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Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study

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20 requirements for the first author.

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31

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37 U.S. Government.

1 **Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study**

2

3

4 **ABSTRACT**

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 **Design:** Qualitative (phenomenological) interviews and analysis.

10 **Setting:** Outpatient UE rehabilitation.

11 **Participants:** Ten patients with acute UE injuries.

12 **Interventions:** Not applicable.

13 **Main Outcome Measure:** Concerns related to UE rehabilitation patients demonstrating
14 discrepancy between outcome measures.

15 **Results:** Five key themes emerged from the interviews of patients demonstrating discrepancy in
16 their self-reported patient outcomes; 1) Desire to return to normal, 2) Initial anticipation of brief
17 recovery, 3) Trust of therapist, 4) Can't stop living, 5) Feelings of ambivalence. Challenges
18 included living with the desire to move back into life. Multiple factors affected patient
19 adherence: Cost of treatment, patient-provider relationship, (difference between therapist and

20 patient understanding on what is important for treatment), Patients expected the treating
21 therapists to be an expert and fix the patient’s problem.

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

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

33

34 **List of abbreviations**

35	GROC	Global Rating of Change Scale
36	MAM	Multidimensional Adherence Model
37	QDASH	Quick Disabilities of the Arm, Shoulder, and Hand
38	UE	Upper extremity
39	WHO	World Health Organization

40

41 Non-adherence to acute upper extremity (UE) rehabilitation programs has a negative effect on
42 outcomes and healthcare costs.¹ The term adherence implies an "active, voluntary, and
43 collaborative involvement by the patient in a mutually acceptable course of behavior to produce
44 a preventative or therapeutic result."^{2,3} In 2003, the World Health Organization (WHO) reviewed
45 the worldwide adherence evidence and created the *Multidimensional Adherence Model* (MAM)
46 (fig 1).⁴ Key predictors of adherence were multifactorial and were grouped into five
47 interdependent dimensions: patient-related, condition, socioeconomic, healthcare systems, and
48 therapy-related. Patient adherence is often merely around 50%.³ Clinicians have control over
49 therapy-related factors, and perhaps to lesser extent, patient-related factors. Therapists could do
50 more to promote patient adherence as clinicians can influence patient beliefs and motivations
51 through skilled therapeutic intervention.

52
53 Patient-reported outcome measures are frequently used in UE rehabilitation practice,⁵ and are
54 often a means for clinicians to gauge health status or outcome. A discrepancy in treatment
55 outcomes may be indicative of the patient's dissatisfaction with treatment. In acute UE
56 rehabilitation, two typical patient-reported outcome measures are the Quick Disabilities of the
57 Arm Shoulder and Hand (QDASH),⁶ a measure of physical function, and the Global Rating of
58 Change (GROC),⁷ a scale of overall improvement. The 11-point QDASH provides a Likert scale
59 with a score of 100% indicating the most disability. The 15-point GROC quantifies the patient's
60 perceived change over time. Both the QDASH and the GROC have been found valid and
61 reliable.^{7,6,8} While it is common to administer both the QDASH and the GROC to patients in UE
62 rehabilitation, a perfect correlation between the two instruments would not be expected given
63 that the two instruments have some different constructs.⁹ Nevertheless, it is reasonable to expect

64 if one instrument shows patient progress, the other instrument should do the same. This concept
65 may be compounded by the fact that on occasion, a therapist sees improvements in a patient via
66 objective measures (e.g. strength, range of motion, etc.), and these are supported by the
67 subjective measures of the QDASH, but not on the more general GROCC measure. The
68 discrepancy between measures could be indicative of the patient’s level of dissatisfaction with
69 treatment outcomes, which in turn may affect the patient’s decision to continue to adhere to
70 treatment recommendations made by the therapist.

71

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

80

81 **METHODS**

82

83

84 Phenomenology was selected as the study design because it is best used to describe the
85 perspectives of a group of individuals who have all experienced the same phenomena;¹⁰ in this
86 case, discrepancy between functional gains and overall improvement. This has not been

87 previously described in the literature. This study was conducted in an outpatient hand therapy
88 clinic in the East South-central region of the US that primarily sees patients with acute UE
89 conditions. The Institutional Review Boards of two local universities approved human
90 experimentation. This study fulfilled part of the doctoral degree requirements for the first author.

91

92 **Sampling**

93

94

95 Our purposive sample of acute UE rehabilitation patients met inclusion criteria of (a) 18 to 89
96 years of age, (b) a discrepancy between QDASH and GROC scores, (c) able to communicate in
97 English, and (d) able to provide informed consent. All patients were routinely administered the
98 QDASH upon initial evaluation, and the QDASH and the GROC forms on every fourth visit. We
99 chose to explore the experience of individuals who reported functional gains in their QDASH
100 outcome measure, but indicated not perceiving improvements in therapy on their GROC. An
101 administrator identified weekly potential candidates from an electronic file who met discrepancy
102 criteria and informed the treating therapists. The therapists contacted patients who met inclusion
103 criteria to volunteer for the study and informed the primary investigator who did not work at the
104 clinic. Participants were enrolled as soon as identified in treatment. Ten participants took part in
105 the study and saturation was obtained with a redundancy in themes.¹⁰

106

107 **Data Collection**

108

109

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

120

121 **Data Analysis**

122

123

124 *HyperRESEACH 3.5.2* was utilized to facilitate data management and analysis. All transcriptions
125 were checked for accuracy by the second author, advising professor. The analysis was guided by
126 Colaizzi's phenomenological method.¹¹ Following this method, all written transcripts were read
127 several times to gain an overall feeling for them. Significant phrases were selected from each
128 transcript that directly explained the lived experience of individuals demonstrating discrepancy.
129 The process of horizontalization was then conducted whereby each expression was given equal
130 weight and labeled. Repetitions were eliminated from the list. The third step was to formulate
131 general meanings for each significant statement. Clusters of themes were formed from the
132 formulated meanings allowing for the emergence of themes common to all of the participants’

133 transcripts and flow charts were utilized to obtain a graphical representation. Following this, the
134 resulting ideas were integrated into an in-depth, exhaustive description of the phenomenon,
135 known as the essence. In the final step, after obtaining the descriptions and themes, the
136 researcher approached interviewees with the exhaustive description by e-mail and phone
137 interviews for validation in the form of member checking. All participants who responded (7/10)
138 agreed with the description and there were no additional data. In addition to member checking,
139 audit trail and frequent peer review were utilized to promote trustworthiness. Furthermore,
140 throughout the study the primary investigator performed “epoch,” or bracketing through written
141 memos, reflections and discussions with his research advisor of his personal biases and
142 assumptions as a certified hand therapist, who had previously observed the phenomena of
143 outcome measure discrepancy in hand therapy practice.

144

145 **RESULTS**

146

147

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

154

155 **Desire to Return to Normal**

156

157

158 The perceived ability to return to normal was a strong determinant for participant adherence.

159 Patients were less inclined to adhere to treatment if they did not perceive some level of normalcy

160 was attainable. Participants wanted to return to normal, usually comparing their injured limb to

161 their non-involved side. They commented about wanting to return to prior functional level for

162 activities such as work, driving, or playing the guitar. This was evident by the following

163 comments from participants: “to be able to use my hand like I didn’t have the accident. To be

164 back to normal” [C] and “I would like to be back the way I was, not having to wear a brace, and,

165 not having to protect it, and think about it anymore” [F]. Participants defined rehabilitation

166 success in terms of their body functions returning to normal, such as recovering strength,

167 sensation, or motions such as “making a fist”, “getting rid of numbness and tingling,” or “having

168 less pain.” They also described success as returning to functional activities such as “wash

169 dishes,” “have a legible signature” and “balance a check book.” One woman indicated, “Typing

170 and writing... I couldn’t write, ‘cause I couldn’t grip a pen, I’m just getting back to where I can

171 do that” [D].

172

173 **Initial Anticipation of a Brief Recovery**

174

175

176 The realization of a lengthy recovery added to the participant’s understanding of the need to

177 adhere to the treatment in order to have success. Participants initially assumed they would have a

178 brief recovery. The majority of the respondents viewed healing as a slow process, “It’s kind of

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

190

191 **Trust of Therapist**

192

193

194 Participants described therapists as either dedicated or non-dedicated, and the level of dedication
195 impacted their adherence. Greater patient perceived therapist dedication led to better patient
196 adherence. Patients wanted to trust their therapists to get them back to regular activities.
197 Participants viewed themselves as laypersons, expecting professional guidance from their
198 therapists and mistrusted them if therapists did not provide full concern expressed as giving “100
199 percent” of themselves. The issue of trust emerged when several of the participants reflected
200 about therapists they had worked with in the past. They were able to compare therapists,
201 indicating: “Not all therapists/rehabs are created equal” [H]. One 66-year-old female stated: “I

202 was trusting the therapist to know what they should have done to have gotten me back to a
203 normal life, and in essence, that therapist...what's the word...[pause], actually denied me a full
204 recovery, because I am still, seven years down the road, they've taken the money, and I'm still
205 not able to do the things that [I] used to be able to do" [F]. Some respondents expressed feelings
206 of mistrust about the therapist's abilities: "But, I'm sure they get a little self-satisfaction from
207 being able to help somebody, and what they think they can do may be a lot more than what I
208 think they can do" [C]. Among the qualities of a dedicated therapist participants valued, was the
209 clinician's ability to research and provide other opinions to assist with care.

210

211 **Can't Stop Living**

212

213

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

225 home] where [my husband] lives” [E]. While participants wanted to engage in therapy, they
226 could not stop living their daily life to accommodate rehabilitation.

227

228 **Feelings of Ambivalence**

229

230

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

247

248 **DISCUSSION**

249

250

251 The findings of this study address a gap in our understanding of how patients experience the
252 discrepancy of making functional gains in therapy while perceiving not making progress in
253 rehabilitation. These findings shed light on the factors affecting the participant’s decisions to
254 adhere to rehabilitation. Patient adherence is complex and involves multiple factors beyond the
255 patient’s decision of simply following through with treatment. The WHO MAM⁴ provides a
256 framework for understanding how the themes that emerged in our study relate to the complexity
257 of patient adherence to UE rehabilitation. When categorized using the World Health’s
258 Organization MAM (see table 2), the themes fell into all five dimensions of socioeconomic,
259 healthcare systems, condition-related, therapy-related, and patient-related.

260

261 In this study, socioeconomic factors had an impact on adherence, which is consistent with the
262 literature.⁴ Some participants mentioned the cost of treatment as an adherence modifier because
263 paying the bills took priority over home programs. Another indicated that to adhere to treatment
264 recommendations they would have to not work. For another participant who was a bus rider,
265 having more efficient modes of transportation could have greatly eased the time constraints that
266 impacted adherence. Clinicians should acknowledge patient financial investment, and design
267 programs that do not compete with work schedules.

268

269 The therapist working as a liaison for the patient among other medical specialties was viewed as
270 a positive determinant of adherence. This result was consistent with results found by others, who

271 found availability of support was a positive determinant of adherence.¹² Most participants
272 experienced a longer than anticipated duration of treatment, yet it played a positive role on
273 adherence by motivating them to continue to seek professional help. In contrast, some
274 participants needed to see an immediate benefit with their results, in order to adhere to treatment.
275 A patient’s motivation to adhere to prescribed treatment may be influenced by the value this
276 person place on following the regimen and the degree of confidence in being able to follow it.¹³
277 Therapists can set as goals to increase the patient’s perceived importance of adherence by
278 building on his or her intrinsic motivation, and strengthening confidence by building self-
279 management skills.⁴ In our study, factors that negatively affected patient adherence were
280 ambivalence and lack of understanding about their condition, as well as negative beliefs
281 regarding the efficacy of treatment and illness. Sluijs found similar results where a bad prognosis
282 was related to non-adherence.¹⁴
283
284 In our study, time spent with a therapist, communication and interpersonal style of the therapist,
285 and the patient-provider relationship were all adherence determinants. This was true particularly
286 related to the issue of trust. Consistently, others have found that patients need to perceive that
287 their clinician listens, understands and appreciates their suffering.¹⁵ The clinician–patient
288 relationship is one of the most important predictors of adherence to medical treatment, patient
289 satisfaction, and overall treatment success.¹⁶ Nonetheless, the current healthcare system and
290 reimbursement may limit the individualized time a therapist can spend with a patient. The
291 demands for therapists to maintain high productivity levels and incorporate insurance
292 requirements appear to increase each year. Therapists can maximize time spent with the patient
293 by explaining the benefits of the treatment intervention and incorporating the patient’s wants into

294 their treatment plan.

295

296 The patient discrepancy between the QDASH and GROC forms could be explained by factors
297 such as the slow rate of healing progression and the participants’ desired treatment emphasis. For
298 example, one participant’s focus was on sensory return whereas the therapist’s emphasis was on
299 progressive motor/strength return. This finding highlights the importance of early discussion
300 about the focus of intervention and expectation of the rate of recovery. In our study, the length
301 and complexity of treatment inhibited participation in normal daily life. For instance, some
302 participants felt orthosis wear and home exercises were cumbersome and interfered with their
303 lifestyle, negatively affecting adherence. Likewise, in a study of patients undergoing distraction
304 treatment for complex finger fractures, the most significant influence on adherence were
305 perceived complexity of treatment, and interference with the completion of daily occupations:
306 productivity, self-care, and leisure.¹² In our study, contrary to anticipated, participants who
307 experienced previous treatment failures at another treatment facility were motivated by their new
308 therapist, which had a positive effect on adherence. The new therapists used a more holistic
309 approach to the intervention by not focusing on a particular body structure, but rather looking at
310 the individual as a whole. This method was consistent with the biopsychosocial model by
311 accounting for the person within the disease.¹⁷

312

313 **Study Limitations**

314

315

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

321

322 **Conclusions**

323

324

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

337

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388 Figure Legends

389 Fig 1 The World Health Organization Multidimensional Adherence Model.

390 “Reproduced, with the permission of the publisher, from Adherence to Long-Term
391 Therapies: Evidence for Action, Geneva, World Health Organization, 2003 (Fig. 3, Page
392 27, http://www.who.int/chp/knowledge/publications/adherence_report/en/ accessed 15
393 November 2014).”

394 Table 1 Participant Demographics.

395 Table 2 Findings associated with the World Health Organization's Multidimensional
396 Adherence Model.

397

Table 1 Participant Demographics.

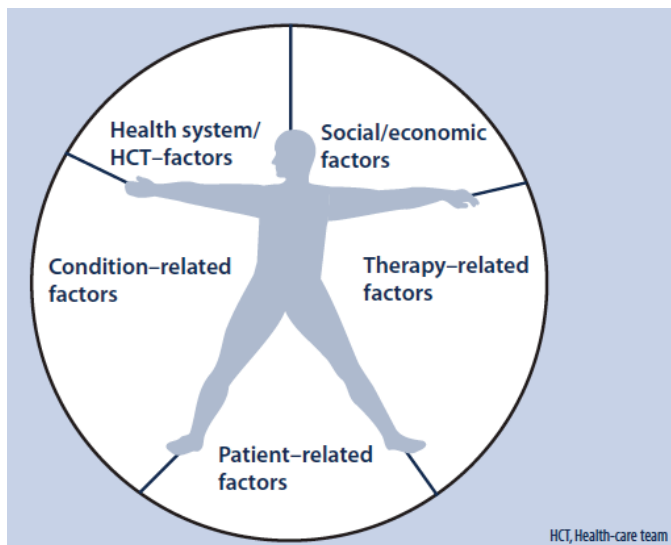
<i>Patient</i>	<i>Gender</i>	<i>Age</i>	<i>Injury to Dominant Hand</i>	<i>Mechanism</i>	<i>Ethnicity</i>	<i>Weeks in Treatment</i>	<i>Occupation</i>
A	F	64	No	Laceration	White	4	Professional
B	F	60	No	Stroke	White	4	Clerical
C	M	49	No	Crush	White	15	Factory
D	F	21	Yes	Laceration	White	8	Clerical
E	F	73	Yes	Fall	African American	8	Homemaker
F	F	66	No	Fall	White	6	Clerical
G	F	30	Yes	Ball Sport	White	14	Professional
H	M	41	Yes	Cumulative Trauma	African American	6	Service
J	M	48	Yes	Cumulative Trauma	White	8	Manager
K	M	43	Yes	Crush	White	18	Service

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

<i>MAM Dimension</i>	<i>Related Factor</i>	<i>Finding associated with adherence</i>	<i>Participant Quote</i>
<i>Social and economic</i>	Long distance from treatment center	Can't stop living because of injury or rehabilitation	"First thing, catch the bus and come out here..." [E]
	Cost of treatment	Can't stop living because of injury or rehabilitation	"You've got to pay the bills, you got to live life. You can't stop because you got hurt." [C]
	Social	Feelings of ambivalence of comparisons to others	"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]
<i>Health-care team and system</i>	Patient provider relationship	Trust of therapist impacts recovery	"Yeah, you put a lot of trust in a therapist...." [F]
	Time spent with therapist	Non-dedicated therapist	"They instruct you to do an exercise and then they walk away. They're very impersonal" [J]
	Communication style of therapist	Collaboration (between patient and therapist)	"Well, first off, I think the goals of your therapist, plus if the therapist and the patient work together as a unit." [G]
	Interpersonal style of therapist	Dedicated therapist (establishes rapport)	"Having somebody that understands first of all what your goal is, and how to get you there, that is the support thing. [G]
	Lack of knowledge & training of therapist	Non-dedicated therapist	"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]
<i>Condition-related</i>	Prognosis	Desire to return to normal	"Yeah, regaining everything... You want it to come right back." [D]
	Rate of progression (difference between therapist and patient understanding on what is minimally important)	Feelings of ambivalence about factors 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] "A little, but, a little bit doesn't help me hold that wrench any better..." [C]

<i>Therapy-related</i>	Complexity of treatment	Can't stop living because of injury or rehabilitation	"I can't spend all day doing these exercises, and wearing this stuff, because I have a life I have to live." [C]
	Duration of treatment	Anticipation of a brief recovery	"You do it overnight, but it doesn't heal overnight." [A]
	Interference with lifestyle/ activities of daily living/ work	Can't stop living because of injury or rehabilitation	I have to make a living, I have to keep going and they want to shut it down." [J]
	Immediacy of benefit	Feelings of ambivalence about factors important for treatment success	"If I can't make a fist, I'm wasting my time." [C]
	Previous treatment failures	Trust of therapist impacts recovery	[The current therapist] focuses on everything. Which has helped, just looking on the elbow, wasn't getting anything accomplished." [G]
	Availability of medical support	Dedicated therapist (liaison)	"[The therapist] has done a lot of research and tried to get other opinions regarding what to do" [G]
<i>Patient-related</i>	Psychological factors: Low motivation	Feelings of ambivalence of comparisons to others	"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]
	Lack of understanding of the condition	Ambivalence in their beliefs about their illness	"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]
	Negative beliefs regarding the efficacy of treatment	Ambivalence in their beliefs about their illness	"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

1

2

3

- *How do you rate success with rehabilitation? Tell me more.*

4

- *How did your results in rehabilitation compare to your success criteria? Tell me more.*

5

- *Do you feel your criteria to measure rehabilitation success was similar to that of your therapist? Tell me more.*

6

- *Do you feel as though your needs are being heard and addressed in rehabilitation? Tell me more.*

7

8

- *What do/did you consider the most important component of your rehabilitation process? Tell me more.*

9

10

- *What do you consider as limitations/barriers in seeking and complying with upper extremity rehabilitation? Tell me more.*

11

12

- *What do you value most of your rehabilitation experience? Tell me more.*

13

14

- *Were those expectations met? Why or why not?*

15

16

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.

17

1 Supplemental Appendix S1 Essence (Deep Analysis): Representative Examples

2

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

6 **Back Into Life**

7 The essence that emerged from the data was an overall picture of the participant's incongruence
8 represented in a desire to move "back into life."

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

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

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

22 Non-dedicated therapists were described as impersonal and unprofessional. Another participant
23 thought a therapist took payment for therapy but did not spend time with him to ensure his

24 success: “They instruct you to do an exercise and then they walk away. They don't stay with you
25 to make sure that you're staying on task. They're very impersonal” [J]. Another described
26 unprofessional behaviors: “When the physical therapist is just there jabbering with somebody
27 else, or they are there to just spend the day, and get a patient in and out, and they don't take the
28 interest, I don't feel they have succeeded that patient...” [F].

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

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

41
42 “*Back into life*” represented being able to return to prior function, to physically accomplish
43 tasks, and to return to work or sports. Participants viewed themselves as laymen and sought the
44 knowledge of a dedicated therapist who they trusted to spend enough time with them, understood
45 what they valued as important, treated their injury, collaboratively made goals, and explained the
46 intervention to help them return to their routine, in the minimal required time. Moving “back into

- 47 life” was influenced by a variety of factors that affected participant adherence to the
48 rehabilitation process.

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