from skipping PT, and these or similar losses convinced them to return to therapy after extended absences and kept them there longer. In contrast, participants found OT to have more finite utility because they believed that the skills gained in OT were less susceptible to decline. After re-learning tasks like dressing or writing during their inpatient stay, certain individuals felt that their day-to-day life was sufficient practice. In the words of one participant, “I don’t need to pay...to have somebody watch me put on a sweatshirt.”

Participants further reported that the patient–therapist relationship not only contributed to their functional gains but also affected the relationship between function and identity. Individuals with little personal connection to their therapist reported more disengagement from rehabilitation, which some felt hindered their physical progress. In contrast, therapists who were personally invested in their patients helped those individuals maintain motivation throughout recovery, which participants believed improved their overall physical abilities. Engaged therapists also aided patients in decoupling function and identity, particularly by lessening participants’ sense that decreased physical abilities meant that their lives were over. In fact, participants stated that therapists helped them to create attainable goals, which prevented them from becoming overwhelmed by physical challenges they faced. In this way, therapists helped participants recognize that they could still craft acceptable identities while simultaneously facilitating positive cycles of improvement and motivation (Fig 2).

Barriers to function

Because most participants viewed access to therapy as the central feature in their functional recovery, the most substantial barriers to functional improvement stemmed from cost and the degree to which insurance helped participants defray costs. Participants had health insurance from multiple sources, including private employer plans, Medicare, Medicaid, and auto insurance-based health care coverage. One patient also received care through Veterans Affairs. There was no obvious relationship between a specific insurance provider and participants’ contentment. Dissatisfied participants felt that insurance limited their function by restricting the amount of rehabilitation they received. Participants reported their strength-maintenance goals were often at odds with insurance companies’ expectations of progress, which sometimes lead to rehabilitation cutoffs. Participants also expressed annoyance that they could not choose how to distribute their rehabilitation sessions but had to attend based on the frequency their insurance company dictated.

Participants who felt that they required rehabilitation beyond that for which their insurance would pay sometimes experienced vicious cycles of poor function. Vulnerable individuals, particularly those whose preinjury jobs required physical strength, had difficulty returning to work. In these cases, disability payments became participants’ main source of income, and to make ends meet, individuals reported restricting everything from food choices to the number of caregiver hours for which they paid. At \$200 to \$450 a session, participants viewed extra PT as a luxury they could not afford. The result was a downward spiral: Poor function lead to meager employment prospects, which limited rehabilitation and lead to poorer function, ultimately eroding participants’ hope for change.

Participants who were able to return to work or school faced fewer financial barriers to rehabilitation but bigger time constraints. Participants working full time reported that their hours

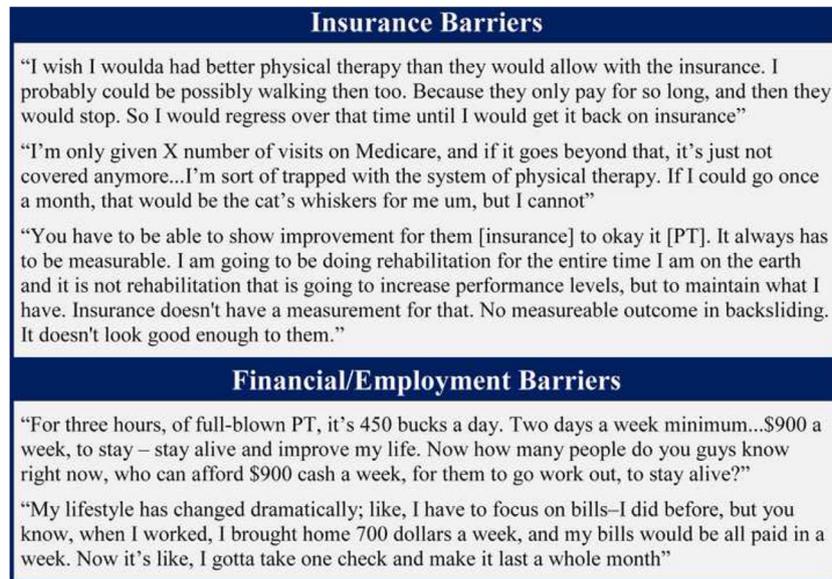


Figure 3. Functional barriers.

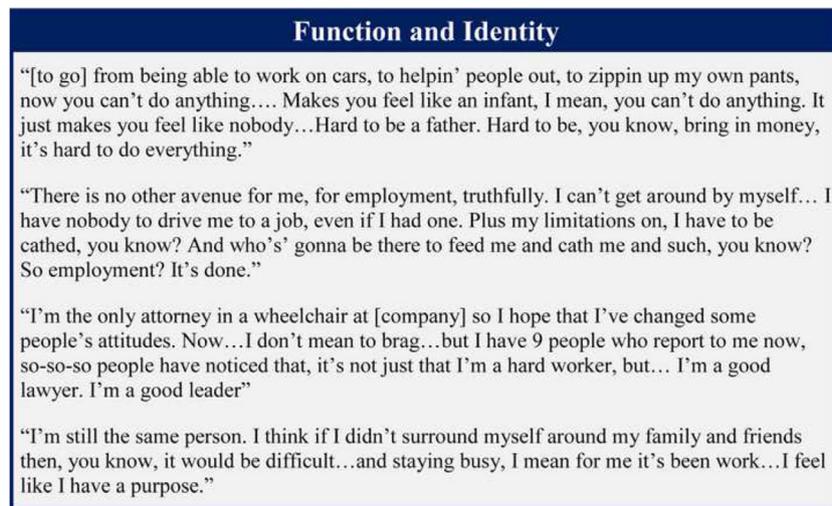


Figure 4. Relationship between function and identity.

limited how often they could attend rehabilitation; others worked part time to accommodate PT. Individuals who were injured as students reported an easier time returning to school than work because academic institutions provided good adaptive support (eg, note takers, accessible buildings). Students could also better accommodate PT because of their flexible schedules. Over time, both students and workers reported that once they reached a functional plateau they increasingly chose to forgo PT or switched to more convenient, home-based routines (Fig 3).

Function and identity

As a corollary to our first analysis, where we reported that participants’ coping depended heavily on their ability to construct a new identity, this analysis found that function and identity were also closely related. Immediate threats to life and intensive treatment during participants’ initial admission tied everyone to a “patient” role. However, for participants with limited function, this identity was difficult to shed even as their medical condition improved. Not only did these individuals have to rely on caregivers’ assistance with hygiene and feeding (which undermined their

sense of self as autonomous and capable individuals), but poor function also affected their positions in their families and communities. Participants reported that their inability to perform routine tasks such as change a diaper or cook undermined their roles as a parents or spouses. Similarly, forced unemployment eroded participants’ self-concepts as breadwinners, ultimately making it more difficult for some to construct a fulfilling identity.

Participants also were highly cognizant of how economic status compounded the impact function had on their identity. Although most participants desired employment, individuals with limited physical abilities did not feel that jobs appropriate for their function existed. Scant economic opportunity then entrenched participants in a patient role. Previously independent participants often had to return to their parents’ homes because they could not afford to live alone. Moreover, without the income to support renovations, participants were not able to modify their homes or vehicles to maximize their existing function, which then further limited their independence and ability to move out of a patient role. Add to this the downward spiral already noted among function, economic opportunity, and rehabilitation access, and the problem only compounded.

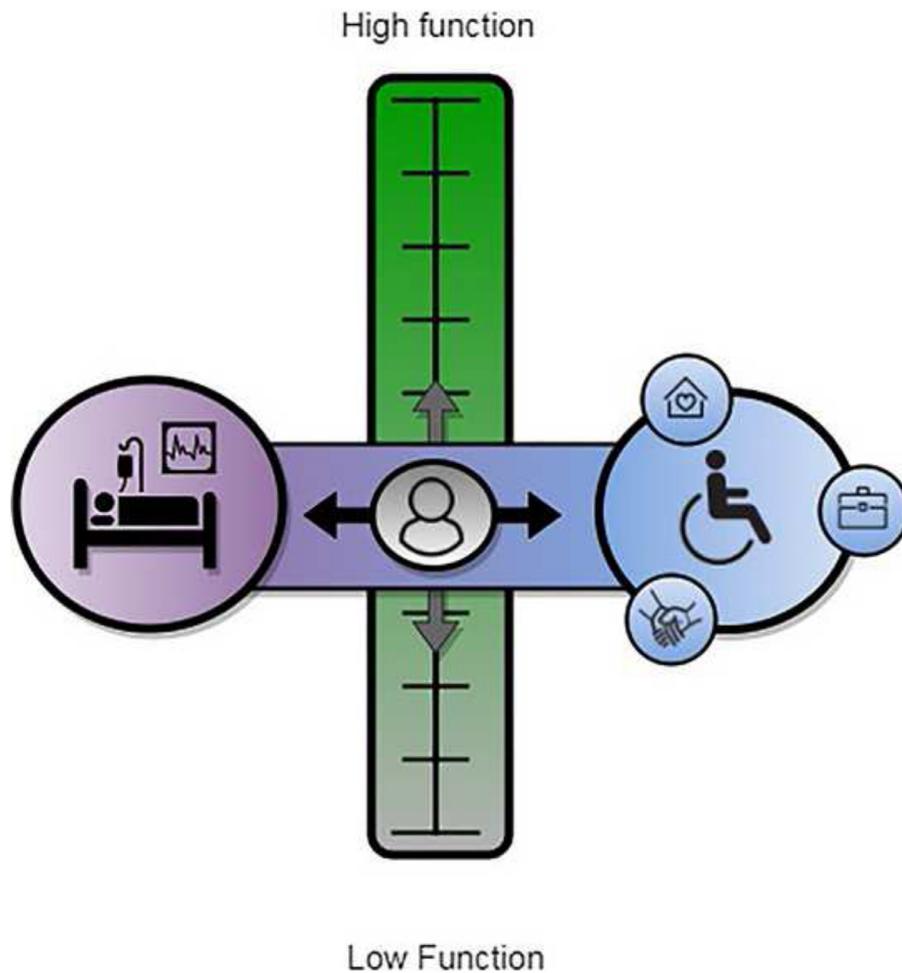


Figure 5. Function and identity spectra.

Evolution Over Time

“I’ve gotten much more functional with using my hands by just needing to accomplish things, so yeah, trial and error, finding things that work, failing, taking it.”

“I think a lot of that, the how often I would see physical therapists largely depended on where I was in life in general. At school, as it kind of shifted towards wanting to do more school, I did less therapy, uh, now, working full-time and having two kids, there’s not a lot of physical therapy time built into my day...”

“I got further out from my initial injury, um, and based on what I read, it sounded like most gains are going to be made closer to when you have your accident... I felt like I wasn’t cheating myself if I dropped off [seeking additional treatment] a little bit, um, that also was a point that coincided with more work opportunities, um and professional development which sort of took precedence”

Figure 6. Evolution of function and identity over time.

In general, participants with enough function to return to work or school reported greater social connections and more satisfaction with their roles. Although greater physical ability did not guarantee participants were able to regain fulfilling identities, employed individuals derived a sense of purpose from their positions and felt that they were able to prove their abilities to the community. Furthermore, participants with greater financial means often did not feel as defined by their physical limitation because they could afford to modify their homes or hire out tasks such as lawn care, which allowed them to retain a sense of autonomy. In fact, in recognition of how important economic independence could be, when asked to give advice to a newly injured person, one par-

ticipant stated, “Pick a profession that’s going to make money!” (Fig 4).

Conceptualizing identity, function, and evolution over time

To better visualize the interaction between function and identity, we suggest picturing each individual’s place on 2 related spectra: high versus low function and strong versus weak patient identity (Fig 5). Our analysis suggests that there is some extent to which individuals move on each axis independently: Participants gain more function as they adapt to their injury and cast off some aspects of the patient role by leaving the hospital. But there is also

a degree to which function and identity are synergistic. As participants' statements indicate, greater physical capability allowed participants to return to work and resume desired roles in their families and communities, whereas cycles of limited rehabilitation, unemployment, and high dependency reported by participants with low function rooted participants in a patient role.

Additionally, there was a degree to which function and identity evolved over time. Early in recovery, participants reported that their function changed as they continued therapy, devised adaptations, and improved neurologically. In other words, their position on the function spectrum fluctuated. Eventually, however, participants appeared to reach a set point around which they made long-term decisions regarding the intensity of their physical therapy, their employment prospects, and the level of caregiver assistance they required. Paralleling this trajectory, their identities also solidified. Although in early recovery participants' identities evolved with their physical capabilities, over time they began to develop norms about the type of parent, spouse, friend, or employee they could be, based in part on their physical ability. Thus their position on the identity spectrum also became fixed (Fig 6).

Discussion

Regaining function is a critical aspect of participants' recovery after spinal cord injury. Accepting the necessity of rehabilitation, experiencing functional gains, and the patient-therapist relationship all kept participants engaged in therapy, which they believed ultimately augmented their physical abilities. Conversely, participants felt that inadequate insurance coverage and high costs hindered their function by limiting their rehabilitation access. Function was closely linked to identity and can be conceptualized as 2 spectra, with participants' position on one axis influencing their place on the other.

Visualizing function and identity in this way facilitates our understanding of patient coping and therefore their relevance to UER. As we discussed previously, the balance of participants' positive and negative coping behaviors strongly influenced their functional dissatisfaction and ultimately progression to surgery.³⁰ If we view participants' responses to their place on the function or identity spectrum as a major component of their coping, it becomes clear that function, identity, and coping are not separate UER benchmarks but related domains that constantly influence each other to shape the context in which individuals progress to surgery.

We can add further nuance to this model by considering the time element. Our results indicate that participants did not leave the hospital with their final positions on either the function or the identity axes set; rather, they continually recalibrated their lives and identity as their function changed. To understand why this is important for UER, we borrow a concept from trauma. R. A. Cowley first introduced the idea of a "golden hour" based on his observation that trauma patients had better survival if they received definitive care within 60 minutes of injury, the tacit principle being that after the golden hour, potentially reversible physiologic processes worsened past the point of cure.⁴⁰ Our findings indicate that a similar phenomenon may occur in participants with tetraplegia. For at least some portion of the time before they become candidates for UER (usually 12 months postinjury, after maximal neurologic recovery has occurred), participants' lives are in flux. During this "golden year" (so termed to indicate a finite period, but which may vary in absolute length by individual) participants' function, roles, and attitudes evolve with their experiences, but as individuals get further out from injury, they settle into routines and belief patterns; their positions on the function/identity axes stabilize.

This stabilization may in turn affect how receptive patients are to surgery. Fundamentally, accepting reconstruction requires that patients believe their function could improve. However, if

individuals develop fixed ideas about who they are and what they can do, they may lack the necessary conviction that their physical status could change and thus the activation to pursue surgery. Furthermore, individuals who successfully transitioned out of a patient role may find the prospect of becoming more dependent, even if just transiently during recovery, especially unappealing. Finally, from a purely practical standpoint, as individuals stabilize medically and physically, they lose contact points with health care providers and decrease their medical information seeking, which further decrease intervention opportunities.⁴¹ Increasing UER use may therefore depend on introducing reconstruction during the golden year before participants' lives are completely reset, even if they are not yet candidates, so that they can appropriately calibrate their expected recovery trajectories and possibly stay open to reconstruction longer.

Our conclusions differ somewhat from the findings of Dunn et al²⁹ in their examination of liminality.²⁹ They reported that although some patients in New Zealand accept reconstruction immediately, others exist in a state of decisional flux, requiring multiple surgical offers before accepting. We also report that participants experienced a period of flux, but this extended only to function and identity, not patients' operative interest, which we suggest declines as participants create norms around their function. Whether these differences stem from differences in care delivery models (introduction to hand surgery is a routine part of rehabilitation in New Zealand, whereas referral is more sporadic and decentralized in the United States^{19,22,26,42}) that change how patients think about reconstruction or represent cultural differences is not well delineated. Prospective studies are needed better quantify how patients' interest in reconstruction changes over time, as well as larger quantitative studies to assess if the sentiments expressed by our participants are borne out in the patterns of reconstruction timing nationally.

This study has several limitations. Participants were recruited primarily from a single geographic region and were predominantly white men, which, although representative of the spinal cord-injured population at our institution, may not reflect the experiences of black or Hispanic patients, who together constitute more than 30% of the US spinal cord-injured population.⁴³ Moreover, the surgical and nonsurgical groups were not identical: The surgical group contained more individuals with injuries at C5 or higher, fewer college-educated members, and more women. Although previous research found that women actually may be more reluctant to have surgery because of concerns regarding increased caregiver dependency during recovery, this imbalance may have unintentionally biased our results.²⁵ In addition, because of "no-fault" state laws, auto insurance covered many participants' medical expenses. Participants in states with different policies may differ substantially in the amount or type of coverage they can receive.

Because our goal was to highlight important conceptual themes, we relied on patient self-report of function rather than empiric measurements; we did not formally correlate participants' perceived function with ASIA grade or cervical spine level. Participants' willingness to participate in the study may also be indicative of higher baseline engagement than exists in the general tetraplegia population. Because most participants were more than 10 years out from injury, they may also have had substantial recall biases that affected how they viewed their function, identity, or general functional satisfaction.

Finally, although this conceptual framework is built on statements from a small and highly specific population, it likely has relevance to multiple areas of surgery. Many complex operations result in prolonged rehabilitation during which patients must work to regain function and adjust their identities. Using the function or identity spectra to conceptualize patients' progress and relate it to their coping may help surgeons better understand their

patients' broader context. Ultimately, building a more complete picture of individuals' experiences can help foster a patient-centered approach that surgeons can leverage to improve care.

In conclusion, function and identity are related domains that make up critical aspects of early recovery and shape participants' initial surgical context through their impact on coping. During the golden year, participants' function and identity evolve with each other; however, both eventually reach a fixed point around which patients build their lives. How satisfied patients are with these positions then directly affects how they cope with their injury and thus builds part of the context in which they make decisions about reconstruction.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.surg.2018.07.009.

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