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Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study

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Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study

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“Back Into Life”: Adherence Experience

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Disclaimer
The authors have no financial relationships to disclose relevant to this manuscript.
The views expressed herein are those of the authors and do not reflect the official policy or position of Brooke Army Medical Center, the U.S. Army Medical Department, the U.S. Army Office of the Surgeon General, the Department of the Army, the Department of Defense or the U.S. Government.
“Back into Life”: Adherence Experience

1 Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study
2
3 ABSTRACT
4
5 Objective: The purpose of this phenomenological study was to describe the rehabilitation
6 experiences, expectations, and treatment adherence of patients receiving Upper Extremity (UE)
7 rehabilitation, who demonstrated discrepancy between functional gains and overall
8 improvement.
9
10 Design: Qualitative (phenomenological) interviews and analysis.
11
12 Setting: Outpatient UE rehabilitation.
13
14 Participants: Ten patients with acute UE injuries.
15
16 Interventions: Not applicable.
17
18 Main Outcome Measure: Concerns related to UE rehabilitation patients demonstrating
19 discrepancy between outcome measures.
20
21 Results: Five key themes emerged from the interviews of patients demonstrating discrepancy in
22 their self-reported patient outcomes; 1) Desire to return to normal, 2) Initial anticipation of brief
23 recovery, 3) Trust of therapist, 4) Can’t stop living, 5) Feelings of ambivalence. Challenges
24 included living with the desire to move back into life. Multiple factors affected patient
25 adherence: Cost of treatment, patient-provider relationship, (difference between therapist and
patient understanding on what is important for treatment), Patients expected the treating therapists to be an expert and fix the patient’s problem.

**Conclusions**: Patient adherence to UE rehabilitation presents many challenges. Patients view themselves as laypersons, and seek the knowledge of a dedicated therapist who they trust, to spend time with them to understand what they value as important, and clarify their injury, and collaboratively make goals, and explain the intervention to get them in essence, “back into life,” in the minimal required time. When categorized according to the World Health Organization's Multidimensional Adherence Model, domains identified in this model include social and economic, health-care team and system, condition-related, therapy-related, and patient-related dimensions. Assessing factors identified to improve efficiency and effectiveness of clinical management can enhance patient adherence.

**Keywords**: Compliance, Upper Extremity; Rehabilitation; Qualitative Research; Patient Satisfaction

**List of abbreviations**

- GROC  Global Rating of Change Scale
- MAM  Multidimensional Adherence Model
- QDASH  Quick Disabilities of the Arm, Shoulder, and Hand
- UE  Upper extremity
- WHO  World Health Organization
Non-adherence to acute upper extremity (UE) rehabilitation programs has a negative effect on outcomes and healthcare costs.\(^1\) The term adherence implies an “active, voluntary, and collaborative involvement by the patient in a mutually acceptable course of behavior to produce a preventative or therapeutic result.”\(^2,3\) In 2003, the World Health Organization (WHO) reviewed the worldwide adherence evidence and created the Multidimensional Adherence Model (MAM) (fig 1).\(^4\) Key predictors of adherence were multifactorial and were grouped into five interdependent dimensions: patient-related, condition, socioeconomic, healthcare systems, and therapy-related. Patient adherence is often merely around 50%.\(^3\) Clinicians have control over therapy-related factors, and perhaps to lesser extent, patient-related factors. Therapists could do more to promote patient adherence as clinicians can influence patient beliefs and motivations through skilled therapeutic intervention.

Patient-reported outcome measures are frequently used in UE rehabilitation practice,\(^5\) and are often a means for clinicians to gauge health status or outcome. A discrepancy in treatment outcomes may be indicative of the patient’s dissatisfaction with treatment. In acute UE rehabilitation, two typical patient-reported outcome measures are the Quick Disabilities of the Arm Shoulder and Hand (QDASH),\(^6\) a measure of physical function, and the Global Rating of Change (GROC),\(^7\) a scale of overall improvement. The 11-point QDASH provides a Likert scale with a score of 100% indicating the most disability. The 15-point GROC quantifies the patient’s perceived change over time. Both the QDASH and the GROC have been found valid and reliable.\(^7,6,8\) While it is common to administer both the QDASH and the GROC to patients in UE rehabilitation, a perfect correlation between the two instruments would not be expected given that the two instruments have some different constructs.\(^9\) Nevertheless, it is reasonable to expect
if one instrument shows patient progress, the other instrument should do the same. This concept may be compounded by the fact that on occasion, a therapist sees improvements in a patient via objective measures (e.g. strength, range of motion, etc.), and these are supported by the subjective measures of the QDASH, but not on the more general GROC measure. The discrepancy between measures could be indicative of the patient’s level of dissatisfaction with treatment outcomes, which in turn may affect the patient’s decision to continue to adhere to treatment recommendations made by the therapist.

Exploring the lived experience of patients who demonstrate a discrepancy between their level of function and perceived overall sense of improvement in hand therapy will help clinicians and researchers identify factors that impact the patient’s decision to adhere to acute UE rehabilitation. Adherence may include attendance, participating in therapist prescribed home programs, and following precautions. Therefore, the purpose of this qualitative study was to describe the rehabilitation experiences and expectations of patients who demonstrated a discrepancy between their functional gains and overall improvement, as well as their decisions to adhere with their treatment plan.

METHODS

Phenomenology was selected as the study design because it is best used to describe the perspectives of a group of individuals who have all experienced the same phenomena; in this case, discrepancy between functional gains and overall improvement. This has not been
previously described in the literature. This study was conducted in an outpatient hand therapy clinic in the East South-central region of the US that primarily sees patients with acute UE conditions. The Institutional Review Boards of two local universities approved human experimentation. This study fulfilled part of the doctoral degree requirements for the first author.

**Sampling**

Our purposive sample of acute UE rehabilitation patients met inclusion criteria of (a) 18 to 89 years of age, (b) a discrepancy between QDASH and GROC scores, (c) able to communicate in English, and (d) able to provide informed consent. All patients were routinely administered the QDASH upon initial evaluation, and the QDASH and the GROC forms on every fourth visit. We chose to explore the experience of individuals who reported functional gains in their QDASH outcome measure, but indicated not perceiving improvements in therapy on their GROC. An administrator identified weekly potential candidates from an electronic file who met discrepancy criteria and informed the treating therapists. The therapists contacted patients who met inclusion criteria to volunteer for the study and informed the primary investigator who did not work at the clinic. Participants were enrolled as soon as identified in treatment. Ten participants took part in the study and saturation was obtained with a redundancy in themes.

**Data Collection**
Data were collected over six months. Face-to-face interviews were completed in a private room in the clinic. Written informed consent was obtained before the interview was conducted. The male primary investigator interviewed all participants, using a piloted semi-structured interview protocol fashioned for this study. Interview questions elicited participants’ responses based on their thoughts and beliefs regarding their treatment progress and their desire to adhere to the treatment program. The intent was to interview patients while they were still receiving therapy as the nature of discrepancy was fluid and multiple factors could cause change over time. Questions were open-ended to allow for emerging-themes throughout the interview process (appendix 1). Each participant interview lasted approximately one hour, was audiotaped, and transcribed verbatim. Interviews proceeded until no new information emerged.

Data Analysis

HyperRESEACH 3.5.2 was utilized to facilitate data management and analysis. All transcriptions were checked for accuracy by the second author, advising professor. The analysis was guided by Colaizzi’s phenomenological method. Following this method, all written transcripts were read several times to gain an overall feeling for them. Significant phrases were selected from each transcript that directly explained the lived experience of individuals demonstrating discrepancy. The process of horizontalization was then conducted whereby each expression was given equal weight and labeled. Repetitions were eliminated from the list. The third step was to formulate general meanings for each significant statement. Clusters of themes were formed from the formulated meanings allowing for the emergence of themes common to all of the participants’
transcripts and flow charts were utilized to obtain a graphical representation. Following this, the resulting ideas were integrated into an in-depth, exhaustive description of the phenomenon, known as the essence. In the final step, after obtaining the descriptions and themes, the researcher approached interviewees with the exhaustive description by e-mail and phone interviews for validation in the form of member checking. All participants who responded (7/10) agreed with the description and there were no additional data. In addition to member checking, audit trail and frequent peer review were utilized to promote trustworthiness. Furthermore, throughout the study the primary investigator performed “epoch,” or bracketing through written memos, reflections and discussions with his research advisor of his personal biases and assumptions as a certified hand therapist, who had previously observed the phenomena of outcome measure discrepancy in hand therapy practice.

RESULTS

A purposive sample of 4 men and 6 women (n=10) was recruited. Participants were predominantly white (80%). Ages ranged from 21 to 66 years, with an average age of 49 years, (SD=16.5). The length of time in therapy averaged 9 ± 5 weeks ranging from 4 -18 weeks, (see table 1). From 289 codes we derived 151 significant statements. These led to 59 formulated meanings, 12 clusters of themes, and five key themes, which are described below using direct quotations as support.

Desire to Return to Normal


The perceived ability to return to normal was a strong determinant for participant adherence. Patients were less inclined to adhere to treatment if they did not perceive some level of normalcy was attainable. Participants wanted to return to normal, usually comparing their injured limb to their non-involved side. They commented about wanting to return to prior functional level for activities such as work, driving, or playing the guitar. This was evident by the following comments from participants: “to be able to use my hand like I didn’t have the accident. To be back to normal” [C] and “I would like to be back the way I was, not having to wear a brace, and, not having to protect it, and think about it anymore” [F]. Participants defined rehabilitation success in terms of their body functions returning to normal, such as recovering strength, sensation, or motions such as “making a fist”, “getting rid of numbness and tingling,” or “having less pain.” They also described success as returning to functional activities such as “wash dishes,” “have a legible signature” and “balance a check book.” One woman indicated, “Typing and writing… I couldn’t write, ‘cause I couldn’t grip a pen, I’m just getting back to where I can do that” [D].

Initial Anticipation of a Brief Recovery

The realization of a lengthy recovery added to the participant’s understanding of the need to adhere to the treatment in order to have success. Participants initially assumed they would have a brief recovery. The majority of the respondents viewed healing as a slow process, “It’s kind of
long, it’s a slow process, but anything out there is going to be a little slow. You do it overnight, (referring to the injury), but it doesn’t heal overnight” [A]. They often first learned from their doctor or therapist about the lengthy recovery process. Understanding that the recovery process would be slow led the participant to seek therapist expertise. “I am used to something happening, getting over it, and going on. But it’s going to take time. So I’m looking for a [therapist] to guide me and work with [the therapist’s] expertise” [F]. Collaboration evolved as being important to the participants’ perspectives of anticipating a brief recovery. They expected collaboration with their therapist to establish goals: “Well, first off, I think the goals of your therapist, plus if the therapist and the patient work together as a unit” [G]. Participants understood their role as a team member in shortening the length of their recovery process: “You have to follow through with what they want you to do” [A].

Trust of Therapist

Participants described therapists as either dedicated or non-dedicated, and the level of dedication impacted their adherence. Greater patient perceived therapist dedication led to better patient adherence. Patients wanted to trust their therapists to get them back to regular activities. Participants viewed themselves as laypersons, expecting professional guidance from their therapists and mistrusted them if therapists did not provide full concern expressed as giving “100 percent” of themselves. The issue of trust emerged when several of the participants reflected about therapists they had worked with in the past. They were able to compare therapists, indicating: “Not all therapists/rehabs are created equal” [H]. One 66-year-old female stated: “I
was trusting the therapist to know what they should have done to have gotten me back to a
normal life, and in essence, that therapist…what’s the word…[pause], actually denied me a full
recovery, because I am still, seven years down the road, they’ve taken the money, and I’m still
not able to do the things that [I] used to be able to do” [F]. Some respondents expressed feelings
of mistrust about the therapist’s abilities: “But, I’m sure they get a little self-satisfaction from
being able to help somebody, and what they think they can do may be a lot more than what I
think they can do” [C]. Among the qualities of a dedicated therapist participants valued, was the
clinician’s ability to research and provide other opinions to assist with care.

Can’t Stop Living

Participants valued rehabilitation, but reflected it was not possible to devote all time and effort to
the process. Daily life did not stop. One participant indicated limited time to dedicate to a home
program: “If I had an ideal amount of time we could go faster, but you know in reality, I can’t
spend all day doing these exercises, and wearing this stuff, because I have a life I have to live”
[C]. Another described the challenges of engaging in work and normal activities while wearing a
brace: “Still having to do things even with the brace on…whatever I can do with the brace on,
that’s what I do…My biggest problem is, I have to continue working and the rehab dictates that I
should not work. So, that’s the biggest conflict. I have to make a living, I have to keep going and
they want to shut it down” [J]. Time devoted to rehabilitation often conflicted with daily routine.
One participant described the challenge of time management: “First thing catch the bus and come
out here, then go back to the transfer center and catch another bus to go back to [the nursing
While participants wanted to engage in therapy, they could not stop living their daily life to accommodate rehabilitation.

**Feelings of Ambivalence**

Participants conveyed feelings of ambivalence about several aspects of the rehabilitation process, which impacted their recovery. For some participants these feelings were maladaptive, negatively impacting adherence to treatment. This ambivalence was expressed in their beliefs about their illness: “I think I’m screwed all the way around. I don’t think it’s ever going to get better, to be honest. I’m just coming here because the insurance says that I have to. I don’t think it’s ever going to get better…” [C]. Others believed they had the wrong diagnosis: “I’m still wondering if there is anything that he missed… A sprain you get over it a couple weeks or so…this is something else” [F]. For others, feelings of ambivalence were adaptive positively impacting adherence. Another participant acknowledged feelings of ambivalence as he compared himself to others in a group treatment. On one hand, he gained motivation from the realization that his injury was less severe than the other patients, but felt guilty for thinking this. On the flip side, he expressed satisfaction at seeing other patients succeed at discharge, even when he was still in therapy: “It helps, anytime I think I am bad off there's always someone, that's unfortunate, but there is always someone who's worse off than me...I guess really the camaraderie, being around other people who are injured, and seeing people succeed. I call that getting paroled when people have been here so long… you know what I mean” [K].
DISCUSSION

The findings of this study address a gap in our understanding of how patients experience the discrepancy of making functional gains in therapy while perceiving not making progress in rehabilitation. These findings shed light on the factors affecting the participant’s decisions to adhere to rehabilitation. Patient adherence is complex and involves multiple factors beyond the patient’s decision of simply following through with treatment. The WHO MAM\(^*\) provides a framework for understanding how the themes that emerged in our study relate to the complexity of patient adherence to UE rehabilitation. When categorized using the World Health’s Organization MAM (see table 2), the themes fell into all five dimensions of socioeconomic, healthcare systems, condition-related, therapy-related, and patient-related.

In this study, socioeconomic factors had an impact on adherence, which is consistent with the literature.\(^*\) Some participants mentioned the cost of treatment as an adherence modifier because paying the bills took priority over home programs. Another indicated that to adhere to treatment recommendations they would have to not work. For another participant who was a bus rider, having more efficient modes of transportation could have greatly eased the time constraints that impacted adherence. Clinicians should acknowledge patient financial investment, and design programs that do not compete with work schedules.

The therapist working as a liaison for the patient among other medical specialties was viewed as a positive determinant of adherence. This result was consistent with results found by others, who...
found availability of support was a positive determinant of adherence. Most participants experienced a longer than anticipated duration of treatment, yet it played a positive role on adherence by motivating them to continue to seek professional help. In contrast, some participants needed to see an immediate benefit with their results, in order to adhere to treatment. A patient’s motivation to adhere to prescribed treatment may be influenced by the value this person place on following the regimen and the degree of confidence in being able to follow it. Therapists can set as goals to increase the patient’s perceived importance of adherence by building on his or her intrinsic motivation, and strengthening confidence by building self-management skills. In our study, factors that negatively affected patient adherence were ambivalence and lack of understanding about their condition, as well as negative beliefs regarding the efficacy of treatment and illness. Sluijs found similar results where a bad prognosis was related to non-adherence. In our study, time spent with a therapist, communication and interpersonal style of the therapist, and the patient-provider relationship were all adherence determinants. This was true particularly related to the issue of trust. Consistently, others have found that patients need to perceive that their clinician listens, understands and appreciates their suffering. The clinician–patient relationship is one of the most important predictors of adherence to medical treatment, patient satisfaction, and overall treatment success. Nonetheless, the current healthcare system and reimbursement may limit the individualized time a therapist can spend with a patient. The demands for therapists to maintain high productivity levels and incorporate insurance requirements appear to increase each year. Therapists can maximize time spent with the patient by explaining the benefits of the treatment intervention and incorporating the patient’s wants into
their treatment plan.

The patient discrepancy between the QDASH and GROC forms could be explained by factors such as the slow rate of healing progression and the participants’ desired treatment emphasis. For example, one participant’s focus was on sensory return whereas the therapist’s emphasis was on progressive motor/strength return. This finding highlights the importance of early discussion about the focus of intervention and expectation of the rate of recovery. In our study, the length and complexity of treatment inhibited participation in normal daily life. For instance, some participants felt orthosis wear and home exercises were cumbersome and interfered with their lifestyle, negatively affecting adherence. Likewise, in a study of patients undergoing distraction treatment for complex finger fractures, the most significant influence on adherence were perceived complexity of treatment, and interference with the completion of daily occupations: productivity, self-care, and leisure. In our study, contrary to anticipated, participants who experienced previous treatment failures at another treatment facility were motivated by their new therapist, which had a positive effect on adherence. The new therapists used a more holistic approach to the intervention by not focusing on a particular body structure, but rather looking at the individual as a whole. This method was consistent with the biopsychosocial model by accounting for the person within the disease.

**Study Limitations**
This sample represents individuals seeking UE rehabilitation from a single outpatient hand therapy clinic in the East South-central region of the United States over a period of six months, so findings are not expected to be generalizable to all hand therapy settings. These findings can be applied to other hand therapy patients with similar characteristics. Readers should consider if their patient population is similar in order to transfer findings.

Conclusions

Patients expected to have a dedicated therapist who they could trust to work collaboratively with them to establish goals and spend time with them to achieve them. The therapist and patient’s perception may differ substantially on what is a clinically important change, and on what is a reasonable expectation for home regimen. Early clarification on the rate of recovery may improve patient adherence. Having an early candid discussion, eliciting the patient’s wants and needs could help clarify patient-therapist differences. The majority of patients expected to quickly return to normal and regain full function. The treatment complexity played a role on the patient’s decision to adhere to the program. Therapists can negotiate realistic goals with patients by discussing cost-benefit scenarios of adhering to the treatment program, while advising the patient of pitfalls of non-adherence. When patients’ exhibit a discrepancy in patient reported outcomes, the therapist should listen to patients with empathy in order to build trust and establish a patient-centered approach to the intervention.
References


“Back into Life”: Adherence Experience

Figure Legends

Fig 1 The World Health Organization Multidimensional Adherence Model.


Table 1 Participant Demographics.

Table 2 Findings associated with the World Health Organization's Multidimensional Adherence Model.
Table 1  Participant Demographics.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Gender</th>
<th>Age</th>
<th>Injury to Dominant Hand</th>
<th>Mechanism</th>
<th>Ethnicity</th>
<th>Weeks in Treatment</th>
<th>Occupation</th>
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<tbody>
<tr>
<td>A</td>
<td>F</td>
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<td>No</td>
<td>Laceration</td>
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<tr>
<td>C</td>
<td>M</td>
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<td>No</td>
<td>Crush</td>
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<td>Factory</td>
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<tr>
<td>D</td>
<td>F</td>
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<tr>
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<td>F</td>
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<td>Fall</td>
<td>African American</td>
<td>8</td>
<td>Homemaker</td>
</tr>
<tr>
<td>F</td>
<td>F</td>
<td>66</td>
<td>No</td>
<td>Fall</td>
<td>White</td>
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<td>Clerical</td>
</tr>
<tr>
<td>G</td>
<td>F</td>
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<td>Ball Sport</td>
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<tr>
<td>H</td>
<td>M</td>
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<td>Cumulative Trauma</td>
<td>African American</td>
<td>6</td>
<td>Service</td>
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<td>K</td>
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<td>Yes</td>
<td>Crush</td>
<td>White</td>
<td>18</td>
<td>Service</td>
</tr>
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</table>
Table 2  Findings associated with the World Health Organization's Multidimensional Adherence Model.

<table>
<thead>
<tr>
<th>MAM Dimension and system</th>
<th>Related Factor</th>
<th>Finding associated with adherence</th>
<th>Participant Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and economic</td>
<td>Long distance from treatment center</td>
<td>Can’t stop living because of injury or rehabilitation</td>
<td>“First thing, catch the bus and come out here...” [E]</td>
</tr>
<tr>
<td></td>
<td>Cost of treatment</td>
<td>Can’t stop living because of injury or rehabilitation</td>
<td>“You’ve got to pay the bills, you got to live life. You can’t stop because you got hurt.”[C]</td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td>Feelings of ambivalence of comparisons to others</td>
<td>“It helps, anytime I think I am bad off there’s always... someone who’s worse off than me... I guess really the camaraderie, being around other people who are injured, and seeing people succeed.” [K]</td>
</tr>
<tr>
<td>Health-care team and system</td>
<td>Patient provider relationship</td>
<td>Trust of therapist impacts recovery</td>
<td>“Yeah, you put a lot of trust in a therapist...”[F]</td>
</tr>
<tr>
<td></td>
<td>Time spent with therapist</td>
<td>Non-dedicated therapist</td>
<td>“They instruct you to do an exercise and then they walk away. They’re very impersonal” [J]</td>
</tr>
<tr>
<td></td>
<td>Communication style of therapist</td>
<td>Collaboration (between patient and therapist)</td>
<td>“Well, first off, I think the goals of your therapist, plus if the therapist and the patient work together as a unit.” [G]</td>
</tr>
<tr>
<td></td>
<td>Interpersonal style of therapist</td>
<td>Dedicated therapist (establishes rapport)</td>
<td>“Having somebody that understands first of all what your goal is, and how to get you there, that is the support thing. [G]</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge &amp; training of therapist</td>
<td>Non-dedicated therapist</td>
<td>“We have several tests and that is not a tore rotator cuff, but they are treating me for it, and [the therapist] says there is nothing we can do” [H]</td>
</tr>
<tr>
<td>Condition-related</td>
<td>Prognosis</td>
<td>Desire to return to normal</td>
<td>“Yeah, regaining everything...You want it to come right back.” [D]</td>
</tr>
<tr>
<td></td>
<td>Rate of progression (difference between therapist and patient understanding on what is minimally important)</td>
<td>Feelings of ambivalence about factors important for treatment success</td>
<td>“[My therapist] is excited when I get strength, when [my therapist] measures the strength I have in my hand. Whereas, I want feelings...” [B]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“A little, but, a little bit doesn’t help me hold that wrench any better...” [C]</td>
</tr>
<tr>
<td><strong>Therapy-related</strong></td>
<td>Complexity of treatment</td>
<td>Can’t stop living because of injury or rehabilitation</td>
<td></td>
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<tr>
<td></td>
<td>Duration of treatment</td>
<td>Anticipation of a brief recovery</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Interference with lifestyle/activities of daily living/ work</td>
<td>Can’t stop living because of injury or rehabilitation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Immediacy of benefit</td>
<td>Feelings of ambivalence about factors important for treatment success</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previous treatment failures</td>
<td>Trust of therapist impacts recovery</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Availability of medical support</td>
<td>Dedicated therapist (liaison)</td>
<td></td>
</tr>
<tr>
<td><strong>Patient-related</strong></td>
<td>Psychological factors: Low motivation</td>
<td>Feelings of ambivalence of comparisons to others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of understanding of the condition</td>
<td>Ambivalence in their beliefs about their illness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative beliefs regarding the efficacy of treatment</td>
<td>Ambivalence in their beliefs about their illness</td>
<td></td>
</tr>
</tbody>
</table>

"I can’t spend all day doing these exercises, and wearing this stuff, because I have a life I have to live." [C]

"You do it overnight, but it doesn’t heal overnight.” [A]

"I have to make a living, I have to keep going and they want to shut it down.” [J]

"If I can’t make a fist, I’m wasting my time." [C]

[The current therapist] focuses on everything. Which has helped, just looking on the elbow, wasn’t getting anything accomplished.” [G]

"[The therapist] has done a lot of research and tried to get other opinions regarding what to do” [G]

"There is always someone who’s worse off than me. It’s kind of a realization; don’t kick yourself in the butt because it could be worse” [K]

“I’m still wondering if there is anything that he missed… A sprain you get over it a couple weeks or so…this is something else. A sprain with some kind of, something else with it.” [F]

"I think I’m screwed all the way around." [C]
Fig 1 The World Health Organization Multidimensional Adherence Model.
Appendix 1 Interview Guide and Corresponding Prompts

- How do you rate success with rehabilitation? Tell me more.
- How did your results in rehabilitation compare to your success criteria? Tell me more.
- Do you feel your criteria to measure rehabilitation success was similar to that of your therapist? Tell me more.
- Do you feel as though your needs are being heard and addressed in rehabilitation? Tell me more.
- What do/did you consider the most important component of your rehabilitation process? Tell me more.
- What do you consider as limitations/barriers in seeking and complying with upper extremity rehabilitation? Tell me more.
- What do you value most of your rehabilitation experience? Tell me more.
- Were those expectations met? Why or why not?

Note: since this was a semi-structured interview, additional questions could arise resulting from responses given by participants. However, the above questions were asked to all participants.
Supplemental Appendix S1 Essence (Deep Analysis): Representative Examples

Following Colaizzi’s phenomenological analysis, from 289 codes we derived 151 significant statements. These led to 59 formulated meanings, providing 12 clusters of themes, yielding five common key themes and seven sub-themes, resulting in one essence “Back into life.”

Back Into Life

The essence that emerged from the data was an overall picture of the participant’s incongruence represented in a desire to move “back into life.”

1. The following descriptions illustrate the patient’s desire to collaborate with a trusted therapist.

   Trust in the therapist was a major factor affecting the patient’s incongruence. Patients sought the knowledge of a dedicated therapist they could trust. Patients quickly realized if the therapist was into their care or not. When the patient perceived the therapist did not to care, patients tended to not follow through with therapeutic instruction. Patients were able to identify and contrast characteristics of a dedicated and a non-dedicated therapist. Dedicated therapists were described using positive attributes such as “intuitive,” “adept,” “personal,” having a good “work ethic,” “wanting their patient to succeed,” “spending time with the patient,” to “listening to patient goals,” and establishing an accurate diagnosis and treatment plan.

   One participant explained that her current therapist: “Actually takes the time to get to know you, to get to know your goals, to get to know what you want, what you need, and takes the time to learn your body. It’s not any one-size-fits-all treatment. It’s tailored to you and your specific needs, and goals from the therapy and what you hope to accomplish” [G].

Non-dedicated therapists were described as impersonal and unprofessional. Another participant thought a therapist took payment for therapy but did not spend time with him to ensure his
success: “They instruct you to do an exercise and then they walk away. They don't stay with you to make sure that you're staying on task. They’re very impersonal” [J]. Another described unprofessional behaviors: “When the physical therapist is just there jabbering with somebody else, or they are there to just spend the day, and get a patient in and out, and they don’t take the interest, I don’t feel they have succeeded that patient…” [F].

2. Some respondents explained their incongruence by identifying feelings of ambivalence represented in the perceived dissonance between their views on factors considered important for treatment success and those of their therapists. This is in addition to the previously mentioned feelings of ambivalence in their beliefs about their illness or comparing themselves with other group members.

For example, one participant described the inconsistency between views of what was important for treatment success: “[My therapist] is excited when I get strength, when [my therapist] measures the strength I have in my hand. Whereas, I want feelings…” [B], referring to the sensory return in her hand. Another respondent expressed some ambivalence toward incremental gains made in therapy: “A little, but, a little bit doesn’t help me hold that wrench any better…They feel better about these things, they had some progress… but, in reality, that progress isn’t squat, unless I can make a fist, and get back to normal” [C].

“Back into life” represented being able to return to prior function, to physically accomplish tasks, and to return to work or sports. Participants viewed themselves as laymen and sought the knowledge of a dedicated therapist who they trusted to spend enough time with them, understood what they valued as important, treated their injury, collaboratively made goals, and explained the intervention to help them return to their routine, in the minimal required time. Moving “back into
Life” was influenced by a variety of factors that affected participant adherence to the rehabilitation process.