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Experience of non-adherence among six rehab patients

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September 1, 2014

Executive summary

The study reported here was triggered by a recognition of remarkably low adherence to doctor's or physical therapist's instruction - like 40-70% [1] - even among people who should be highly motivated. We wanted to understand how that was so. People often blame themselves for lack of willpower or claim they don't have time. This corresponds nicely with prevalent assumptions in a related field, that of fitness technology, where non-activity is often understood to be lack of motivation or lack of time, thus the technology will try to create reminders or nurture motivation, see for instance Consolvo et al. [2]. We reviewed the literature on adherence to physical therapy programs, e.g., K. Jack et al [4]. While such studies provide a wide array of explanations, they are hard to translate into actionable data. On the other hand, they are useful to verify general applicability of findings from a smaller, more detailed study.

To understand adherence challenges we wanted to take a closer look at a population where motivation may be high (want to get well after surgery) but adherence nevertheless comes out low. We looked at self-confessed adherence-challenged physical rehab patients.

Also, speaking with both health providers and fitness trainers suggested that exercises are often performed wrong, potentially causing more damage than good. This may lead to a yo-yoing effect where the client will never proceed to a fully functional level and lots of effort are put into repair activity.

We report on an informal pilot study that was carried out in the area of exercise and rehab practices. We took a quick look at how six actual rehab patients experience problems with adherence to "doctor's orders". The study suggests focus and topics for more detailed user research and experimental prototyping. Some details on the experience of the users is reported below as study findings.

Even in its brevity the study *confirms our initial intuition* that technology injections of various kinds might make a positive change in many areas of rehab, including the following.

- Focus on transitions in full lifecycle support
- Provide quality assessment of physical exercise execution
- Provide rich, ad-hoc communication between medical provider and client
- Help on the mere mechanics of physical exercise execution

- “Opportunistic rehab” or “micro exercises”

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Areas of potential technology injection

Focus on **transitions in full lifecycle support**: A smart rehab system should support exercising when and where it happens. That includes transitions between stages of rehab, e.g., transition out of rehab treatment should be handled as a preparation of a fitness cycles, i.e. something that need to be explicitly designed and planned.

Provide **quality assessment of physical exercise execution**: Rehab clients are often concerned about the quality of their exercising and may err towards less activity if in doubt. Quality assessment modules in the rehab system might work to reduce/prevent injuries by giving early warning of faulty execution.

Provide **rich, ad-hoc communication between medical provider and client**. There is really no good reason why provider and client could not engage more interactively during the rehab period, incl. easy consultation by video exchange or hangout. These are parts of a smart rehab system to consider.

Help on the **mere mechanics of physical exercise execution**: certain things are just hard for humans while really easy for a smart rehab system, incl. provide a clear listing of current exercises, do automatic coaching through program (e.g., counting).

“Opportunistic exercising” or “micro exercises” as a promising way to rethinking rehab and technologies in support of rehab. Exciting technology support can be designed from state discovery and activity recognition and sensemaking - by sensors and such, combined with push notification (like Google Now). Rehab and fitness work are usually seen as deliberate and structured sessions. However, a stronger focus could be put on suggestions of useful physical movements to be injected into the everyday practices. Similarly, often we find ourselves in situations where we have some time available but it would not be appropriate to change into gym clothes and start the exercise program. Given that our devices “know” what we are doing, where we are and where we are headed, and also what time we might have available, it seems reasonable to overlay data about what would be good for you. Small and subtle movement, including almost the entire range of isometric exercises can be done while in the waiting room, on the bus or even in the car, while you sit at your desk waiting for the machine to reboot, or while you are standing in line in the supermarket.

Study method

The pilot study covers data from six self-confessed non-adherent clients in physical therapy. Clients span from one-time rehab clients (severe strain from sports injury) to long-time rehab clients with need for major movement education.

The informant were selected informally. Over one week in the Bay Area and one week in Copenhagen, Denmark, the author used any social encounter off work to interject statements like this one as a conversation trigger, “Studies suggest that close to 50% of patients in physical therapy are not adhering to the instructions; often they simply do not do the homework” [1]. When a conversation partner reacted acknowledging, like “Oh boy, that is me!” and furthermore confirmed that this was a recent experience (within the last two weeks), the author would ask for a more in-depth interview. A total of 6 people were interviewed in depth, four from the San Francisco Bay Area and two from the Copenhagen area. It was remarkable that most people encountered over these two weeks seemed to have personal experience with non-adherence. Thus, there were no shortage of potential informants, and practical time availability or scheduling limitations determined who to include.

After initial screening for actual and recent non-adherence in physical rehab, each informant took part in a 1-2 hour long in-depth contextual inquiry [3]. The researcher had the informant focus on the most recent visit with the health provider and any exercising that had been done since. The informant described their ailment, current status, and demonstrated the current exercise program as they remembered it. The physicality and enacting helped trigger memories of earlier situations and issues. Every now and then the interview went even deeper to uncover problematic situations.

Study findings, details

The following details the findings. Text in green are light paraphrases of actual client statements. The findings are organized into main categories of Behavior, Life cycle, and Rehab environments. The findings can be used for inspiration in rehab technology innovation, or they can inform a more thorough investigation.

A. Behavior

Main Obstacles / hindrances

Difficulties keeping track during exercising

1. Counting is the worst part; I feel so utterly incompetent when I cannot even keep track of sets and reps.
2. I had this PT who suggested counting: 1-2-3-4-... , 2-2-3-4-..., 3-2-3-4-... I felt like screaming! After time and time again producing garbled series like 6-7-eh-3-....

Doing things wrong - doubt and pain

3. Pain is my bane! Sometimes, in the middle of an exercise, I feel discomfort/pain, that is not usual - and I immediately stop exercising. I guess I could just go on to another exercise, but I seem to be too anxious. Sometimes I will stay inactive for almost a week if the scheduled appointment is that far out.
4. I would like to do my exercises; I know they do me well. But shortly after I start the session in the morning I am overcome with all kinds of doubt: is this the right posture? should the knees be straight or slightly bend? And it feels such a drag to go on with all this doubt - so I stop and quickly engage my mind with something more tractable
5. Often I stop and do something else because doubt (about it is done right) turns into feeling of inadequacy and eventually discomfort.
6. I overdid it - and was left with more problems than I started with.

Being unclear about or forgetting program

7. My therapist showed me 2 new exercises; next morning I had completely forgotten one of them, and I was not really sure I remembered the other right? Perhaps I mixed it up with an old one. Funny, when we did the exercises in the session it seemed like a piece of cake....

Difficulties translating gym stuff to home environment

8. I guess I did a ton of exercise that first day pushing the guest bed out of the way, trying to rig up a books and a shelf for stepping, and scooting the big mirror into the guest room. But then I had it!
9. All the stuff we did in the gym was great, but when I got home I was not sure how to do the movements. I don't have room for a real exercise setup in my shared apartment. I may have to use the gym at work for this.

Being unsure about relation between exercises and goals (long term and more important short term goals)

10. I need the therapist to give me a goal and a set of steps to reach it; I often feel that I am not getting anywhere and that de-motivates me
11. Even if I know it is absurd, I yearn to know each time I exercise that I am demonstratively better than before.
12. I was not getting anywhere. So I stopped. And I feel ok now, though it hurts when I run more than 1 mile on asphalt. I know it isn't right, but what can I do?
13. I get so excited about the new program, and I read up on things, and add more exercises/activities that I find on the web. Shortly after I am exhausted or in pain because I overdid things

Transitions - Things fall between the cracks

14. I get new exercises but I am not sure if I should still do the old ones. Doing them all seems too much; doing only the new ones seems like too little

15. At some point we decided that I could go on by myself from now on. We both suffered some treatment fatigue I guess ;-). But I kind of lost track of time and forgot to do my home exercises.

Low priority of rehab work

16. I will do it tomorrow - and so I keep saying
17. I have tried to put exercises into my work schedule, but it doesn't work. For instance, I see it is 5 minutes till exercise time, but I am battling this bug - think I have a solution just around the corner (I always think that). So I skip the scheduled exercise.
18. As I consider starting on the exercises I also feel an urge to do A, B and C -- it is never the exercises that wins!

Workarounds

Build habits - put it on "auto pilot"

1. I can only do exercises if I do them first thing in the morning, before I really wake up. I have to be on auto-pilot. If I need to think and make decisions, exercises seem to fall low in priority.
2. I usually succeed in exercises that happens before I really start the day, before breakfast. Anything later on drown in the unpredictable obstacles of a work day and social calendar.

Engage social forces

3. Exercising alone doesn't work for me, I need a group or a trainer.

Solve by scheduling

4. I am only "compliant" as you call it when it is in my schedule.
5. Doing exercises on my own is just not my thing. I need scheduled session with a personal trainer - or perhaps I just need to have it scheduled. On second thoughts, No, I did try that once. I just filled out the slot with work stuff I was behind on.

B: "Life cycle": e.g., what are stages in rehab? how do people progress?

Rehab may differ from general fitness in several ways: rehab treatment happens under medical professional guidance. That may cause the client may be less self-driven and more dependent on professional feedback (e.g., in cases of pain, discomfort). And rehab treatment typically happens in specialized medical professional settings, and the difference between these and client's home setting (or general gyms) may be too big.

To support the pilot study, a model of movement / fitness practice was gently adapted to rehab and used to organize the client testimonies (Consolvo et al, "Designing for Healthy Lifestyles").

Rehab major cycle

Using cycle / stages model from Consolvo et al

1. Pre-injury / pre surgery (equivalent to fitness cycle, pre-contemplation, Consolvo-et-al)

2. Injury / surgery and initial healing (equivalent to fitness cycle, contemplation, Consolvo-et-al)
3. Rehab - minor cycle
 - Preparation: Periodical PT visits (equivalent to fitness cycle, preparation, Consolvo-et-al)
 - i. Status/ assessment
 - ii. Treatment
 - iii. Homework teaching & assignment
 - Action: Self-driven activity (equivalent to fitness cycle, Action, Consolvo-et-al)
 - i. Perform opportunistic rehab activities (e.g., use stairs, chair exercises)
 - ii. Perform occasional rehab activities (e.g., go swim 3 days a week)
 - iii. Perform daily rehab routines (e.g., morning and evening programs)
4. Maintenance: Slide back into normal state (equivalent to fitness cycle, Maintenance, Consolvo-et-al)
 - At some point the PT and I decided I could go on on my own. Honestly, I was starting to feel PT fatigue; I bet she was too. But the fact of the matter was that I was not really sure what my maintenance program should be, if any.
 - It seemed less and less productive to see the therapist. He just checked on a few of the exercises and I felt pretty ok. So why spend 2 hours weekly on PT session and driving.
 - I did not continue on my exercise program after I stopped seeing the PT. At first I just needed a break. But apparently I never returned from it.

Watching for transitions and break of continuity

Pinpointing the most “dangerous” transition, we get:

1. Rehab minor cycle -> maintenance:
 - a. sometimes a negative experience; often not a transition “by design”, but just absence of continuation.
2. Within Rehab minor cycle - prep -> action:
 - a. details of what happened in the gym may be forgotten
 - b. the setting feels too different
3. Within Rehab minor cycle - action -> prep:
 - a. no review of past exercises

C: Rehab Environment

Where does rehab happen?

1. Dedicated sessions of ½ - 1 hour's duration; at home, in gym
2. Freeforms, such a walk with or without the dog
3. Opportunistic
 - a. Intertwined with other work
 - b. while waiting

- c. while standing in line, ...
- d. while traveling (several said that travel breaks their good exercise habits, but this informant sees the idle time in hotel rooms as perfect for exercising)

How do people keep track of their rehab session?

- 4. Self paced
 - a. Counting reps
 - b. Watching time
 - i. Plain watch time
 - ii. Duration of selected music track
- 5. Being coached
 - a. virtual
 - b. real

Scheduling and structure - for some people applying structure is NOT the solution

- 1. Scheduled and organized - everything needs to fit into a slot in the calendar
- 2. Unscheduled, irregular - no two days look alike. For some things depend on outside forces (though this type usually become enforced "scheduled" to cope; for others the irregularity is a choice of lifestyle.

Iterative improvement - just doing more

- 1. Make what you already do more productive and effective w.r.t. the rehab goals. A normal workday may actually involve a fair amount of movement. For instance, your fitbit may easily clock 4000-6000 steps during a day of meetings and such, without any dedicated exercise time.
- 2. Add something extra to what you already do! There are lots of opportunities for doing rehab activities, intertwined with everyday activities. But PT also says one needs be alert / aware (i.e. not watch TV while working out). Examples:
 - a. take stairs whenever you can
 - b. park the car a bit further away
 - c. add "funny walk" to a normal walk, e.g. jogging, marching, and backwards walking/jogging, crab walk...
 - d. inject a series of squats every now and then when sitting for long periods of time
- 3. As opposed to "New Year's resolution mode"
 - 1. I tend to make these big decision for self-improvement: want to lose 20 lbs; want to play professional tennis; want to get ready for Boston Marathon (never having done any such before). And it all fizzle out within a day or two - partly due to the enormous task ahead.
 - 2. I feel so good after the first couple fitness classes, so I decide to start running. I love running, but I never learned how to do it right. One month later my left foot is hurting and - actually - it has never been good since.

D. Others

Rehab complexity

1. “Just” strengthening, just get back into shape
2. Rebuild functionality after trauma (injury or surgery)
3. Major re-learning - address compensatory movements

Personalities with respect to motivation

4. fitness junkie - fitness is an essential part of stable self-image
5. quantified self - not necessarily fitness eager, but addicted to everything quantified about self.
6. fitness-foreign - not really thinking about the movement system; it should just work
7. “New self” - suddenly deciding to make major change and primarily seeing the lofty goal, not so much the steps to get there

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