Sharing Automatically Tracked Activity Data: Implications for Therapists and People with Mobility Impairments

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ABSTRACT

The ability to share automatically tracked health and fitness behaviors has yielded benefits ranging from increasing user motivation to providing therapists with greater insight into their patients' progress. While past work on sharing this data has primarily focused on users with typical motor abilities, features are now emerging in mainstream tracking technologies to extend to people with mobility impairments (e.g., tracking wheelchair rolling). This paper explores opportunities specifically for users with mobility impairments to share this automatically tracked data both with peers and with physical, occupational or recreational therapists. We conducted semi-structured interviews with 10 therapists and 10 people with mobility impairments. The interviews focused on current and desired activity-tracking and sharing practices, and included a design probe activity to more concretely assess the perceived utility of sharing tracked fitness data. We report on attitudes and concerns toward sharing fitness data from the perspective of therapists and people with mobility impairments as well as outline design opportunities to explore in future work.

Author Keywords

Accessibility; mobility impairments; wearable devices; fitness; personal informatics; therapists; online communities; support groups; self-tracking

ACM Classification Keywords

• **Human-centered computing~Empirical studies in accessibility**

INTRODUCTION

Wearable technologies that track health and fitness activities have surged over the past decade. Many of these technologies offer the ability to share tracked activities, often within online social networks but also for therapy purposes. Sharing fitness activity with peers, for example,
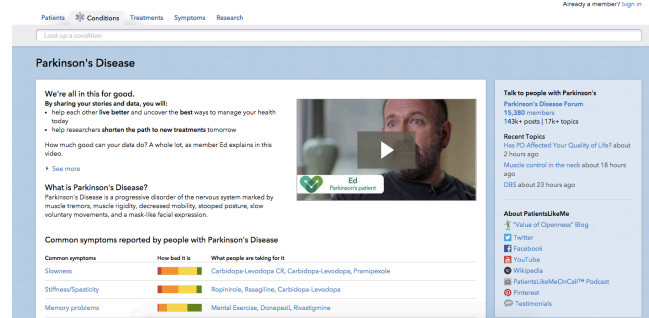
Figure 1. Screenshot of the website *PatientsLikeMe* which was used as a design probe. This screenshot shows symptoms experienced by people with Parkinson's disease and treatments.

has been identified as an important strategy for fitness tracking technologies [9,28] and can yield benefits such as motivation and peer support [35].

These devices have traditionally been inaccessible for people with mobility impairments, such as people using walkers, wheelchairs, or canes [7,24]. The recently released Apple Watch 2 [2], however, is the first widely available mainstream device to track wheelchair rolling. As activity tracking becomes more accessible to people with mobility impairments it is timely to consider what opportunities automatic tracking may offer to this population.

This paper explores two opportunities for sharing automatically tracked health and fitness data that are particularly relevant to people with mobility impairments. First, therapists often recommend that patients with mobility impairments engage in physical activities outside of therapy sessions, but self-reported data on these activities can be unreliable or inaccurate [21,31]. How can automatic tracking technologies address this issue and potentially impact therapy practice? How do patients feel about sharing data in this way? Second, sharing health data with peers in online communities can have benefits such as learning about one's own health, gaining motivation and support, and helping patients to make informed medical decisions [4,22,32]; finding peers who have similar fitness goals can also help an individual stay motivated and engaged towards the goals [16]. For users with mobility impairments, how might these benefits translate and how do users define who is a peer (e.g., other wheelchair users)?

To answer these questions, we conducted semi-structured interviews with 10 therapists (physical, occupational, and recreational) and 10 people with mobility impairments. Both sets of interviews focused on current and desired activity-tracking and sharing practices and advantages and disadvantages of the same. To provide a concrete example of how tracked data could be shared both with therapists and with peers, we employed *PatientsLikeMe*[1] as a design probe with therapists and described the website to participants with mobility impairments. This website is a platform where people living with chronic conditions share and learn from each other's health experiences to improve their personal health outcomes (Figure 1).

Our contributions are: (1) identification of opportunities for building tools to help therapists make personalized therapy decisions about their patients using data from activity-tracking wearables; (2) characterization of attitudes and concerns about sharing health and fitness data from the perspective of both therapists and individuals with mobility impairments; (3) design recommendations to build tools that support inclusive sharing of fitness-related activities with peers who have similar mobility impairments.

RELATED WORK
We cover three areas: activity-monitoring and rehabilitation tracking technologies for people with mobility impairments and sharing of health and fitness data.

Activity-Monitoring Technologies
Activity-monitoring technology has become ubiquitous, with solutions targeted at tracking sleep [20], mental well-being [26], and physical activity [28], along with support for medical conditions like diabetes [25]. However, issues like lack of support for goals [13], forgetting to wear the device [15], and the need for manual entry [10] can lead to abandonment. Epstein et al. [14] recommend strategies for data aggregation and representation to support such lapses.

Most work on activity-tracking for people with mobility impairments has focused on algorithms that classify a wheelchair user's activities (e.g., wheelchair propelling [12]). As well, a few design-oriented studies have identified accessibility challenges with existing mobile and wearable fitness trackers, characterized preferences, and discovered a desire to share health and fitness data with other users who have similar impairments [7,24]. More recently, the Apple Watch 2 became the first mainstream device designed to track activity for users with mobility impairments—specifically, it tracks slow and fast wheelchair rolling [2]. While accessibility for other types of mobility impairments is still a challenge (e.g., walking slowly or with extraneous movement [24]), the Apple Watch 2's move toward inclusive tracking makes it timely to consider how automatically tracked data from people with mobility impairments can be utilized.

Tracking Technologies for Rehabilitation
There has been extensive research on human motion tracking technologies for rehabilitation purposes. The goal of these technologies is to help restore functionality by tracking movements specific to the person's condition and providing feedback. For example, sensors on and around the knees have been used to track and guide patients to perform exercises for knee rehabilitation [3] and in some cases also share that data with their orthopedists [18]. Huang et al. [19] used the sensors in an iPod that was attached to a cap worn on the head of a patient to track his activities at home. Another system includes multiple motion tracking cameras to provide guidance and feedback for doing exercises at home [34].

Another type of tracking for rehabilitation comes from exergaming technologies that track the user's movement while he/she is playing a game to exercise. For stroke rehabilitation, Nintendo Wii games have been effective and fun for arm recovery and upper limb weakness [30,36]. Deutsch et al. [11] demonstrated improvements in gait and postural control among adolescents with cerebral palsy. Various motion-based games have also been developed for wheelchair users to encourage physical activities [17]. While the goal of these rehabilitation technologies is specific to the patient's condition/injury, general-purpose activity-tracking technologies can provide a more comprehensive picture of a person's physical activities.

Sharing Health and Fitness Data
Online support groups with shared goals to manage different conditions have been widely studied for long-term behavioral change (e.g., [33]). For people without mobility impairments, sharing data from automatically tracked fitness activities has been shown to offer benefits such as motivation and reflection, but concerns can also arise around privacy and feelings of self-consciousness [16]. Previous studies have recommended types of health and fitness-related data to share (e.g., calories burned) [28] and with whom to share (e.g., people with similar goals) (e.g., [28]). At the same time, sharing broadly with an entire social network can lead to a disinterest in sharing owing to lack of support from social networks [28]. Another concern with sharing health and fitness data on the internet is that users will misdiagnose themselves [1], but previous work also suggests that patients do not use these communities as primary sources of medical information [33].

As already mentioned, people with mobility impairments may be interested in sharing health and fitness data with other users who have similar conditions [7,24]. However, what data to share, how to share it, and the potential impacts of this sharing have received little attention for people with mobility impairments. One exception, published only as a poster, is a study where 248 people with multiple sclerosis (MS) used a commercial wearable, Fitbit One, to track and share their activity data (e.g., number of steps) with other MS patients in the online community

PatientsLikeMe [27]. Sixty-eight percent of participants reported that the Fitbit One helped them track and manage their MS better. Inspired by this work, we conduct a technology design-oriented study with both therapists and participants who have a broad range of functional abilities, and report in greater depth on the perceived implications of sharing this automatically tracked data.

METHOD

We conducted semi-structured interviews with 10 therapists (physical, occupational, recreational) and 10 people with mobility impairments. The interviews with therapists focused on understanding the opportunities and value of automatically tracked health and fitness data to therapy, while the interviews with people with mobility impairments focused on participants' interest in sharing such data both with therapists and with peers who have similar impairments. We employed the *PatientsLikeMe* website as a concrete model for how online sharing could work.

Participants

Participant details are in Tables 1 and 2. Participants were volunteers and were recruited through online advertising, word of mouth, and local organizations. All participants were compensated for their time. For the therapist group, we only recruited participants who had experience working with wheelchair users.

Interviews with Therapists

These semi-structured interviews were one hour long and consisted of the following sections.

Background (~5 minutes)

This section covered demographic information about the therapists, conditions and mobility impairments of their patients, and information about the number of patients they see and how often they see them.

Current Activities (~5 minutes)

We asked therapists about the activities performed by their patients during formal therapy sessions and use of any mechanisms to perform those activities. We also asked about what physical activities patients performed beyond regular therapy sessions and concerns patients may have about sharing those activities with the therapists.

Current and Desired Tracking Practices (~10 minutes)

We asked therapists about what physical activities contribute toward a patient's progress, the tracking mechanisms therapists use (if any) to monitor those activities, and the extent to which those mechanisms work. Therapists also answered questions about what physical or psychological data (the latter would need to be self-reported) they would want to see from outside of regular therapy sessions, as well as the perceived impact of this data towards therapeutic goals.

Existing Wearables and Exergames (~15 minutes)

We asked therapists whether they or their patients used any wearable or exergaming technology for health and fitness

ID	Age	Gender	Type of therapist	Years of practice
T1	27	Female	Recreational therapist	4 years
T2	27	Female	Recreational therapist	4 years
T3	33	Female	Physical therapist	7 years
T4	42	Female	Physical therapist	1 year
T5	29	Female	Physical therapist	4 years
T6	29	Female	Physical therapist	5 years
T7	28	Female	Physical therapist	4 years
T8	26	Male	Physical therapist	1 year
T9	33	Female	Physical therapist	5 years
T10	44	Female	Occupational therapist	21 years

Table 1: Demographics of therapists.

tracking purposes and the extent to which these technologies met their goals. We then explored the utility of these technologies toward therapeutic goals.

Design Probe (~20 minutes)

We used the website *PatientsLikeMe* as a design probe to explore opportunities that a similar website, but for health and fitness tracking of people with mobility impairments, could bring for therapists. *PatientsLikeMe* is a social network where patients share their health experiences with other patients who have similar conditions. As an example, searching for Parkinson's disease yields results including reported symptoms experienced by patients, drug treatments and patients' perceived effectiveness of those treatments, and demographic information of the patients who reported this data. We also asked therapists to predict patients' interest-level in sharing health and fitness activities on a website like this.

Interviews with People with Mobility Impairments

These semi-structured interviews were 30 minutes long. They began with demographic questions and current or previous therapy practices related to health and fitness. We asked participants about the physical activities they performed outside regular therapy sessions. We also asked questions to capture attitudes and concerns towards sharing these physical activities with others like therapists, friends, family members and peers. We roughly described a design idea of a platform like *PatientsLikeMe* for health and fitness tracking purposes and asked about the perceived utility of such a site.

Data and Analysis

Except for two participants with mobility impairments, all sessions were audio recorded and transcribed. We used a thematic coding technique with both inductive and deductive codes [6] and created two codebooks – one for each group. For example, codes for advantages of a website like *PatientsLikeMe* from interviews with people with mobility impairments included "motivation," "peer support" and "other." One member of the research team iteratively refined the code set with multiple rounds of feedback from a second member, including adding new codes, merging and deleting. For validation, we adopted a peer debriefing approach [5] where another person not on the research team investigated randomly selected coded transcripts of two therapists and two people with mobility impairments. A total of 22 conflicts were identified and

ID	Age	Gender	Diagnosed Medical Condition	Mobility Aid(s) Used	Previous/current experience with a therapist
M1	64	Female	Mixed connective tissue disorder	Forearm crutch	Physical and hand therapist
M2	65	Male	Quadriplegic	Manual wheelchair	Physical and occupational therapist
M3	45	Male	Friedreich's ataxia	Power wheelchair; scooter	Physical therapist and physical trainer
M4	32	Male	Quadriplegic C4-C5	Power wheelchair	Physical and occupational therapist
M5	32	Female	Incomplete spinal cord injury	Manual wheelchair; walker (at home)	Physical, occupational and recreational therapist
M6	64	Male	Complete paraplegic	Manual wheelchair	Physical and occupational therapist
M7	63	Female	Hemiplegia, stroke	Manual wheelchair (for long distances); cane (at home)	Physical, occupational and recreational therapist
M8	73	Female	Osteoporosis	Walker with wheels and a seat	Physical therapist
M9	43	Female	Arthritis	Mobility scooter	Physical and occupational therapist
M10	49	Male	ASIA A complete CSC T5-T6 level	Manual wheelchair	Physical, occupational and recreational therapist

Table 2: Demographics of people with mobility impairments. MX is used to indicate a person with a mobility impairment.

resolved with discussion. The final code set included 2–12 codes per open-ended question, for a total of 106 codes from the interviews with therapists and 107 codes from the interviews with people with mobility impairments.

FINDINGS

We first report on the interviews with therapists followed by the interviews with people with mobility impairments. Therapists are referred to by IDs T1-T10, while participants with mobility impairments are referred to as M1-M10.

Interview with Therapists

We asked therapists about their existing and desired health and fitness tracking and sharing practices for their patients. As already mentioned, only therapists who had experience working with patients who use wheelchairs were recruited. More specifically, the responses here are also based on the therapists' experiences working with patients with a variety of conditions like spinal cord injury (9 out of 10 therapists), stroke (9/10), traumatic brain injury (9/10), knee/hip replacement (4/10), multiple sclerosis (3/10), and amputation (3/10).

Current Fitness-Related Activities and Tracking Practices

To get a general sense about therapists' interest in tracking patient activities, we asked them about existing patient activities during and outside of therapy sessions, tools used to track those activities and therapist's engagement with patients and their family members outside of sessions.

Outside therapy sessions, five therapists said only some of their patients were physically active, four were unaware, and one (T8) thought his patients did nothing to stay physically active. Therapists recommended different strategies to patients to stay active: exercises to perform at home (2/10), wheelchair propelling (3/10), adaptive sports (3/10), and wellness programs (T5). Only T5 and T8 thought their patients would have concerns about sharing these activities with them. T8 said his patients may want to hide activities that they are not supposed to do, for example, a spinal cord injury patient trying to stand on his own. The two main factors therapists felt impacted a patient's progress included compliance with doing exercises at home (5/10) and self-motivation (4/10). T7 describes home compliance as the biggest factor, "*If they're practicing what we ask them to practice, that would be the best way to make improvements, I think.*" Other factors included financial stress (T1) and cognitive levels of the patient (T4).

All therapists tracked their patients' progress by manually recording it using online documentation tools (e.g., MediTech) and four also used files or charts. While four therapists had no concerns with these existing documentation tools, two thought they could be improved. For example, T4 specifically wanted to see statistical data of her patients, "*So, there's definitely room for improvement in terms of seeing statistics of improvement on a very granular level from day-to-day, week-to-week.*" In terms of access to these documentation tools, T5 wanted her patients to have access to these tools to see their progress over time. Furthermore, three therapists were also dissatisfied with the existing methods of assessing a patient's progress (also identified in [23]), including that their existing system was insurance-driven (T8) or did not capture all relevant activities (T4, T7). Related to this lattermost point, T7 commented on the difficulty of knowing how performance within a therapy session pertained to general fitness level:

> "*The only thing I think that is a barrier is on the day that we assess patients. If they're having a bad day, it might look like they're not doing better, but I might know that they are on it most other days, kind of thing.*" (T7)

We also wanted to understand therapists' engagement with their patients beyond therapy and with the family members of the patient. Only T1 and T4 had the time to speak with their patients outside therapy sessions, while the others were too busy, "*I just don't know that that'd be realistic to have time to talk to people outside of their normal therapy session* (T6)." T1 and T2 used Facebook groups for their adaptive sports teams to communicate about research studies, upcoming events and news. All therapists except T1 communicated with the family members of the patients,

> "*I usually get family involved or encourage the family to have the patient do more of their activities at home or do their exercises more regularly.*" (T5)

Summary: Similar to past work [23], therapists spoke about the uncertainty regarding patient's physical activities outside therapy. Although all therapists used documentation tools to track progress, some reported improvements including seeing statistical data. A barrier to further engagement with family members was therapist time constraints, confirming past work [8].

Wearables and Exergaming Technology

To assess general attitudes towards wearable physical activity trackers and exergames, we asked therapists about use of these technologies by them or their patients. In terms of personal interest, all but two therapists (T9, T10) had owned a wearable such as a Fitbit to track their health and fitness activities and six of them had had positive experiences. T1 used a Fitbit HR with a heart rate monitor and talked about its potential benefits for patients:

> "*So, I think that's good for a wheelchair user because their heart rate does go up when they're pushing their wheelchair despite that it's not a step.*" (T1)

When we asked therapists about their patients use of wearable technologies, only two therapists (T1 and T2) were aware that a few of their patients used activity-tracking technologies; five others thought none of their patients used such technologies, while the remaining two were unsure. T2's patients complained about Fitbit's limited tracking abilities, while T1 had two wheelchair patients using a Fitbit and an Apple watch. T1's patient was mainly interested in the device's tracking ability for a wheelchair user:

> "*He wanted to be this person that's showing Fitbit, if it's working or not. He was giving them feedback and stuff. He wanted to do it for the pushes... So, it's a little different and he was trying to give feedback to Fitbit to try and have them develop something different.*" (T1)

Although not many patients were using an activity-tracking wearable, therapists identified potential benefits of such devices: holding patients accountable for the activity or lack thereof (5/10), collecting reliable data (4/10), capturing activities beyond therapy (3/10), motivation (2/10), and goal setting (2/10). T5 talked about patient compliance to activities outside of therapy sessions as follows,

> "*It would be an easy way to say, you say you're doing stuff at home, but this is saying you're active like five minutes out of the day, so that's not really very active.*" (T5)

Besides benefits like seeing weekly patient progress, T7 described the broader impact of this wearable technology with respect to insurance, "*I think it's also good to kinda show insurance, hey, we are making changes, you know, getting them better in this aspect.*" However, T7, along with T3 and T5, thought that cost could be a barrier. T1 also commented that the wrist-based form factor of the Apple Watch had interfered with wheelchair pushing for one of her patients, "*...he wore his watch and put his glove over it and then would tape around his glove so his Apple Watch wouldn't move.*" T2, T3 and T6 also said that existing wearables did not track activities their patients currently did, such as wheelchair propelling.

In terms of exergaming technology, all 10 therapists had previously used or were currently using exergames for rehabilitation purposes (e.g., Wii's balance board to improve balance). All therapists believed that exergames were useful for therapy as they made exercises fun and engaging (8/10) and helped with motivation (T1, T10). Two therapists (T3, T6) thought that cost or access to such technology could be a barrier to this group.

Summary: Patient interest in wearable technologies that track health and fitness is evident from T1 and T2's patients using Fitbits and Apple Watch. Similar to previous work [8], our therapists thought the primary value of automatic activity tracking was accountability and making informed decisions for patients.

Desired Tracking and Sharing Practices

To know more about what patient activity data would be beneficial to therapists, we asked about different types of activities and data. While activities performed during therapy were important to teach proper form (8/10), revamp fitness (T1, T2) and set appropriate goals (T3), all therapists except T4 and T8 thought activities performed *outside* of therapy sessions were equally important. (T8 only assigned basic activities to perform outside therapy because he was concerned about the safety of his patients.) Reasons cited included importance for understanding decline in progress (4/10), improving independence (3/10). T3 highlighted the importance of performing activities outside therapy:

> "*If they're coming to me with complaints of pain and feeling fatigued and they're just spending 30, 40 minutes with me and then going home and sitting on their couch or laying in bed all day, it's really... I'm not gonna be able to help them. So I think I need to have a better understanding of what their daily lifestyle is to help them better.*" (T3)

We asked therapists open-ended questions about their interest in tracking different physical (Table 3) and psychological (Table 4) data. Most of the therapists (8/10) were interested in tracking their patient's wheelchair pushes. Therapists also wanted to track mood (6/10) and energy levels (4/10). Additionally, three therapists (T3, T5, T9) wanted to see correlations between their patients' physical and psychological features:

> "*Okay. I guess the only other thing is how they feel after they do activities, maybe. Like their mood. Did it make their mood worse, better, the same?*" (T9)

All therapists except for T1 thought it would be useful to track overexertion, for example, to prevent injuries (T2). T1, in contrast, thought her patients were aware of their own abilities, so was not as concerned.

Owing to time constraints, therapists were interested in quick, easy-to-understand information about their patients' progress like: progress-decline towards goals (4/10) and activity versus no-activity in a day (2/10). Some therapists spoke about the potential benefits of receiving this information, like setting/modifying patient goals (6/10) and monitoring compliance (3/10). Therapists wanted to receive these updates with varying frequencies: weekly (6/10),

Type of physical activities	Therapists
Wheelchair pushes (going up/down an incline)	T1, T2, T3, T4, T5, T7, T8, T10
Number of active minutes	T3, T4, T5, T6, T7, T8, T9
Heart rate	T1, T2, T3, T6, T9
Distance pushed/walked (if applicable)	T3, T6, T7, T9, T10
Compliance with home exercises	T4, T5, T10
Stroke force and length while pushing	T4, T6, T8
Pressure relief	T4, T6, T7
Pushing speed	T3, T4, T8
Strength training (e.g. lifting weights)	T1, T2
Transfers	T4, T5
Safety	T7, T8
Curb negotiations for power wheelchair users	T3

Table 3: Therapists interest in tracking physical activities of their patients.

monthly (2/10), daily (2/10) or only during patient visits (3/10). T8 said, though unrealistic, he would like daily updates.

We asked therapists whether they thought their patients would be concerned about sharing physical and psychological data. Three therapists thought there would be concerns about sharing both physical and psychological data, while three others thought only psychological data would cause concern. T9 commented on the distinction between the two types of data:

"*I think with psychological just cause it's very personal, and how you're feeling and your mood and all that. Physical, I think just because they may not want their therapist to know what they are doing or what they're not doing outside of therapy.*" (T9)

T3 and T8 felt they already had access to a lot of patient data from the documentation tools and hence their patients would not have concerns about sharing tracked data.

Summary: Therapists spoke of the importance of physical activities both during and outside therapy sessions. Therapists also expressed interest in tracking patients' physical and psychological data and finding correlations between the two, though there may be some concern from patients about sharing psychological data.

Findings from Design Probe Activity with Therapists
During the design probe activity, we showed the website *PatientsLikeMe* to our therapists. None of the therapists had seen this website before or knew if their patients had used it. *PatientsLikeMe* encourages its members to share their health experiences with peers who have similar conditions, with the goal of positively impacting health outcomes. We asked therapists to imagine a website like *PatientsLikeMe* but for health and fitness tracking where their patients would share their automatically tracked fitness data. We wanted to get a therapist's perspective on: (1) the potential utility of such a website, (2) their patient's potential interest in sharing health and fitness data in this way, and (3) possible impacts of the site on therapy delivery.

Therapists' Perspective on Patients Sharing Fitness Data
All therapists except T4 and T10 thought their patients would be interested in sharing their health and fitness data,

Type of psychological data	Therapists
Mood	T1, T2, T6, T7, T9, T10
Energy	T5, T7, T8, T9
Level of tiredness	T3, T7, T9
Level of pain	T2, T6
Exertion	T2, T3
Sleep	T4, T10
Restlessness, alertness and gaze	T4

Table 4: Therapists interest in tracking psychological data of their patients.

but anonymously. Similar to previous work [9,35], therapists also thought their patients could reap benefits such as motivation (7/10) and peer support (4/10), such as:

"*It would kind of be like a support group. Because without having to get to a physical place and meet people one-on-one, they could look at this data and be like, "Oh, these are the things that I could potentially be doing at my level."*" (T3)

Additional perceived benefits for delivering therapy included being able to compare a patient against others with similar functional abilities (4/10), discovering new activities (2/10), and setting relevant goals based on patient abilities (T7). T2 also thought sharing could lead to competition within her adaptive sport group:

"*If they are able to track and compare it [...] with each other on the basketball team, I think that might improve their competitive side to try to get them to do more activity.*" (T2)

An unexpected outcome was that three therapists identified different stakeholders like family members (T8), people at same level of injury as the patient (e.g., newly injured) (T3), and people with similar impairments (e.g., spinal cord injury) (T9) who may also benefit from such a website. For example, T3 talked about the benefits to newly diagnosed patients:

"*I think sometimes for patients that are newly diagnosed with a condition that is going to keep them in a wheelchair, they might feel very isolated and almost depressed because of their condition, but something like this would help them feel like, Oh, I can still do so many things.*" (T3)

Contrastingly, three therapists (T6, T9, T10) stated that there could be adverse side effects of sharing, specifically mentioning a risk of depression. For example:

"*Some patients might be very interested to know how other people with the same condition are faring, [...] 'cause if somebody else is doing better, it might make you depressed 'cause you're not there or you can't get there because of some other reason.*" (T10)

Two therapists (T2, T7) also believed that their patients should consult a professional before trying new activities that they discover on the website.

Summary: Most of the therapists thought their patients would want to share their health and fitness-related data

anonymously. Besides potential benefits to patients, a few therapists identified three other groups who may benefit from this shared patient data. Therapists also pointed out that depression could be a potential side-effect of sharing.

Potential Impact of Aggregated Fitness Data on Therapy
We asked therapists about the potential advantages and drawbacks of using a website like *PatientsLikeMe* to make therapy decisions—specifically, being able to view data from their own patients and from patients with specific types of profiles. Four therapists felt this website would be most useful to learn about activities other patients with similar functional abilities may be doing. T1 described the potential impact towards her practice as, "*It would give me fresh ideas, it would give me different adaptations that I might not have thought of.*" T3 also felt that she could use the data to help motivate her patients:

> "*I like to use evidence-based data or research to say like, Hey, this is what you should be doing at your diagnosis, at your age, at your gender, kind of a thing.*" (T3)

However, potential disadvantages of using a site like *PatientsLikeMe* in their practice were also identified by some therapists. Issues mentioned by one therapist each included the amount of therapist time it would require, the potential for patients being exposed to misleading information, and the potential for therapists getting distracted during therapy sessions. T10, for example, stressed the importance of providing concise information to save time:

> "*There'll be a lot of information on that screen. I don't know if therapists have enough time, yet again, to go through everything. So, it would have to be somewhat concise.*" (T10)

Summary: Therapists outlined more potential benefits than drawbacks of using aggregated fitness data to inform therapy decisions, and were particularly enthusiastic about being able to learn about new activities that could be useful for their patients.

Interviews with People with Mobility Impairments
To understand the impact of sharing automatically tracked data with peers with similar impairments, we interviewed 10 people with mobility impairments. All participants with mobility impairments except M1 shared their health and fitness data with their therapists, family members (8/10), friends (6/10), people with similar conditions (3/10), and Facebook friends (2/10). Although seven participants were part of online social media groups pertaining to their condition, none of them shared their health and fitness-related data on such groups.

Current Health and Fitness Data Sharing Practices
None of the participants had any concerns about sharing their health and fitness-related activities with their therapists (M1 was currently physically inactive due to her condition and hence is not included in this section). Six

participants already shared their activities in detail, for example:

> "*I tell her quite a bit of detail. But they are not formal fitness activities in the sense of having goals usually [...] I talk to her about anything related to my recovery.*" (M7)

Three participants shared only to some extent. Consistent with findings from therapist interviews, participants mentioned benefits of sharing with therapists like providing a realistic picture of activities outside of therapy sessions (4/9), increasing motivation levels (3/9), and setting appropriate goals (2/9).

As for sharing health and fitness data with peers who have similar conditions, only M2 and M10 expressed concerns. M10 currently only felt comfortable sharing his health information with people he already knew, including his Facebook friends, "*Yea I do status updates, I tell them about, its central to me maintaining my positive outlook on life.*" Participants also found that sharing with people with similar conditions exposed them to new activities:

> "*If I see people in a similar situation with similar disability looking for things to do and way to do things. Quite often I would discuss with them and I find that generally other people make a decision if they want to share things you've done and allow you to tell them what you've done and get help.*" (M3)

Summary: Most of the participants had no concerns sharing their health and fitness-related data with therapists and with peers with similar conditions. Participants also spoke about various potential benefits of sharing this data with both the groups.

Sharing on a Website like PatientsLikeMe
All participants thought they would feel comfortable sharing and interacting with others on a website like *PatientsLikeMe*. However, four participants wanted to share anonymously or use nicknames, reflecting the predictions of the therapists. M1 also mentioned that the website itself could present accessibility issues due to her dexterity impairment.

All participants said that sharing on a website would be most useful to learn from and experiment with new activities that others with similar conditions may be doing. Participants said this website could be useful in getting activity recommendations (7/10), getting support from users who had similar impairments (6/10), comparing with others to gauge one's functional abilities (4/10), motivation in seeing other people's successes (3/10) and finding similar patients to interact with (2/10). M5 described how getting ideas on new activities was important:

> "*Maybe you're just like pushing your wheelchair to the store and back each day and you think that's all you need to be doing or all that you can do but on a site like this if you are seeing other shared data of a whole bunch of*

other activities then that may give you some ideas, you know try something new or talk to your therapist about other things people are doing." (M5)

However, some participants mentioned that looking at other people's data on a website like this could have adverse effects: demotivation (5/10) and misleading information (M10). Therapists also had the same concerns.

Social interaction was also desired, a theme that the therapists we interviewed did not anticipate. Participants wanted interaction to be able to ask other users follow-up questions (4/10) and details about activities (4/10), for example:

"If I view that specific individuals were doing something that I had never considered doing or that I thought that I probably couldn't do I would be interested in interacting with them to find out how are they doing it, how they started doing it." (M6)

Other social interaction motivations mentioned by one participant each included learning about others' personal experiences, finding places to exercise together, and encouraging and building confidence with each other. M5, for example, described finding people with similar interests to build a community:

"If you could see that they lived in your area and you could kinda do like a meet up like hey lets meet up at track and we could hand cycle together or you know go to this pool or ask about accessibility features or hey have you been to this venue to work out." (M5)

Despite personal reservations in sharing, some participants were interested in seeing health and fitness-related activities from people with similar impairments (7/10), improvements after certain exercises (3/10) and information about their own condition (2/10). M1 describes learning about her condition as follows,

"I would like to learn some more about my condition. I would like to see other individuals. I never heard of my condition until I was diagnosed with this. I've never run into anyone else who have had this. I've gone online and read some stuff about it but it doesn't seem to have much information about it." (M1)

Despite these potential advantages of an online forum for data sharing, drawbacks were also mentioned. Reflecting social and privacy concerns about sharing tracked data that have been expressed in other studies [16], two participants mentioned not wanting to share vitals or other tracked data. M6 also thought looking at other people's data may not be useful to him due to the personalized nature of therapy:

"Therapy is basically an individual sort of thing; it has to be tailored to the specific needs of the individual and to me that's something that my therapist and I have to decide and I'm not sure what other people are doing would necessarily be very helpful." (M6)

Summary: At least four participants wanted to share their health and fitness-related data on a website like *PatientsLikeMe* anonymously. Some participants cited concerns like demotivation. There were also unexpected results like: desire for social interaction and reservations sharing objective data within this group.

DISCUSSION

Our study contributes to an emerging body of work on tracking and sharing physical activities for people with mobility impairments. Our findings show that from the perspective of a person with a mobility impairment potential advantages of automatically tracking and sharing data include learning more about one's condition and about new physical activities to try. From the therapist's perspective, having access to automatically tracked activity data could improve understanding of patients' actions outside of therapy sessions and, when aggregated on a website like *PatientsLikeMe*, could inform and inspire personalized therapy decisions.

These findings point to the unique benefits and challenges in sharing health and fitness data for people with mobility impairments compared to other users.

Peers. A strong theme from both therapists and participants with mobility impairments was the desire to compare to and/or share data with peers who are in some way similar based on their mobility impairment. Our participants also strongly desired social features and the ability to interact with peers, not just passively view their data. Most obviously, these peers could be defined as others who have similar functional abilities, but other possibilities worth exploring include people who are at the same stage (e.g., recently diagnosed) or who have the same medical diagnosis (e.g., cerebral palsy). An online system such as *PatientsLikeMe* could support searching for users along these criteria. Future work should also explore how these competing definitions of peer groups may offer different types of support or motivation for an individual.

New Activities. Another theme that arose was the potential seen by both the therapists and the participants with mobility impairments to learn about new physical activities. A user with a mobility impairment may need specific physical activities that are adapted to their particular motor abilities. An online portal could thus inspire users to try new activities by seeing what other users with similar functional abilities are doing. One therapist even thought such data could help her to convince patients to try new activities. This focus is different from the more general social support benefits of sharing automatically tracked fitness data among users *without* mobility impairments [16].

Challenges. In terms of challenges, while sharing specific activity data (e.g., number of steps) may benefit people without mobility impairments, as suggested by Fritz et al. [16], there may be a greater possibility among people *with* mobility impairments that comparison data could lead to

demotivation or depression; this suggestion was made both by therapists and by our participants with mobility impairments. Therapists' need for statistical information indicates how both groups wanted different information about people with mobility impairments: therapists wanted objective data, whereas people with mobility impairments wanted subjective data. Future work should explore how different types of data could be automatically shared to benefit different groups. At least one therapist was also concerned about the safety of his patients when performing new activities outside of therapy sessions. A potential solution presented by a few therapists and people with mobility impairments could be to explore ways to allow the website to professionally validate any suggested activities.

Psychological Data. Though it is not currently possible to automatically track psychological measures such as mood, several therapists were interested in having access to this data in addition to physical data (e.g., miles rolled). Correlations between the psychological and physical data were especially of interest. However, whether patients would be comfortable sharing their psychological data with therapists is an open question; it was mentioned as a concern by some of our participants. Additionally, because psychological data would likely be collected through self-report it may be affected by issues of compliance and could be unduly burdensome for users with dexterity impairments (e.g., if done through a webpage or mobile app). Further work is needed to assess the extent to which psychological data is in practice a useful complement to automatically tracked physical data for therapy decisions and, if useful, how to appropriately collect it from this population.

Broader Impacts. Our study explores the opportunities that automatically tracked activity data can bring to stakeholders like therapists and people with mobility impairments. However, our findings also highlight potentially unintended implications for insurance companies. Though based on only one therapist's interest in showing her patient's progress data to insurance companies, this clearly raises issues of privacy. Researchers should seek answers to: How comfortable would people with mobility impairments be towards sharing their data with their insurance companies? To what extent will insurance companies rely on this data to make decisions about the patient's healthcare?

Design Opportunities. Finally, based on our findings, we identify the following design opportunities to explore in future work with people with mobility impairments:

- Support anonymous sharing or use of nicknames when sharing with peers with similar impairments
- Support the ability to find people based on similar conditions, goals and functional abilities.
- Support selective sharing (e.g., objective data with therapists, personal experiences with peers with similar impairments).

- Support social/peer learning for both therapists as well as people with mobility impairments.
- Support professional validation on physical activities before others with similar impairments can try.
- Support seamless integration with the existing documentation systems used by therapists.

LIMITATIONS
All findings from our study are based on the perceptions of therapists and people with mobility impairments rather than actual use. It will be important to confirm and compare our findings with a field study and actual use of tracking technologies. Second, automatically tracked health and fitness data could be sensitive, private information for many users. Even though most of our participants were open to the idea of sharing this data, by recruiting a broader pool of people with mobility impairments we will be able to identify concerns with sharing health and fitness-related data that were not already captured from our work.

CONCLUSION
We conducted semi-structured interviews with 10 therapists and 10 people with mobility impairments to understand the potential impact of sharing automatically tracked activity for users with mobility impairments. Our findings highlighted the potential benefits of sharing this data both with therapists and with peers who have similar functional abilities, such as learning about new activities to try and informing therapy decisions. At the same time, we also bring to light open questions associated with sharing. Lastly, we present design guidelines based on our findings to build tools to support sharing of this tracked data with peers with similar impairments and therapists.

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