Crafting a View of Self-Tracking Data in the Clinical Visit

Helena M. Mentis[1], **Anita Komlodi**[1], **Katrina Schrader**[2], **Michael Phipps**[2],
Ann Gruber-Baldini[2], **Karen Yarbrough**[2], **& Lisa Shulman**[2]
[1]Department of Information Systems, University of Maryland Baltimore County, Baltimore, MD, USA
[2]University of Maryland School of Medicine, Baltimore, MD, USA
{mentis, komlodi}@umbc.edu {kschrader, mphipps, abaldin, kyarbrough, lshulman}@som.umaryland.edu

ABSTRACT

When self-tracking encounters clinical practices, the data is reshaped by goals and expertise that exist within a healthcare framework. To uncover these shaping practices, we provided a Fitbit Zip step-count sensor to nine patients with Parkinson's disease. Each patient wore the sensor for four weeks and then returned for a clinical visit with their neurologist. Our analysis focuses on this first clinical visit after four weeks of data had been collected. Our use of conversation analysis of both talk and action makes visible the practices engaged in by both collaborative members to 'craft a view' of the data toward shared decision making. Our findings reveal the deliberate guiding of attention to specific views and interpretations of the data through both talk and actions and we explain how our systematic analysis has uncovered tools for the mutually beneficial crafting practices of the clinician and patient.

Author Keywords

Activity tracker; quantified self; self-tracking; perception.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

For those with difficult-to-manage chronic conditions, aligning self-tracking data with health goals is a crucial step in sustaining healthful behavior. As self-tracking data is increasingly being integrated into electronic health record (EHR) patient portals the potential is there for bringing this data into the clinical office visit [34,36]. These new tools offer the possibility for relating the information that is generated during doctors' visits with the information from people's daily lives. In a sense, self-tracking is blurring the line between the home and clinic [9], and a challenge for the design and use of self-tracking tools is how to design for this bridging moment. For instance, the US-based EHR provider, EPIC, is now supporting patients to upload certain self-tracking data through the patient portal. But there is no indication that clinicians nor patients know how to incorporate this data during routine clinical visits. Despite incentives under the U.S. Affordable Care Act to support more data-driven medicine, questions still remain about what practices and tools needs to be in place so self-tracking data can be integrated into patient records and used to monitor health in a patient-centered manner. Self-tracking data needs to move beyond the rhetoric of simply being there to "inform" as that will be greeted as more work by clinicians. And yet there is a lack of evidence in how to support the discussion and use of this data in order to integrate it into clinical management of chronic conditions.

This is a challenging question if you consider that when self-tracking encounters clinical practices the data is reshaped by goals and expertise that exist within a healthcare framework [34]. One can not simply fold self-tracking data into established clinical practices without some work on the part of both the patient and the clinician. For one, the data differs from what is reflected upon at home. For instance, one's multiple blood sugar readings when at home have very different implications on care trajectories when discussed during the clinical visit [32]. This is because of how the data is shaped and co-interpreted by both the clinician and patient [1,19–21,37]: an object of scrutiny may take on many different forms as a result of each of the different actors' viewpoints [31]. Data is only understood via manipulation and interpretation based on context and experience. This means that data viewed by oneself may transform and take on an entirely different meaning in a collaborative viewing full of negotiation and interpretation [1,20,37].

In our research program, we were motivated to explore the practices that emerge by both the patient and clinician in utilizing that data within a clinical visit. Although self-tracking practices as well as the integration of self-tracking data into the clinical sphere have been of great interest to the HCI community, the studies to date have not explored the talk and actions that surround the use of the data within the clinical realm [2,22,46]. Our immediate questions are not whether self-tracking data will be used in clinical healthcare settings or if it has some measurable effect on health outcomes (although this is an interest of ours in the

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long term), but *rather how is the presentation and shaping of self-tracking data enacted via talk and actions.*

These questions translate to our focus on the work required to *shape the data to engage in the co-construction of knowledge and shared decision-making*. In this paper, we show that clinicians and patients do not simply look at the data, but they engage in *crafting a view* towards some mutually agreed upon understanding. By 'crafting' we are building on the work of Mentis, et al. [28] who described this collaborative data usage process as a deliberate execution on what view of the data is of importance to invoke a particular view of the body and actions on the body to be shared. The data is visualized and configured in such a way that it conforms to the needs of the collaborator and thus plays an important role in the way the visualized data is discussed and acted upon [19][37]. Interactions with the visualization of the data does not simply highlight data as much as actually produce a particular view of the body. Thus, through crafting a view of the data during discussion, each collaborator is disciplining the data leading to a particular presentation towards a particular aim. Typically, this aim is to argue towards a particular co-interpretation of the data. We are specifically discussing how the dialogue and actions enacted by both the clinicians as well as patients have a shaping effect on what is attended to in the data visualizations as well as how that data is interpreted.

We provided a Fitbit Zip activity tracker to nine patients with Parkinson's disease – a group of patients that could significantly benefit from a regular walking practice. Each patient wore the sensor for four weeks and then returned for a follow-up appointment with their neurologist. The analysis presented here focuses on this first clinical visit after four weeks of data had been collected. Our use of conversation analysis of both talk and action makes visible the practices engaged in by both collaborative members to make sense of the data towards a shared care decision. Our findings reveal the deliberate guiding of attention to specific interpretations of the data through both talk and actions. We also show the discrepancy between the clinicians' actions on the data and the patients' 'hands off' nature with the physical data objects. Finally, we explain how this analysis has uncovered suggestions for designs of shared data viewing tools in the clinic to support crafting.

BACKGROUND

Self-Tracking Data within the Clinical Health Context

Advances in self-tracking technologies and infrastructure including health monitoring sensors, EHR patient portal integration, and web-based self-management apps have the potential to transform how people with chronic conditions manage their care. Yet there is still very little known about how to harness these opportunities to meaningfully enhance quality of care and self-management within the clinical visit [32,34]. Both patients and clinicians perceive self-tracking technologies as an opportunity to improve communication [2,46], however patients and clinicians are uncertain of the data's role in disease management [23,45]. With time, though, self-tracking data will increasingly be integrated into EHR patient portals and web-based apps. For instance, the University of Maryland Medical System EHR provider, EPIC, recently began to support data uploading from FitBit and Apple HealthKit sensors and plans to expand to a larger range of accelerometers in their next release.

With this future integration in mind, there has been an interest in understanding how self-tracking data can be usefully integrated into the clinical health context [2,22,46]. Of note is the work by Chung et al [6] who adopted the framework of boundary negotiating artifacts [25] to investigate how patient-generated data was transformed into different physical or conceptual forms to support collaboration. Their specific notion of inclusion artifacts – the data patients bring to the clinic visit – is the type of object we are investigating in this study. Around that object, we are exposing the talk and actions by each party that shape that data into a meaningful artifact. Chung et al [6] also uncovered in their study that patients were frustrated with not being able to focus on their most pressing questions. The authors state that this was uncovered a design opportunity to create goal-oriented visualizations or summaries to help focus the collaborative review. With the following study, we argue that the visualization itself is not at issue; rather it is the mechanism with which a collaborator has to craft a view of the data in order to guide the other's gaze. With our study, we are uncovering how each collaborator currently guides the gaze of the patient-clinician pair on the data in order to focus on questions of interest.

Co-interpreting Self-Tracking Data towards Shared Decision-Making

As the clinical sphere moves towards embracing 'messy' life data for more meaningful clinical encounters, there is also a shift in the way that knowledge and power are manifest in the clinical realm. This is particularly important to address as there is often negotiation and interpretation of data in clinical decision-making [1,19–21,37]. Studies show that health data is not self-evident and work must be done in order to use the data in practice. Despite the trajectory of technological innovations to reveal more information about the body, assessing its health and functions is still a matter of negotiation and interpretation [3,20,37].

In collaborative contexts, this is especially true as different experiences can significantly affect one's ability to 'see' the same data interpretation as well as communicate about it [27]. A stimulus that is held constant can still evoke different interpretations due to it being embedded in a context as well as the experiences and knowledge one brings to bear on the perception of what is before them [15]. All seeing of data is interpretation – no matter if you are a patient on which the data is being collected or a clinician whose training provides medical explanation and data reading skills – and interpretations differ in how they are linked to past experiences, motivations, and the role of each person [31].

As self-tracking data begins to be more accepted in medical context, we are then at risk of blindly reproducing traditional disease-centric assumptions and power asymmetry in the discussion and use of that data [42]. A solution to sidestep that problem is to support the co-construction of knowledge [42]. Mentis et al [30] highlighted the iterative and constructive data interpretation acts that are reliant on an alignment of shared perceptions between clinician, patient, and lay caregiver – that which they termed *co-interpretation*. In their follow-up work [29] they further showed the changes that occur in clinical co-interpretive practice by the use of a simple movement sensing system in clinical practice. Some of these changes were of benefit such as the sensor validating the patient's felt experience and the clinician using the data as prompts for patients to further reflect and share their perceptions. However, there were also drawbacks to the introduction of a movement sensor to the co-interpretive practice, most notably the raising of the sensor data as embodying truth as well as the clinicians providing their own interpretation of the data before allowing for patients to form and articulate their perspective. These are both benefits and concerns we wished to observe within the context of self-tracking data – data collected outside of the clinic walls and of which the movements were not directly observed by the clinician.

Daily Walking for Patients with Parkinson's Disease

With this study, we are particularly interested in activity monitors and, in particular, those that provide a daily step-count. Numerous studies show the feasibility and benefits of step-count monitors across many chronic conditions [8,10–13,26,33,39,44]. The Parkinson's disease (PD) patient population can attain considerable health benefits from a daily walking practice. PD is the second most common neurodegenerative disorder and the incidence of PD is likely to increase as the proportion of older individuals within the population increases [43]. PD symptoms show individual differences, disease progression is variable, and the degree of disability can fluctuate over the course of a day. As the disease progresses, people with PD experience losses in mobility and independence and subsequently a strong negative impact on the quality of life of patients and their family caregivers. Daily walking for patients with Parkinson's disease is 1) pivotal to maintain independence, 2) improves diverse symptoms of chronic conditions and 3) is a key component of prevention – delaying disability and reducing risks of disease progression [5,41]. However, sedentary behavior and poor adherence to activity/exercise recommendations are overwhelmingly persistent problems [24,35].

METHODS

The fieldwork was performed at a neurology ambulatory center associated with the University of Maryland Medical System. We obtained Institutional Review Board approval from the University of Maryland Baltimore Office of Human Research Protections and participants consented before beginning the study. Currently, the neurologists in this center discuss the importance of regular activity and ask their patients about their activity levels, but the discussions are not substantial and the physicians are concerned that the patients are not aware of how little they are actually walking. The following study was an opportunity for the neurologists to have some real data during these discussions.

Study Design

Patients were recruited after their regularly scheduled clinic visits with their neurologist. If they expressed interest, they were provided with a Fitbit Zip (that they would keep as a thank you for participating in the study) and a thorough explanation and walkthrough by the research coordinator on how to use the activity tracker. The patient would log-on to the Fitbit website with their own email address and a self-assigned password, which they then would share with the research coordinator for her to use to download the data at the end of the study. At the end of this session the patients were also provided with a document explaining how to use the activity tracker and how to regularly sync the activity tracker data with their app or the web.

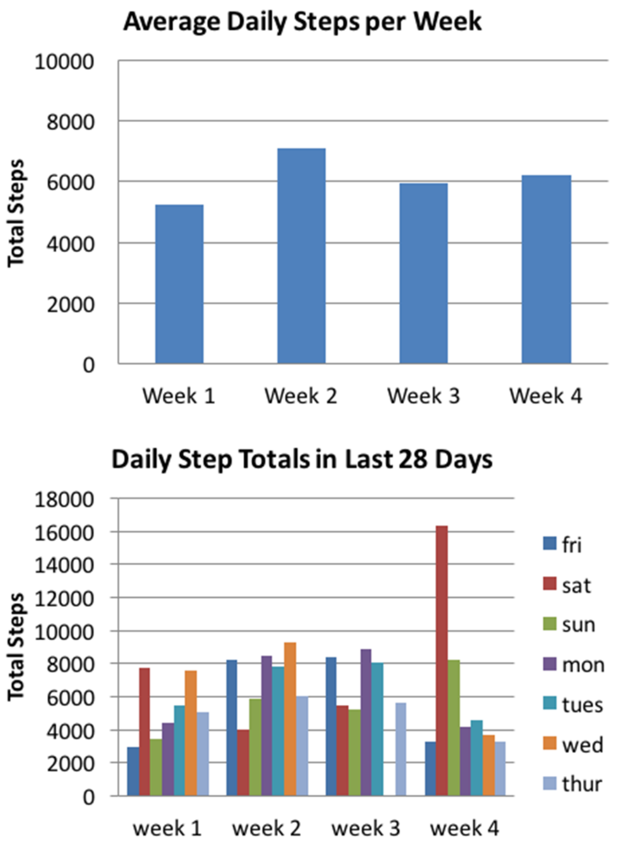


Figure 1. Weekly and Daily Step-count Graphs. Each clinician-patient session was provided these two graph views created from their downloaded Fitbit Zip data.

Table 1. Patient Demographics

	P1	P2	P3	P4	P5	P6	P7	P8	P9
Age	67	57	55	65	66	59	70	64	53
Gender	Male	Male	Male	Female	Female	Female	Male	Male	Female
Neurologist	DR1	DR1	DR2	DR2	DR2	DR1	DR2	DR2	DR2

For four weeks, the patients wore the activity monitor and had access to view their step count data on their personal tablet, phone, or computer of their choice. Patients then returned for an office visit with their neurologist to discuss the data. Due to the length of time between regularly scheduled meetings (typically a 3-6 months' time period), these 1-month follow-up office visits were scheduled for the sole purpose of discussing the activity tracker data. Thus, the office visits were scheduled for only 10 minutes.

During these visits, the clinician and patient were seated in a private clinic room and provided with two graphs that would be similar to planned presentations of self-tracking data within EMR systems such as EPIC: a daily step-count view and a weekly average step-count view (Figure 1). Although the patients had access to their data through the Fitbit apps or web interface, the neurologist had not seen the data prior to the office visit and neither the patient nor the neurologist had seen these specific aggregate graphs. The patient-clinician pair were presented with two copies of these graphs in cases where both the patient and clinician desired their own view.

Study Participants

The patient inclusion criteria for the study was: 1) Idiopathic Parkinson's disease diagnosed by a movement disorders specialist, 2) ability to walk with or without a cane, 3) optimization of anti-parkinsonian medications, 4) successful completion of the Evaluation to Sign Consent. The patient exclusion criteria included: 1) presence of aphasia, 2) patients requiring use of a walker or human assistance, 3) presence of active/unstable medical conditions, 4) non-fluent in English. A total of nine patients were recruited.

Two attending neurologists who specialized in PD were recruited for this study. This was a targeted recruitment as both neurologists see the most Parkinson's patients in the clinic and are interested in motivating their patients to increase their walking behavior. They had little experience, though, with including and discussing patient-generated data as their current patients either do not use self-tracking technologies or do not bring the data to their appointments.

Table 1 describes the patient demographics and which neurologist conducted the follow-up session. Throughout the findings, we refer to patients with the code PT#, referring to the patient number that is found in Table 1. Likewise, DR# refers to one of the two neurologist.

Data Collection

We employed observations, video recordings, and field notes for analysis. We also had the opportunity to ask questions of the clinicians following the assessments to further clarify and provide insight with what we observed during the clinical appointments. Video recordings were used for systematic action analysis. We positioned a video camera on a shelf over the desk pointing down to capture actions and talk while not capturing faces. Video recordings included discussions of the graphed Fitbit data between patients, clinicians, and any caregivers that may be present. As a further step in data collection and validation, we employed member-checking throughout the study by discussing our interpretations with the clinicians.

Data Analysis

For the evaluation of the captured videos, we followed the analytical practice outlined in detail in Heath, Hindmarsh, and Luff [16]. We began by conducting an ethnomethodologically-informed Conversation Analysis [18]. This entailed a detailed Conversation Analysis transcription that captured utterances, pauses, inflection, and overlap as well as a notation of visible conduct as outlined by Goodwin [14] and Heath & Luff [17].

We then engaged in an iterative open-coding method that categorized the resulting practices until clear themes were revealed. Our focus for this analysis was around uptake and use of the data as a resource for co-interpretation. We progressively refined and compared concepts to one another to gain internal coherency. We achieved this by focusing the analysis on how the clinicians, patients, and caregivers assessed and communicated about motor and functional ability based on the use of the data, talk and body language. The practices entailed by the clinicians were interpreted as needs for the data in care practices while the challenges identified were interpreted as opportunities for sensors in facilitating co-interpretation practices.

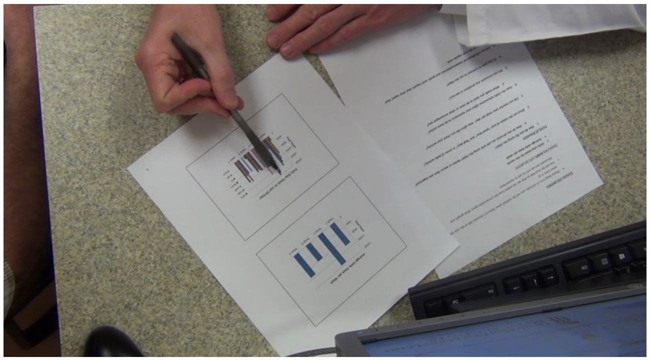
RESULTS

Despite the patient-clinician pair viewing the same data throughout the session, there were three different ways that the data was taken up and shaped to inform the conversation. Each of the following three sections corresponds to one of these three different crafting moments. As our motivation was to explicate the talk and action that come together in these uses of the data – this is not achieved with one quote, but rather a series of action and talk. Thus, we present our findings as vignettes from our observed data, each illustrating key moments for the co-interpretive process of self-tracking data use. The examples provided are indicative of these data use moments, but are by no means the only occurrences witnessed – these are clear trends seen across our data sample.

Co-Interpreting the Data Outliers

When presented with the data for the first time, it was understandable that the first characteristic the clinician would highlight in the dialogue were the data outliers. These were either high or low step counts that perceptually popped out. Thus, clinician typically began with the Daily Step-Count graph. This is the graph that presented the total step-count for every day in the prior four weeks. Oftentimes it revealed these outliers had nothing to do with the patient's motivation, or lack thereof, to walk. More often these anomalies were due to some intricacy of life. For instance, the following patient's high days were entirely due to the ebb and flow of his work.

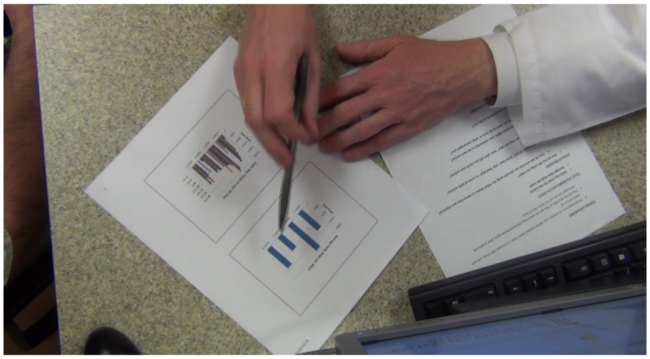
1 DR1 ((Leans over graphs)) Let's see if there's any patterns that we can se::e at all_ (0.2) It seems like (0.2) on that one Saturday you >kind of took it a little< easier maybe(,) but otherwise it was >pretty consistent around< the 10,000 >which is the recommendation<(.) (0.2) [Wow this is amazing, here you reached 20,000 steps on one day(,)] [((points to day with pen, hovers))] 2.0



2 PT2 I know what day that was(.)
3 DR1 What was that(?)
4 PT2 We had a lot of deliveries that day, hospital beds and chairs_ I deliver medical supplies_ That one day there, we were pretty well swamped(.)
5 DR1 OK(.) So you did lots of walking clearly_
6 PT2 Yeah(.)
(2.0)
7 DR1 >That's right(.)< So you're still working full time right(?)
8 PT2 Yeah(.)

In the first half of this vignette, we see the clinician identifying a very high step count on one day and this revealed how the patient's job played an important part in the amount of walking he was achieving. Later in the session, the clinician had turned his attention to the Weekly Step-Count graph – this presents each of the four weeks as an average daily step-count. He is now beginning to see the impact of the patient's uneven work schedule on his walking behavior and brings into focus outliers in the averages asking how they are being affected by this factor.

50 DR1 [What do you think ((Points to Weekly Step-Count Graph))] (1.5) were the factors that made you a little less active maybe in the third and the fourth week(?) Was it just not as busy [at work(?)]



51 PT2 [>Not as busy<], probably(.) That would almost have to be::e, it was slow for a few days(.) (0.2) It runs in spurts(.) Some weeks >we're really busy< and then other weeks we're not real busy it depends on what we've got to do_=
52 DR1 In your free time, unrelated to your work, how much physical activity do you do then?=
53 PT2 Mmm::mm Not a lot(.)

Here the outliers identified in the Daily Step-Count graph and the Weekly Step-Count graph came together to spur a discussion regarding activity outside of work – i.e. activity that is self-motivated by the need to maintain one's mobility due to the PD as opposed to required activity due to one's job. The patient was not consciously aware of how much he was walking overall, but, more specifically, he was not aware of the impact his job had on the amount of activity he was and was not getting. The clinician guided the review of the data by calling attention through both talk and action to the daily step count and then the weekly step count. Along with the conversation around the significant highs and lows that were evident in the presented data the patient was able to contribute his knowledge towards specific moments of interpretation to provide a better understanding of his walking behavior in the context of his life. What is important is that this guided use and co-interpretation of the data began to emerge for the clinician as well as the patient and highlighted a problem with the patient's activity level that might have been missed had they been simply discussing average over the week or month. Addressing one's self-motivated walking behavior early, while one is still fairly functional, is an important step in maintaining activity as the disease progresses.

Having one variable in one's life that would impact the data so noticeably was a bit of an anomaly for our data set. What we saw happen much more often was a mix of various life factors that had some fairly large step-count impacts. With the following patient, his low days were primarily linked to a vacation while his high days were due to being back into the routine of work and after work exercise.

```
29 DR1  Overa::ll >we can see that< there are
   some days that are (0.2) lower(,) Like
   [here green is (0.5) Thursday(.)]
   [((Points to Daily Step-Count graph))]
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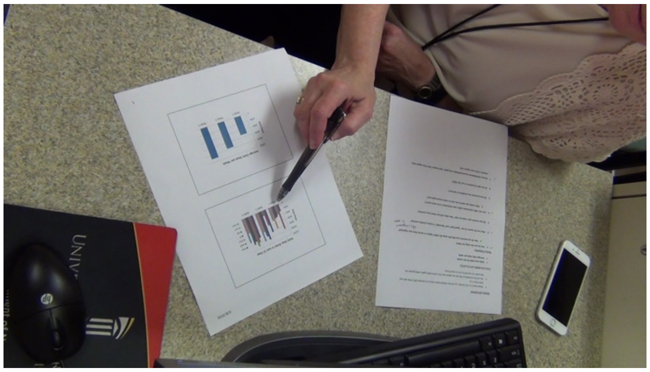

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   But then the thi::rd week on Thursday is
   >your highest day in fact<. What is your
   explanation [for days that are a little
   lower or higher(?)
30 PT3         [Well, I can explain that easy
   enou::gh is week 2 ((Gestures to graphs))
   that very, very low Thursday, that was
   the drive day home(.) That accounts for
   being fairly sedentary in a vehicle and
   then when you do get home, you don't do
   too much to make up for that (0.2) or at
   least I didn't. Then u::m the previous
   Thursday ((Gestures to graphs)) on week
   1, was one of those days where I think
   largely, we did our fishing(.) That
   started with our little fishing trip, so
   I was out on a lake in a boat for a good
   part of the day and then when I wasn't, I
   was recuperating from being out in the
   boat because that takes it out of you,
   you know. You're in the sun all day.
   You're having fun, but nevertheless, all
   that stuff. Then that third week
   ((Gestures to graphs)) where Thursday was
   (0.5) higher than average days in
   general, I think was just a (0.5) typical
   work day along with some after work
   exercise or activities where we did some
   walking and running in addition to the
   routine of work(.)
```

At the start of this vignette the clinician called attention to specific days in the Daily Step-Count graph through both talk as well as explicitly pointing to the graph. This then subsequently set the stage for the patient to highlight his own experience for each of the days in question. Throughout this interchange, the patient is highlighting that it is not his internal motivation to walk or not, but the realities of leisure and work that had led to the outliers.

However, understanding of anomalies was not very informative with regards to devising walking strategies and goals. It only provided small snapshots of understanding that might not be very informative going forward. For instance, incidents we saw such as a vacation in August, a family death, forgetting one's Fitbit, or bad medication reactions are all singular life events that do not address how the patient is managing to integrate walking into their lives. What we see next is how the clinician begins to shape the way the conversing pair identify a walking *trend*.

Building Up the Story from Trends

After a review and discussion of data outliers, the clinicians would turn once more to the data and begin to look for trends. This might entail the Weekly Step-Count graph view at this point or still the Daily Step-Count graph. Whichever data they took up, this was typically led by the clinician who was seeing the data before them. But the process of co-interpretation was also engaged in by the patients who were adding their perception of what they sensed from their lived experiences as well as what they saw in the data.

In the following vignette we see the clinician begin to craft a view of a trend based on days of the week. Her use of the pen is meant to specifically guide the eye of the patient to see and confirm this day-based trend.

```
13 DR2  When we look at the day by da::y
   graphs the (0.2) one consistent thing
   that pops o::ut to me is that the
   [orange bars are consistently, even in
   recent weeks, >I don't know about the
   week five here, but in week three, week
   four, and week two, they're the low]
   [((Points to each orange bar on the Daily
   Step-Count graph))]
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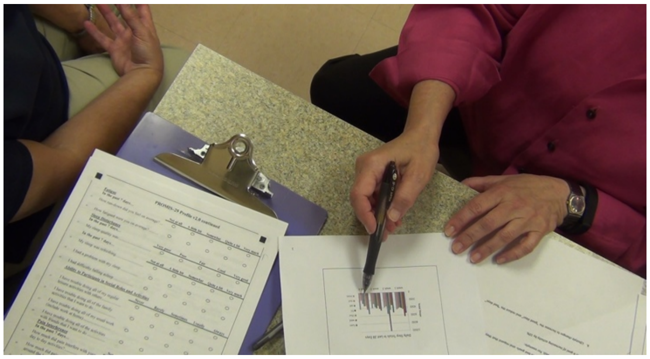
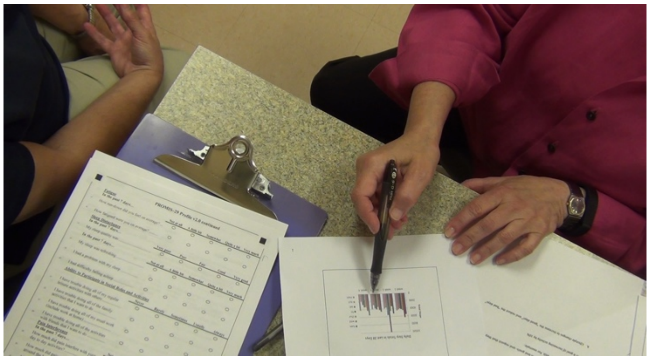
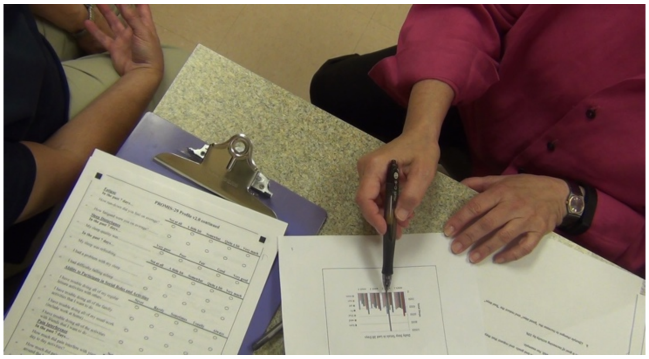






and that's Sunday so Sunday was=
14 PT4 >I probably do< less on Sunday. I might read a lot or you know_
DR2 I mean it's good to know that because here is the average ((Points to Weekly Step-Count graph))so even if we focused on days where you are low in order to try to [focus on that(.)]
15 PT4 [Well there] ((Gestures to Weekly Step-Count graph)) are many days when I want to go out and wa::lk but when the medication wears off it's like I'm a little shaky and my right foot >kind of< like dra::g you know I'm like almost limping kind of(.) When I'm like that (0.5) there's not much I can do. I mean, I can do some things-

We first see in this vignette the clinician noticing a small pattern with Sundays being a low day. She points to each of the Sundays on the Daily Step-Count graph for the patient to see the relative difference. The patient adds that those are most likely low days due to her desire for leisure. The clinician then refers to the weekly averages stating that the Sundays may be having the unintended effect of an overall low average step-count. But this is where the patient moves the conversation in the direction of a barrier that is really causing the problem for her – her chronic illness and the ineffectiveness of her medication. This is a common problem when a patient has been on levodopa for a few years – the medication will not last as long as it had before and this requires a closer spacing of medication being taken or higher dose. This discussion again brings up that overall trends are not due to one's lack of motivation, but rather a problem associated with one's health condition. It was the change in shaping the way the data was viewed that is interesting here, though. Whereas the clinician wanted to see the trend in the daily total step count and deduce that as the cause of the low weekly averages, it is the patient who wanted to change the way the weekly averages were seen. She wanted to highlight how the weekly averages were due to her medication problems and that was a pervasive underlying problem not linked to any one day.

Identifying trends though was not an easy task. Anomalies 'popped' out and were usually better remembered. Trends is where the real work began between the patient and clinician. This required both parties to feel they had something to contribute to the conversation. It required both parties to be looking at the same data in the same manner. In the following vignette we see how difficult the identification of a trend can be for the patient that is aware of how many different life variables come into play, but has no way to organize them and share them with her clinician. Despite specific points of data called out and a trend beginning to emerge, the patient is still unable to link what she is seeing to what she is experiencing.

41 DR2 Then it looks like overall on your weekends, you tend to walk less(.) Do you think that that's accurate(?) [That's your orange bars-((Points to each orange bar on the Daily Step-Count graph))]

42 PT5 Right(.)
43 DR2 And the [blue before it(.)]
[((Points to last blue bar on the Daily Step-Count graph))]

```
   You see how those tend to be- Because out
   here is actually Tuesday(.) Tuesday could
   be quite low. So you see any patterns
   there or you just really can't make head
   nor tail out of it(?)
44 PT5  I don't really see a pattern^
   Although I would like to. I'm a very
   (2.0) organized neat(.) I like repetition
   of things and all(.) I don't feel like I
   have my ducks in a row yet(?) For the
   summer(?) There's too many variables(.)
   With vacation and-
45 DR2  Also with your medicine problems(.)
46 PT5  With the medicine problems(.)
```

As we had seen with PT4, other factors get in the way of regular walking. Although the clinician used the same tactic as she had with PT4, pointing to each of the bars she wanted to highlight as a trend, the patient felt she had nothing to offer in terms of an understanding of that data trend. Instead this patient directly spoke of the challenges in seeing some patterns in her data; particularly as there were other life events occurring (i.e. vacation breaks) and health problems (i.e. a new medication making her feel ill) causing so many anomalies in her data. In fact, this was still very useful information as the trend was most likely not laying within the graphs, but rather a confluence of events that caused high and low walking days. This in turn changes the focus when discussing walking strategies.

Identifying a Walking Strategy

It is understandable that up to this point, the data has been called upon within the discussion – it has been the focus of their interaction and actions were directed towards shaping what graph or bars the pair would attend to. But there is a point in each of these visits where the conversation shifts to discussing potential strategies for increasing walking. This is a point in the conversation where the same old recommendations could be trotted out by the neurologist. What we see instead is the identification of walking strategies that are attuned to the evolving interpretation of the data while still actively shaping what aspects of the data are under scrutiny.

Based on their experience to date, identifying a suitable step-count goal was fairly difficult for most of the patients. They looked at a goal as a maximum as opposed to something that was regularly achievable and maybe even oftentimes passable every day. This was a good opportunity to refocus the attention of the patient on what the data is showing them so far.

For instance, we had a number of patients that had significant health issues that were preventing them from walking as much as they would like. In the following vignette, we continue with PT4 who had medication problems preventing her from walking long distances. Through a further discussion she also indicated severe pain preventing long bouts of walking. The strategy posed by the clinician took into account that even shorter walking sessions spaced out over the day was more feasible for her. Then, later in the session, we see this knowledge coming into play when devising a suitable daily step goal.

```
49 DR2  What would you say(,)- based on the
   fact that >I mean your high day is
   obviously< 10,000(.) Your
   [low da::y is below 2,000 on a Sunday
   over here(.)] ((Points to Daily Step-
   Count graph))
   What would you think would be a
   reasonable goal for you, as an average
   for the week(?)
50 PT4  Steps(?)
51 DR2  Yeah(.) (3.0)
52 PT4  Seven or eight(,) Seven(?)
53 DR2  Seven would be really (0.2) great(.)
   I think that we should say five. Pick a
   practical goal for you that you could
   really with the pain-
54 PT4  That I would achieve in short-
55 DR2  That you could really achieve(.)
56 PT4  ((Leans over and looks at graphs))
   Well, then I guess it would be five(.)
57 DR2  Five would be good. See five is over
   [here
   [((Points to Y axis on Daily Step-Count
   graph))]
```

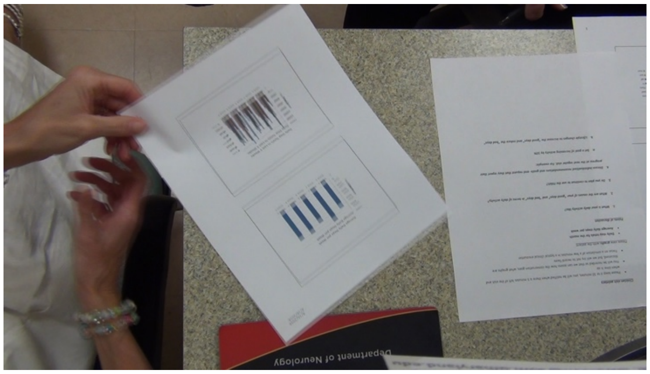
```
   so still it's the minority of days(.) See
   (0.5) [if I put a line across here,]
   [((Draws invisible line with retracted
   pen tip on the Daily Step-Count graph))]
```

```
   it's the minority of days that you hit
   five (0.5) you know so-
```

We begin this vignette with the clinician using talk and gesture to highlight the lowest daily step counts as a means to devise an attainable walking strategy. The patient, though, aims much higher than the clinician had in mind so her attempts at shaping the conversation had not been met. So he suggests another number which the patient agrees to as well. However, at this point, the clinician uses the data to highlight *why* this number is an attainable goal. She uses her pen to draw an imaginary line across the data at the goal they just agreed upon. This makes visible for the patient how the prior four weeks' data would fall within that goal.

Compared to our prior vignette, in the following vignette, both the clinician and the patient use the data to support their argument through both talk and gestures.

```
28 DR2  What do you think would b::e based on
   your knowledge now- what do you think
   would be a good goal for you to consider
   for activity(?)
29 PT9  In terms of steps(?)
30 DR2  Yeah(.)(4.0)
31 PT9  Probably 15,000 steps a day would be
   a good reach for me(.) >I think there's
   one< or two days ((Gestures to Daily
   Step-Count graph)) that I made 15,000
   steps and I was very pleased with that(.)
32 DR2  That is a big goal(.)
33 PT9  I think all I would have to add to my
   daily routine would be a serious walk
   (0.5) every day(.)
34 DR2  It's always important when you set a
   goal it has to be a realistic goal(.)
   Otherwise, you (0.2) can be really (0.2)
   disincentivized by really not reaching
   your goal(.) Probably you want to do that
   in phases-
35 PT9  Okay well shall we knock it down to
   10,000 a day then(?)
36 DR2  Yeah(.) Yeah(.) Let's do that(.) But
   if you reach 10,000 a day
37 PT9  [((Picks up shared graphs))]
```



```
38 DR2  [at least three days a week] (0.5) I
   would think that that was quite good(.)
   [((Picks up second copy of graph))]
   [>Let's see what you're doing here.<]
   This is the 10,000 mark(.) There was,
   week two you did that. You reached 10,000
   or more.
39 PT9  Mm-hmm^
40 DR2  Week four(.) Week three(.) Actually
   you reached 10,000 three days a week
   almost every week except for week one(.)
```

We begin this vignette by seeing the patient use the data as evidence of her ability to achieve a 15,000 step count. She uses both talk and gesture to call attention to these points on the graphs – lending evidence to be co-interpreted by the clinician. The clinician then provides her assessment of that number as being a large goal and perhaps a lesser number is more incentivizing. When they agree on 10,000 steps per day, the patient picks up the graphs to better read them based on their ongoing discussion. This was a unique moment that we did not see with our other patients. This then leads to the clinician picking up the second copy of the graphs and point out on the Weekly Step-Count graph that her average step count was above that step-count goal. She then continues to turn their attention to the Daily Step-Count graph and point out how each week had at least a few days of reaching that goal. This shared use and shaping of the data through talk and actions is how a walking strategy evolved in a co-interpretive practice.

DISCUSSION

In this study of self-tracking data use during clinical visits, we have foregrounded the talk and actions that bring various aspects of the data into focus for the collaborative pair to interpret and act upon together. We wanted to reveal the work that is conducted beyond simply looking at the data 'to be informed' in order to make the data clinically relevant. We showed that the same data comes into being three different ways towards achieving co-interpretation in the clinical visit. More importantly, we have shown how crafting a view of the data through talk or actions turns the data into a resource for these moments in order to be able to collaboratively identify health strategies and goals. This work constitutes the difference between simply looking at the data to one of co-construction and integration of the data.

It is important to note that all of our participants coincidently did not have prior experience with an activity tracker. Although we did not capture their engagement with the Fitbit app or website during the intervening four weeks, most participants mentioned they looked at their step count every day, but did not engage in looking at trends on their own via the app or website. This is important as this means the majority of the interpretation practices were conducted in the clinic. In this light, we are seeing an unequal distribution of crafting between the clinician and patient, both in terms of when data is brought in as evidence (e.g. "let's look at the data", "as you can see here") as well as how actions around the data shape the seeing practices of the pair (i.e. pointing or annotation). Despite the low-tech and equally available placement of the graphs, the interaction of the patients with the graphs was minimal beyond simply viewing. Crafting on that side entailed primarily talk. These moments were especially unique to the patient, though, as it was an opportunity for them to share their lived experiences to explain the data. On the clinician side, they had limited additional information to help co-construct the narrative, and so crafting involved talk around the data as well as physical actions to bring into focus what they saw in the data. In a longer study, we may see these trends change, though, as the patient or clinician may engage in trend analysis prior to the regularly scheduled clinical meetings.

Although this may seem like a effective and efficient idea, there is cause to not encourage that to occur. On the physician side, Anderssen et al [4] showed that the interpretation of implantable cardioverterdifibrillator data was a collaborative practice engaging both clinicians and patients and that, in a telemonitoring setup, much of that interpretation process could not be completed. In other words, the neurologists may not be able to do more than identifying outliers. As for patients, there is a danger to patients drawing incorrect conclusions from the data, which can be detrimental to their health[38]. However, there is some intervention that may be needed as we are seeing the same need for a patient to really look at and understand the data and form their own interpretation as was shown in Mentis, et al. [29]. Only then is the patient able to engage with the clinician in a co-interpretation process. We thought that the use of data that was captured outside of the clinic would have a more equalizing effect in the amount of time both parties needed to start creating their own understanding and so we would see an equal amount of crafting practices, but this turned out to not be so. We think these two studies are beginning to show a clear need for interventions that allow patients to craft a view of the data.

This is where we return to a discussion of the tools that bring the patient and clinician together into the practice of continually crafting a view of the data through actions and talk throughout the clinical session. Our analysis of the talk and actions used have uncovered mechanisms that could easily be enhanced through further interactive tools. In the following section, we explore two design opportunities for the presentation of self-tracking data in the clinical visit.

Tools for Crafting a View of Self-Tracking Data in the Clinical Visit

Our findings have led us to some clear design implications. However, by design, we do not entirely mean design of the visualization of data being reviewed during the clinical visit. The opportunity for changing the EHR interface is minimal. However, there are specific tools that would have an enhancing effect on the practices of crafting a view that we aim to support.

Annotation capability: Pointing and annotating were common actions taken up by both the clinician and patient. These are the tools that allow the data visualization to be disciplined. If these were interactive graphs, then we might expect further interactions such as zooming in or clicking on a week to highlight the week's days. However, the act of pointing and annotating should not be dismissed even in such interactive scenarios. Providing a digital pen for annotation and pointing allows for the display of these gestures on the graph as well as the capture and later review of these gestures. For instance, a patient could review what was circled or pointed to or where the line was drawn across on the graph when they returned home. Likewise, at the next follow-up visit, the clinician could review what they focused on last time and use those annotations to help craft a viewing of the newly collected data.

Personal views: Presenting personal and shared views is not a new concept for those within CSCW. However, we see this as a mechanism for facilitating patient access for data shaping through actions as well as talk. Providing the patient with a tablet, for instance, set to the patient portal view of the data, reduces the barrier for a patient to interact with the data. This would also likely reduce the patient being always led by the crafting of the clinician and instead allow the patient to shape the viewing practices at all. If also augmented by the annotation capability we outlined, such annotations on the tablet could then be transmitted to the clinician's view of the data and vice versa. Bringing these two functionality together would be a powerful opportunity to further investigate the changes in data crafting.

CONCLUSION

Many questions can to be debated around the usefulness of self-tracking data in clinical care, but we can not ignore that this data is indeed being brought into the clinical sphere and can have real value. This study took a systematic look at how *the presentation and shaping of self-tracking data is enacted via talk and actions* with an eye towards creating opportunities for fully co-constructive decision-making practices to emerge. Our data points to two tools that, although not technologically novel, may provide a needed support to the bridging between the mutually beneficial crafting practices of the clinician and patient.

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