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# Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study

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# Accepted Manuscript

Adherence of Individuals in Upper Extremity Rehabilitation: A Qualitative Study

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

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18 Surgeons of the United States (AMSUS). This abstract was accepted for the 2016 American  
19 Occupational Therapy Association Meeting in Chicago, IL. This study fulfilled part of the degree  
20 requirements for the first author.

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31

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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.<sup>1</sup> 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."<sup>2,3</sup> In 2003, the World Health Organization (WHO) reviewed  
45 the worldwide adherence evidence and created the *Multidimensional Adherence Model* (MAM)  
46 (fig 1).<sup>4</sup> 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%.<sup>3</sup> 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,<sup>5</sup> 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),<sup>6</sup> a measure of physical function, and the Global Rating of  
58 Change (GROC),<sup>7</sup> 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.<sup>7,6,8</sup> 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.<sup>9</sup> 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;<sup>10</sup> 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.<sup>10</sup>

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.<sup>11</sup> 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  $9 \pm 5$  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 MAM<sup>4</sup> 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.<sup>4</sup> 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.<sup>12</sup> 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.<sup>13</sup>  
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.<sup>4</sup> 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.<sup>14</sup>  
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.<sup>15</sup> The clinician–patient  
288 relationship is one of the most important predictors of adherence to medical treatment, patient  
289 satisfaction, and overall treatment success.<sup>16</sup> 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.<sup>12</sup> 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.<sup>17</sup>

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

338 **References**

339

- 340 1. Martin C, Perfect T, Mantle G. Non-attendance in primary care: the views of patients  
341 and practices on its causes, impact and solutions. *Family practice*. Dec  
342 2005;22(6):638-643.
- 343 2. Meichenbaum D, Turk D. *Facilitating Treatment Adherence*. New York, NY: Plenum  
344 Press; 1987.
- 345 3. O'Brien L. The evidence on ways to improve patient's adherence in hand therapy.  
346 *Journal of hand therapy : official journal of the American Society of Hand Therapists*.  
347 Jul-Sep 2012;25(3):247-250.
- 348 4. WHO. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva, Switzerland:  
349 World Health Organization; 2003.
- 350 5. Winthrop Rose B, Kasch MC, Aaron DH, Stegink-Jansen CW. Does hand therapy  
351 literature incorporate the holistic view of health and function promoted by the  
352 World Health Organization? *Journal of hand therapy : official journal of the American*  
353 *Society of Hand Therapists*. Apr-Jun 2011;24(2):84-87; quiz 88.
- 354 6. Beaton DE, Wright JG, Katz JN. Development of the QuickDASH: comparison of three  
355 item-reduction approaches. *The Journal of bone and joint surgery. American volume*.  
356 May 2005;87(5):1038-1046.
- 357 7. Kamper SJ, Maher CG, Mackay G. Global rating of change scales: a review of strengths  
358 and weaknesses and considerations for design. *The Journal of manual &*  
359 *manipulative therapy*. 2009;17(3):163-170.
- 360 8. Gummesson C, Ward MM, Atroshi I. The shortened disabilities of the arm, shoulder  
361 and hand questionnaire (QuickDASH): validity and reliability based on responses  
362 within the full-length DASH. *BMC musculoskeletal disorders*. 2006;7:44.
- 363 9. Stucki G, Daltroy L, Katz JN, Johannesson M, Liang MH. Interpretation of change  
364 scores in ordinal clinical scales and health status measures: the whole may not equal  
365 the sum of the parts. *Journal of clinical epidemiology*. Jul 1996;49(7):711-717.
- 366 10. Creswell JW. *Qualitative inquiry & research design: Choosing among five approaches*.  
367 3rd ed. University of Nebraska, Lincoln: SAGE Publications, Inc; 2013.
- 368 11. Colaizzi PF. Psychological research as the phenomenologist views it. In: Valle R, King  
369 M, eds. *Existential phenomenological alternatives in psychology*. New York: Oxford  
370 University Press; 1978:48-71.
- 371 12. O'Brien L, Presnell S. Patient experience of distraction splinting for complex finger  
372 fracture dislocations. *Journal of hand therapy : official journal of the American Society*  
373 *of Hand Therapists*. Jul-Sep 2010;23(3):249-249; quiz 260.
- 374 13. Miller W, Rollnick S. *Motivational interviewing*. New York: Guilford Press; 1999.
- 375 14. Sluijs EM, Kok GJ. Correlates of exercise compliance in physical therapy... including  
376 commentary by Turk DC and Riolo L with author response. *Physical therapy*.  
377 1993;73(11):771-786.
- 378 15. Schofield NG, Green C, Creed F. Communication skills of health-care professionals  
379 working in oncology--can they be improved? *European journal of oncology nursing :*  
380 *the official journal of European Oncology Nursing Society*. Feb 2008;12(1):4-13.
- 381 16. Martyn C. Field guide to the difficult patient interview. *BMJ*. Sep 18  
382 1999;319(7212):792.

- 383 **17.** Vranceanu AM, Cooper C, Ring D. Integrating patient values into evidence-based  
384 practice: effective communication for shared decision-making. *Hand clinics*. Feb  
385 2009;25(1):83-96, vii.  
386  
387

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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/](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.

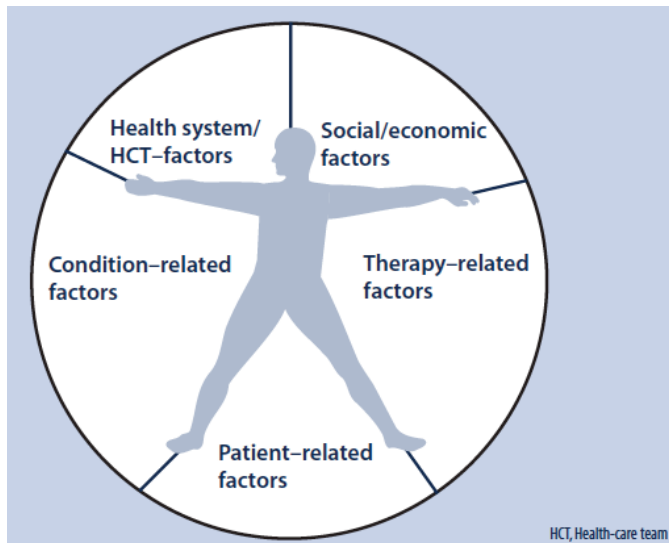
<i>Patient</i>	<i>Gender</i>	<i>Age</i>	<i>Injury to Dominant Hand</i>	<i>Mechanism</i>	<i>Ethnicity</i>	<i>Weeks in Treatment</i>	<i>Occupation</i>
A	F	64	No	Laceration	White	4	Professional
B	F	60	No	Stroke	White	4	Clerical
C	M	49	No	Crush	White	15	Factory
D	F	21	Yes	Laceration	White	8	Clerical
E	F	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*

6

*therapist? Tell me more.*

7

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

8

*me more.*

9

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

10

*Tell me more.*

11

- *What do you consider as limitations/barriers in seeking and complying with upper*

12

*extremity rehabilitation? Tell me more.*

13

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

14

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

15

Note: since this was a semi-structured interview, additional questions could arise resulting

16

from responses given by participants. However, the above questions were asked to all

17

participants.

## 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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