



Telling the Story Right

How Therapists Aid Stroke Patients Interpret Personal Visualized Game Performance Data

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Telling the Story Right: How Therapists Aid Stroke Patients Interpret Personal Visualized Game Performance Data

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ABSTRACT

Data visualizations of training performance can provide patients with insight and motivation to engage in future self-training sessions. Still, patients are in practice prone to misinterpret their data in practice due to lack of health numeracy. This paper contributes an ethnographic case study of how an occupational therapist employed storytelling to help 14 sub-acute stroke patients interpret visualizations of their training performance from a cognitive rehabilitation game. The Trail Making Test based game visualized performance through a timeline, heat maps, and aggregate visualizations co-designed with the therapist. The interactive visualizations enabled the therapist to strategically order and emphasize information to support patients' understanding of their health. We provide an analysis of the therapist's storytelling strategy in cognitive training that depended on patient self-awareness. The paper concludes with a discussion of tensions for designing storytelling in visualizations of health data for self-care systems targeted at stroke patients in clinical and home contexts.

CCS CONCEPTS

• **Human-centred computing** → **Field studies**; *Visualization design and evaluation methods*; Ubiquitous and mobile computing systems and tools;

KEYWORDS

Self-care technology, storytelling, heat map, time line, health monitoring, stroke rehabilitation, trail making test, data interpretation, self-awareness, patient-generated data, health numeracy, framing effects, self-tracking

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1 INTRODUCTION

Ageing societies increase demand for and cost of health care due to higher chronic disease frequency. Stroke is a neurovascular disease requiring rehabilitation for months to restore physical and cognitive abilities. Occupational therapists coach stroke patients in goal-setting and collective training to restore function but face limited capacity to attend to individual patients' needs, crucial for patient-centered goal-setting.

Self-care technologies provide patients with opportunities to increase rehabilitation intensity both during and after hospitalization. But low levels of motivation and self-awareness of patients pose a barrier for the adoption of self-care systems. While the visualization of trends and patterns in patient performance data can foster insight and motivation, mere data visualizations fall short of supporting patients with limited data literacy or health numeracy to interpret their data [18, 30]. In rehabilitation contexts, occupational therapists can assist patients in the process. But how self-care system should provide assistance in contexts without health care professionals as an intermediary is poorly understood.

Over the course of three months, we collaborated with an occupational therapist at a regional neuro-rehabilitation center and observed her training sessions of 14 stroke patients suffering from poor focus and visual neglect. The therapist employed a tablet game *Trail it* and we learned how *Trail it*'s current presentation



Figure 1: Occupational therapist storytelling illustrated in a cognitive training session context.

of performance data impaired the therapist's ability to enter discussions aligned with the patients' self-awareness. We therefore re-designed Trail it to include interactive heat maps and time lines to visualize patient performance. Field study observations focused on how the therapist used these interactive visualizations in her verbal storytelling (see Figure 1), which differed based on the patients' self-awareness level. Patients responded diversely to therapist feedback ranging from rejection, objection to feeling assessed, to improvement anticipations and optimism.

This paper contributes a) qualitative thematic analysis of therapist storytelling during cognitive training sessions and b) tensions in designing storytelling in visualizations of health data. We envision storytelling as a missing link in visualization research that will empower patients to overcome health numeracy barriers and foster their insight and motivation in the absence of health care professionals.

2 BACKGROUND

Stroke is a sudden event caused by disturbances in the brain [35]. Survivors with impairments undergo rehabilitation to recover lost abilities. Rehabilitation routines rely on individual or group training linked with personal meetings focusing on progress review and goal setting [32]. Rehabilitation is costly and challenging because patients hold negative world views [35], lack hope and self-awareness, or are in denial [29]. Occupational therapists utilize models from neurorehabilitation research to understand patient behavior and awareness. The models support therapists in creating treatment programs, proposing goals, establishing trust, and provide feedback to develop awareness in the patient [24, 32, 34].

Malia's model of self-awareness for patients with brain injury contains four levels of awareness [24]:

- *No Awareness*: Unawareness of cognitive deficits, demonstrated by the patient's motoric, social, recall, or problem solving behavior. An unaware patient will deny having difficulties and find excuses to justify apparent indications of a cognitive deficit.
- *Intellectual Awareness*: Intellectually perceiving diminished function. Patients with intellectual awareness are aware of their deficits and can explain their nature, but fail to act appropriately when confronted with challenges, for example solving a trail making test.
- *Emergent Awareness*: Recognizing a problem while it is occurring. Patients with emergent awareness use assistive tools or deploy strategies to overcome challenges.
- *Anticipatory Awareness*: Anticipating that a problem will happen due to diminished function. Anticipatory awareness is rarely reached in the initial months of hospitalized rehabilitation. Patients with anticipatory awareness predict how their deficits affect coming situations (for example an upcoming birthday party) and plan how to work around them.

Self-care technologies aim to empower patient self-management and reduce the burden for therapists and caretakers by having patients self-track health related data [20]. Rehabilitation games, for example, provide immersive training activities to patients and measures the patient's performance which can be visualized and

provided as session summary feedback after training [22]. Visualizations of the collected data supports reflection [9, 10] and relating data to past events [1]. In a clinical context, health technology visualizes patient clinical parameters and progression, which contribute to new training schedule changes and strategies, jointly decided in the goal meetings [32]. General research in visualization has studied self-reflection and decision-making by designing visualizations in a negative framing [21], designing user interfaces to facilitate annotation [27] and providing computer-generated prediction [13], but it is unclear whether these findings and suggestions apply in clinical contexts. In such contexts, self-care systems face poor patient adherence and difficult integration into existing clinical systems [33]. Interactive visualizations are suggested as a means to explore data and gain insight [1, 8, 10], but patients are prone to misinterpret their data due low *health numeracy* [12], i.e., "*the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions*". For example, patients self-tracking health related data displayed unawareness of contextual parameters [25] and overlooked trends [18] when reviewing time-oriented data visualizations.

Research on how to support interpretation of visualizations in clinical and self-care contexts is scarce. Some studies suggested that patients need additional textual features for interpretation [11, 30]. In a clinical setting, Mentis et al. [25] found that therapists helped patients with walking deficits overcome misinterpretation barriers by guiding attention to specific views of outliers and trends in time-oriented bar chart visualizations of step count data. In a self-care setting, Bagalkot and Sokoler let rehabilitation patients self-track by video recording exercises which were overlaid with information to enable self-reflection, articulate concerns, and involve the spouse actively in the patient's physical rehabilitation [4].

To present data effectively and support interpretation of visualizations Kosara and Mackinlay [23] proposed elements of storytelling. In their information visualization context, storytelling did not refer to the old cultural art, but instead to the inclusion of time-course properties in the visualization design process, for example as found in the structural analysis of narratives [5]. Kosara and Mackinlay defined storytelling as "*an ordered sequence of steps, which can contain words, images, visualizations, video or any combination thereof*." They pointed to slideshows as a metaphor for visualization with storytelling and suggested leveraging sub-disciplines such as screenwriting and choreography, but provided otherwise limited design relevant guidance on how to employ storytelling for the effective communication of data.

No study has so far investigated how therapists harness storytelling in the presence of data visualizations to construct feedback for stroke patients during training sessions. For example, what strategies do therapists devise to aid data interpretation for patients who are in denial and how do these patients respond to the training? Neither has the talk and actions surrounding actors and boundary objects in rehabilitation been articulated into applicable knowledge for the design of self-care technology with storytelling in visualizations to empower patients and aid therapists in meeting daily work demand.



Figure 2: Trail it's aggregated data summaries & buttons leading to the timeline (left) and the heat map (right).

To address this, we re-designed an existing Trail Making Test [7] based rehabilitation game called *Trail it* (see [15, 18]). Co-design with an occupational therapist advised the re-design to include a heat map, timeline, and aggregate visualizations of patient performance. The visualizations enabled field observations of talk and actions between the therapist and patients training with *Trail it* in cognitive training. This paper contributes thematic analysis of interactions observed between therapist and patients across three months of cognitive training and derives design guidelines for enabling storytelling in visualizations to provide patient motivation and insight in self-care contexts.

3 DESIGN PROCESS

At the beginning of the study, the occupational therapist had been using a tablet application called *Trail it* for more than a year in cognitive training sessions. In *Trail it*, patients performed visual search to connect numbers and letters consecutively. The game was modelled on the Trail Making Test a neuropsychological instrument used in clinical work to assess processing, sequencing and visual-motor skills [7]. *Trail it* measured patient's reaction time to connect numbers or letters, which appeared as circles across the screen semi-randomly in a grid of 12×8 possible positions. After each ended level, the median reaction time, level duration and remaining time of training highlighted the patient's performance. When a training session finished, *Trail it* displayed a median reaction time across the entire training and for the left and right side of the patient's field of view. Prior to the re-design work, these measurements were shown through four sentences of text, for example, *The average reaction time on your left hand side was 5.65 seconds.*

Trail it was subsequently redesigned, deployed, and studied seven times through field observations with 14 patients and one occupational therapist in a rehabilitation context. Initial iterations of *Trail it* introduced individual patient profiles and adjusting difficulty, training length, additional visual or auditory training assistance, and logging of data. At the end of a training session, *Trail it* collected performance data and these served as a baseline, which informed the subsequent designs of the data visualizations. At the end of field

visits, we approached the therapist for debriefs, which included collaborative reviews of visualization design proposals and discussions of our observations of the therapist's practices. The observations of the patient-therapist interactions around *Trail it* together with the therapist's remarks from the debriefs resulted in the following requirements:

- Present results such that the therapist can adjust her storytelling to the patients' awareness. The therapist expressed difficulty articulating the patient's story with *Trail it*'s textual feedback, compared to other rehabilitation activities (e.g. paper exercises).
- Hide detailed visualizations by default to let the therapist skip them if she deems them irrelevant as tools for her storytelling. This helps hindering patients from attempting to process material with high data granularity which may lead to incorrect interpretation.
- Keep the system's visuals simple (colors, focal points, composition) to reduce mental workload, enabling stroke patient reflection of their performance.
- Use of colors to highlight performance enables better therapist recall of past results.

These insights directed the re-design of *Trail it* which implemented an aggregate data summary, a timeline visualization, and a heat map visualization shown in Figure 2. The summary described the training time, compared correct hits to errors, and calculated the session median reaction time using text, symbolic icons, and a donut chart. Two buttons placed underneath the aggregate data summary provided access to the timeline and heat map.

3.1 Timeline

An interactive timeline showed the daily average of the median reaction times. The x-axis utilized a fixed scale to show daily reaction times and became scrollable when data exceeded screen width. When reaction time for the present day was less than 5 seconds, the Y-axis ranged from 0 to 5 seconds. If the current reaction time was higher, the Y-axis range was twice the reaction time to adapt relatively to patient performance and ensure that smaller fluctuations in the reaction time would not appear as steep changes. Each

data point showed a textual representation of the reaction time it represented and the Y-axis was hidden to minimize superfluous information. The latest training session was given extra emphasis in the timeline through a pulse animation and a clearly marked label. Clicking a data point would show textual information about the data point's ranking and how long time the patient had trained that day.

3.2 Heat Map

A heat map showed median reaction times across the screen, which was divided into six fields, inspired by cancellation tests [16] (with the two middle fields joined). The heat map used an algorithm to interpret and color reaction times red, orange or green. Due to high variance in stroke patient reaction times, the algorithm decided the colors using a combination of absolute values and values calculated relative to the patient's overall median reaction time. Reaction times, which were twice the overall median reaction time or higher than 7.5 seconds were colored red. Other reaction times, which were higher than $1.5\times$ the overall median reaction time or higher than 5 seconds were colored orange. Remaining fields were then colored green.

4 METHODOLOGY

The study aimed at understanding storytelling in therapist-patient dialogue around stroke patient performance, which Trail it visualized at the conclusion of a training unit. Action-based research [17] and technology probes [6] inspired the study design, which involved close collaboration with a single therapist and of patients who attended cognitive training at a rehabilitation center. A three-month collaboration provided opportunity for design and evaluation of four iterations of Trail it. The first iteration provided textual feedback on patient performance but was followed by iterations, which provided performance visualizations. Note-taking captured patient-therapist interactions during seven cognitive training sessions followed by a debrief with the therapist to discuss events of interest. The ongoing collaboration created fluid boundaries between field observations, design, and evaluation to accommodate rapid iteration and deployment.

4.1 Therapist Collaboration

We collaborated with an experienced occupational therapist responsible for the rehabilitation center's cognitive training on the re-design of Trail it, which she had been using in training for a few years. For therapy she relied on Malia's hierarchical model of self-awareness [24] and Townsend and Polatajko's Canadian Practice Process Framework [32]. She provided empirical knowledge and judgement during the visualization design process and important visual changes and behaviour of Trail it user interface underwent her review before implementation. Deployments were tested in cognitive training where she identified abnormal system behavior and made suggestions. The structure and order of cognitive training was not changed, except for the presence of an observer and the provisioning of additional tablets to allow for multiple patients to train in parallel and use them outside these sessions for self-care. The regional ethical review board deemed this kind of app-based intervention too insignificant for formal review.

Patient	Age Est.	Condition	Self-awareness
Brad	25	Undetermined	No awareness
Joe	55	Undetermined	No awareness
Amy	55	Poor focus	Intellectual
Eric	55	Undetermined	Intellectual
Zack	55	Undetermined	Intellectual
Alfred	75	Visual neglect	Near emergent
Flora	65	Visual neglect	Emergent
Eddy	45	Undetermined	Emergent
Sara	75	Poor focus	Emergent
Martha	75	Visual neglect	Undetermined
Jasper	55	Poor focus	Undetermined
Lenard	65	Undetermined	Undetermined
Jessie	55	Undetermined	Undetermined
Charlie	55	Undetermined	Undetermined

Table 1: Patient profiles with age estimates, diagnosed conditions, and self-awareness assessed by therapist.

4.2 Participants and Setting

Fourteen patients with moderate to severe brain injury anonymously participated in seven cognitive training sessions, in which nine used Trail it. We estimated patient age (see Table 1) and where possible the therapist determined the patients' condition and level of self-awareness. For each session, the therapist selected between two to five patients to participate based on type of deficit and schedule availability. The patients had displayed varying levels of self-awareness in cognitive training with the highest level being emergent awareness. Three patients (Flora, Alfred, Martha) were diagnosed with visual neglect, which entails failing to respond to visual stimuli on the contralateral side of their lesion and typically poor insight into this deficit [16]. Other patients participated in cognitive training due to poor focus or for other reasons associated with hand-eye coordination.

Patients typically performed two hours of cognitive training per week. The cognitive training took place in an open space used for leisure and dining. Patients sat in groups of up to four around a table and trained using tablet rehabilitation games or paper assignments selected by the therapist. During the study, a few patients were given the opportunity to continue training on their own with the rehabilitation games during off-schedule hours or home visits.

4.3 Data Collection and Analysis

An open coding analysis [31] identified themes of patient-therapist interactions in the collected field notes after each interview and training session. The qualitative analysis used an ongoing inductive process to refine the interpretation of how the therapist used patient performance visualizations. Patients were cross-identified, represented in the data by pseudonyms and matched to available quantitative data.

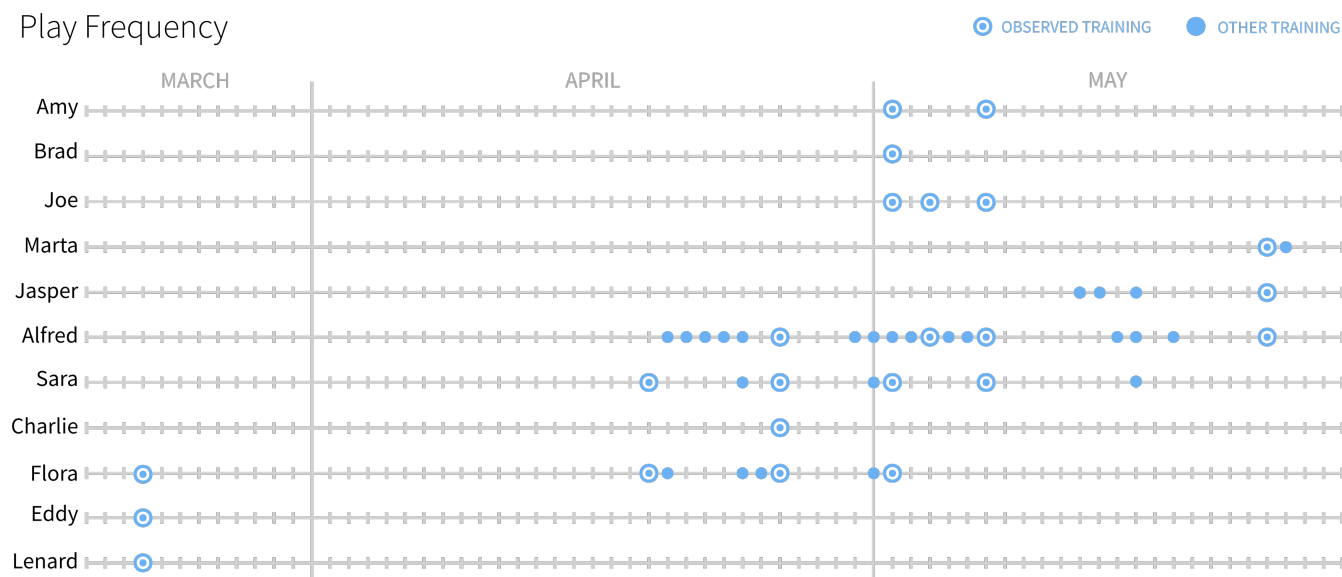


Figure 3: Measured daily play frequency of Trail it for 11 patients from 23rd March to 23rd May.

5 FINDINGS

Data collection in cognitive training measured patients' training on 27 days across three months (see Figure 3). Table 2 summarizes the analysis of the gathered qualitative data which produced six storytelling themes and 3 patient response themes. Additional insights have been divided into three topics: *Therapist Assessment of Patient Ability*, *Self-Awareness Moderates Storytelling*, and *Trust and Distrust in Cognitive Training*.

5.1 Therapist Assessment of Patient Ability

The therapist assessed patients' abilities through her interactions with them in cognitive training. She selected three patients (Alfred, Flora and Sara) whom she determined could benefit from cognitive training as self-care. When patients finished training, she asked them whether they found the training easy or hard. Their response, together with her review of their results, gave her understanding of the patient's level of self-awareness. The therapist identified lack of self-awareness if a patient responded that assignments were easy, but showed poor performance in solving them or if the patient did not recall previous performance. The therapist commented that patients who refuse to train or interrupt training like Brad were difficult to assess because they did not want to perform at their best. The visualizations compared to text-only feedback, enabled the therapist to enter discussion with self-aware patients around the patient's deficit. The heat map informed the therapist of possible signs of visual neglect and was the most frequently used more detailed visualization. The therapist used the timeline less frequently but she anticipated using to understand how the patients' cognitive performance would evolve over a time of several weeks and how much they trained outside the training sessions.

5.2 Self-Awareness Moderates Storytelling

The therapist assessed varying level of patient awareness, from no awareness to emergent awareness (see Table 1). Patients initially hesitated to interact with Trail it upon receiving visualization feedback and awaited the therapist's guidance. The therapist gave patients individual verbal feedback while pointing towards specific visualization elements to direct their attention. The patients' self-awareness determined their emotional response and acceptance of the feedback given on their performance:

Patients with no awareness did not accept that they had a deficit and were unaware of the symptoms associated with it. Brad and Zack stated that they found the training easy to perform and responded defensively to the therapist when she pointed out their mistakes in her feedback. Joe refused the therapist's suggested strategies to help him solve assignments and Brad refused to continue training with Trail it, which he belittled with aggressive wording.

Patients with intellectual awareness were aware of their deficit, but displayed annoyance when they were reminded of it. They had difficulty accepting their results when no short-term improvements were visible. Alfred commented that he would only play if he got better.

Patients with emergent awareness displayed acceptance of the therapist's feedback by replying in agreement. Flora understood that the slow reaction times she saw on the left side of the heat map were visual neglect associated to her deficit. When confronted with challenges stemming from neglect, she demonstrated the capability of using a ruler to help guide her attention to her neglected side.

Table 2: Emerged themes of storytelling (1-6) and patients' reactions (7-9) from analysis of dialogues on patient performance.

Theme	Description	Illustrative Quote
Self-Awareness Assessment	The therapist used dialogue around perceived difficulty to assess the patients' level of awareness, which she used to form her feedback after.	Therapist: <i>"Let's see if I can review this. It's a hard one."</i> Zack: <i>"I don't think it was hard."</i> Therapist: <i>"The first one is right. Good, Both of them look fine."</i> The therapist later clarified she had omitted mistakes because Zack lacked self-awareness. 23/03/2018
Guiding Interpretation	The therapist showed patients how to read and interpret the visualizations through verbal explanation and pointing gestures.	The therapist inspects Joe's heat map and explains: <i>"This one shows where you have been slow. It shows something over in this corner here, but it might be because there is a longer distance to it. But next time we can take a look again and try to see if there is a general trend to be focused to form her feedback after.d here."</i> 04/05/2018
Awareness of Deficit	The therapist used the visualizations to explain self-aware patients how their deficit linked to symptoms, such as fatigue.	Alfred was dissatisfied with his performance in Trail it. The therapist explained to Alfred by knowing that he has issues on the left side, he could try to remember to look over there when struggling with finding targets. 26/04/2018
Relative Change Emphasis	The therapist and patient discussed performance, improvement and anticipation of improvement relative to results of previous training sessions.	The therapist inspects Alfred's heat map. Therapist: <i>"Well, I can see that you have improved"</i> . <i>"Up here, I'm pretty sure it used to say four seconds."</i> The therapist switches to the timeline. Therapist: <i>"Yes, well there definitely is a decrease."</i> 04/05/2018
Needs Positive Support	The visualizations can become discouraging reminders of the patient's deficit.	Alfred <i>"I think the result is the same again."</i> Therapist: <i>"What do you think about it?"</i> Alfred: <i>"If it doesn't get better, then I don't want to play."</i> 26/04/2018
Improvement Anticipations	Therapist and patients had anticipations of future improvements. The therapist shared her positive anticipations to provide encouragement.	As Alfred left the room, the therapist told him that she was excited to see how the timeline in Trail it looks on his return from his weekend home visit. 26/04/2018
Patients Felt Evaluated	Patients with no self-awareness felt that the therapist was testing their intelligence.	The therapist reviews Brad's assignments and points out a mistake. Brad spurts that he recognizes that his whole assignment is wrong and that the therapist should give him a poor grade. He writes "02" (lowest passing grade) on the assignment with his pen. 02/05/2018
Result Perception Mismatch	Patients saw results, which they believed were wrong compared to their own performance perception.	Alfred: <i>"(...) I made 7 mistakes. I don't think I made those mistakes."</i> 07/05/2018
Need for Data Transparency	Patients wanted additional information on how the calculation of their reaction time was made.	While playing a new training session, Alfred asked, <i>"A reaction time, is that the average?"</i> 04/05/2018

5.3 Trust and Distrust in Cognitive Training

The cognitive training studies gave opportunity to observe the relations between patient, system and therapist. Alfred questioned how Trail it calculates his results and perceived his performance differently from Trail it's measurements, which resulted in what appeared to be distrust in the system. Brad rejected training with Trail it and did not understand why he had to solve assignments, which he perceived to be below his intellectual level. Brad appeared to display distrust in the system's ability to provide adequate training for him and appeared to display distrust in the therapist.

The therapist's actions tied to trust through her design and execution of cognitive training. When Brad asked why he could not just play his own preferred video games, the therapist explained that she distrusted the games as training utilities because too many variables impact performance.

6 DISCUSSION

The thematic analysis presented nine themes of which three (emphasis on relative change, guiding interpretation & anticipation of improvement) re-occurred in other non-stroke contexts [4, 25].

6.1 Trail it in the Rehabilitation Context

In the early design iterations, Trail it used a summary text (e.g. "You have connected 233 circles without problems.") as training feedback on patient performance and relied on familiarity with the measurement unit from the training task. But this constrained the dialogue between therapist and patients and we involved the therapist in the redesign Trail it's training feedback. It gave less granularity, only a formal summary of the patient's results, and did not attempt to contextualize the training performance within past training sessions. The redesign used colored heat map to highlight spatial performance differences (for neglect patients) and scaling in time line visualizations to depict relative improvement. These visualizations allowed the therapist to better form stories of the patient's performance and served as evidence for the patient's deficit if the patient lacked self-awareness.

The therapist found prediction of cognitive development difficult because this process was less linear compared to improvements of motoric function. But interacting with Trail it's visualizations made it possible to understand how patients' cognitive function improved over time - by scrolling through the heatmaps or timeline. For self-care scenarios, we are aware of the problems in the way Trail it provided access to visualizations regardless of performance and sample size. Timelines with too few data points risk giving wrong impressions of trends in patient performance to patients, exemplified by Alfred who commented on his timeline "It is annoying that I don't get any better." (*Improvement Anticipations*), after five days of consecutive training. Trail it did not synchronize patient across devices, which left patient time line data spread across multiple devices in some cases. Using measurement data without contextualization or interpretation poses a hazard for both visualizations and textual representations which can lead to aversion of use, overreaction to fluctuation, and reinforcement of inappropriate goals [19]. Further contextualization of performance could be provided by communicating upper limits on performance or

communicating performance in relation to predefined performance goals.

6.2 Self-awareness in Storytelling

Self-awareness determined much of the therapist's feedback which indicate that self-care systems should adapt their feedback based on patient awareness level. Lack of self-awareness level hindered patients' ability to provide input. Instead of co-constructing the data interpretation as observed by Mentis et al. [25], the interpretation was performed dominantly through the therapist's storytelling, with the goal of achieving a view-shift in the patient world view and increased awareness. The therapist's storytelling adapted to patient awareness levels by a) forcing an upper training limit for patients who lack self-awareness to prevent fatigue from overwork b) linking deficit to results for patients with intellectual awareness and c) provided strategies which can help patients with emergent awareness overcome problems as they encounter them and train the patient in becoming able to predict when his deficits will affect his normal day.

6.3 Structural Analysis of Storytelling

Kosara and Mackinlay originally proposed storytelling in visualization and our case study has demonstrated how the therapist constructs different stories based on visualization. However, at present we lack methods to analyse and design visualizations to support storytelling. By borrowing concepts from structural analysis of narratives, we expect to gain a better understanding of how to design visualizations and create a common vocabulary for the design, analysis, and evaluation of storytelling through visualizations.

Narratologists separate *story* from *storytelling* (narration) [2] the latter of which can take several forms. In the cognitive training context studied here, the therapist was the storyteller who drew on the interactive visualizations in the self-care system. The story revolved around the patient's performance after training ended and the audience was the patient. Storytelling contributes a temporal element through which we can analyze experiences of visualizations. To analyze and design the temporal element of storytelling in visualizations, we draw on the three dimensions from Attack et al. [3], namely: *Order* (in which information is presented), *frequency* (how often information is repeated) and *duration* (how much time is spent conveying the information).

Narrative selection and narrative gaps [2] refers to the storyteller's conscious choice of highlighting and omitting information from the story. This occurred when the therapist used pointing gestures to direct the patient's attention to specific features while speaking. The therapists made her narrative selections based on what she deemed appropriate given the patient's emotional state and level of self-awareness. Self-care systems should similarly harness narrative selections for what information to present and convey while basing it on the patients level of self-awareness.

By making choices in narrative selection combined with order, frequency, and duration, the therapist could provide a framing of the visualization data through storytelling, which served a purpose similar to the visual framing employed by Kim et al. [21]. In context of self-awareness, making decisions on framing appeared essential for the therapist to keep patients motivated. It might in some

cases, for example, not be ideal to show a time line visualization of performance to patients with low self-awareness or vulnerable emotional states. Especially, if the performance fluctuates heavily and does not indicate progress. In such cases, it might be better for the therapist to focus on performance in such visualizations and instead focus on the patient's training frequency or time spent training. Framing was also evident when the therapist interpreted the visualizations relative to a standard of reference, for example past training performance. This matched Mentis et al.'s finding that therapists shape patient's view of data [25]. Furthermore, we found that the visualizations shaped what the therapist chose to highlight in her dialogue with the patient and that the visualizations provided different points of departure for the therapist's narrative.

Seen through the lens of storytelling the therapist created a progression of time, by ordering the information shown in the visualizations through interactions with the Trail it tablet, talk and pointing gestures at specific moments in time to highlight information. In the absence of a therapist, the temporal order was merely dictated by the self-care system's use of composition and contrast in its visualizations paired with the patients interactions with it and (if it were available) their gaze. Taking the therapist out of the equation would require augmenting the therapist's talk and actions into multi-modal feedback provided by the self-care system itself.

6.4 Tensions in Trust

Problems relating to trust emerged during cognitive training when patients did call into question the therapist and Trail it. This typically was due to a lack of patient self-awareness. Brad refused to train and reacted negatively towards the therapist's feedback indicated a lack of trust in the therapist and Alfred called into question what Trail it reported as he perceived his results to be better than that. The role of trust in a goal-setting driven context such as rehabilitation, fits with the self-tracking model proposed by Niess and Wozniak [26]. A trusting and open relationship is necessary for the therapist to develop the patient's self-awareness [24]. In our context, it appeared that for new patients the therapist focused on establishing trust, by asking the patient's questions to gauge self-awareness level and personality before she attempted to give the patients' advice.

Our study revealed tensions between designing for what patients wanted to know and what patients benefit from seeing according to the therapist and motivation theory. Visualization of positive results is ideal to achieve feelings of competence [28] in motivation theory, but patients may occasionally benefit from dissatisfaction to fuel the desire to overcome challenging situations [34]. When visualizations showed poor results, it became hard for the therapist to arrive at a positive data interpretation. Visualization of patient performance along with normative performance may seem useful to aid interpretation, but this may hinder positive data interpretation. If visualizations showed no progress, the therapist would rarely highlight it to the patient. In this context, visualization aggregates (c.f. [14]) became useful for the therapist to skip detailed visualizations that didn't fit the storytelling.

6.5 Study Limitations

The cognitive training sessions ran with minimal disturbance from the study setup, in part to benefit study results and in part to adhere to the therapist's schedule. Talkative patients such as Brad and Alfred inevitably contribute more themes through their increased interactions and dialogue with the therapist. Observed interactions between the therapist and patients were limited by each patient's personality, emotional response, and individual deficits.

7 CONCLUSION

Stroke patients in self-management contexts lack motivation to train and face health numeracy challenges when interpreting data visualizations. The case study used a tablet game to study how therapists in rehabilitation communicated visualizations of patient performance to patients and found that therapist's aid in the patient's data interpretation based itself on patient's self-awareness level. Co-design with a therapist and field observations of patient cognitive training laid foundation to the implementation of timeline, heat map and aggregate visualizations. The therapist used the visualizations to link patient performance to the patient's injury and devised strategies for patients to help understanding the symptoms of their deficit. The visual feedback in the self-care system yielded rich verbal and gesture-based interactions compared to textual feedback. Patients and therapist showed anticipation of training results, but tensions in trust appeared to arise between patient, therapist and system when a patient in denial refused to continue training. The paper has analyzed the therapist's behavior from a structural lens of storytelling and discussed how incorporating storytelling into visualization design could provide a frame for patients to overcome health numeracy. We hope the case study can stimulate further research on storytelling affordances in information visualization for pervasive health technology.

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REFERENCES

- [1] A stage-based model of personal informatics systems. Atlanta, Georgia, USA. ISBN 978-1-60558-929-9.
- [2] Narrative: Linguistic and Structural Theories. In M. Toolan, editor, *Encyclopedia of Language & Linguistics (Second Edition)*, pages 459–473. 2006. ISBN 978-0-08-044299-0. doi: 10.1016/B0-08-044854-2/00528-9.
- [3] Atack, M. Atack, G. Genette, and J. E. Lewin. Narrative Discourse Revisited. *The Modern Language Review*, 86(2):387–388, 1991. ISSN 0026-7937. doi: 10.2307/3730539.
- [4] N. L. Bagalkot and T. Sokoler. Designing for Lived Informatics in Out-of-Clinic Physical Rehabilitation. *Human-Computer Interaction*, 33(1):93–129, 2018. doi: 10.1080/07370024.2017.1312405.
- [5] R. Barthes and L. Duisit. An Introduction to the Structural Analysis of Narrative. *New Literary History*, 6(2):237–272, 1975. ISSN 00286087, 1080661X. doi: 10.2307/468419.
- [6] K. Boehner, J. Vertesi, P. Sengers, and P. Dourish. How HCI Interprets the Probes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, CHI '07*, pages 1077–1086, New York, NY, USA, 2007. ACM. ISBN 978-1-59593-593-9. doi: 10.1145/1240624.1240789.

- [7] C. Bowie and P. Harvey. Administration and interpretation of Trail Making Test. *Nature protocols*, 1:2277–81, Feb. 2006. doi: 10.1038/nprot.2006.390.
- [8] P. Brennan, S. Downs, and G. Casper. Project HealthDesign: rethinking the power and potential of personal health records. *J Biomedicine Informatics*, (43):3–5, 2010. doi: 10.1016/j.jbi.2010.09.001.
- [9] E. K. Choe, S. Abdullah, M. Rabbi, E. Thomaz, D. A. Epstein, F. Cordeiro, M. Kay, G. D. Abowd, T. Choudhury, J. Fogarty, B. Lee, M. Matthews, and J. A. Kientz. Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications. *IEEE Pervasive Computing*, 16(1):74–84, Jan. 2017. ISSN 1536-1268. doi: 10.1109/MPRV.2017.18.
- [10] E. K. Choe, B. Lee, H. Zhu, N. H. Riche, and D. Baur. Understanding Self-reflection: How People Reflect on Personal Data Through Visual Data Exploration. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, PervasiveHealth '17, pages 173–182, New York, NY, USA, 2017. ACM. ISBN 978-1-4503-6363-1. doi: 10.1145/3154862.3154881.
- [11] P. M. Desai, M. E. Levine, D. J. Albers, and L. Mamykina. Pictures Worth a Thousand Words: Reflections on Visualizing Personal Blood Glucose Forecasts for Individuals with Type 2 Diabetes. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, CHI '18, pages 538:1–538:13, New York, NY, USA, 2018. ACM. ISBN 978-1-4503-5620-6. doi: 10.1145/3173574.3174112.
- [12] A. L. Golbeck, C. R. Ahlers-Schmidt, A. M. Paschal, and S. E. Dismuke. A Definition and Operational Framework for Health Numeracy. *American Journal of Preventive Medicine*, 29(4):375–376, Nov. 2005. ISSN 0749-3797. doi: 10.1016/j.amepre.2005.06.012.
- [13] M. Greis, N. Henze, and A. Schmidt. Predicting the Future: Towards Personal Simulation. In *CHI'15: Workshop on 'Beyond Personal Informatics: Designing for Experiences of Data'*, New York, NY, USA, 2015. ACM.
- [14] M. Greis, E. Avci, A. Schmidt, and T. Machulla. Increasing Users' Confidence in Uncertain Data by Aggregating Data from Multiple Sources. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, CHI '17, pages 828–840, New York, NY, USA, 2017. ACM. ISBN 978-1-4503-4655-9. doi: 10.1145/3025453.3025998.
- [15] K. Hald and H. Knoche. Using Spatio-Temporal Data from Trail-Making Tests to Assess Neglect. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, PervasiveHealth '16, pages 245–248, Cancun, Mexico, May 2016. doi: 10.4108/eai.16-5-2016.2263741.
- [16] P. W. Halligan, J. Cockburn, and B. A. Wilson. The behavioural assessment of visual neglect. *Neuropsychological Rehabilitation*, 1(1):5–32, Jan. 1991. ISSN 0960-2011. doi: 10.1080/09602019108401377.
- [17] G. R. Hayes. Knowing by Doing: Action Research as an Approach to HCI. In *Ways of Knowing in HCI*, pages 49–68. Springer, New York, NY, 2014. ISBN 978-1-4939-0377-1 978-1-4939-0378-8. doi: 10.1007/978-1-4939-0378-8_3.
- [18] B. I. Hougaard and H. Knoche. How annotated visualizations in self-care technology supported a stroke survivor in goal setting and reflection. *EAI Endorsed Transactions on Serious Games*, "4"(12), Dec. 2017. ISSN 2034-8800. doi: 10.4108/eai.8-12-2017.153400.
- [19] M. Kay, D. Morris, M. Schraefel, and J. A. Kientz. *There's No Such Thing as Gaining a Pound: Reconsidering the Bathroom Scale User Interface*. Nov. 2016. ISBN 978-1-4503-1770-2.
- [20] C. Kelley, B. Lee, and L. Wilcox. Self-tracking for Mental Wellness: Understanding Expert Perspectives and Student Experiences. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, CHI '17, pages 629–641, New York, NY, USA, 2017. ACM. ISBN 978-1-4503-4655-9. doi: 10.1145/3025453.3025750.
- [21] Y.-H. Kim, J. H. Jeon, E. K. Choe, B. Lee, K. Kim, and J. Seo. Timeaware: Leveraging framing effects to enhance personal productivity. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, CHI '16, pages 272–283, New York, NY, USA, 2016. ACM. ISBN 978-1-4503-3362-7. doi: 10.1145/2858036.2858428.
- [22] H. O. Knoche, K. Hald, D. Richter, and H. R. M. Jørgensen. Self-rehabilitation of acquired brain injury patients including neglect and attention deficit disorder with a tablet game in a clinical setting. *EAI Endorsed Transactions on Pervasive Health and Technology*, 17(11), July 2017. doi: 10.4108/eai.18-7-2017.152895.
- [23] R. Kosara and J. Mackinlay. Storytelling: The Next Step for Visualization. *Computer*, 46(5):44–50, May 2013. ISSN 0018-9162. doi: 10.1109/MC.2013.36.
- [24] K. Malia. Insight after brain injury: What does it mean? *The Journal of cognitive rehabilitation*, (May / June), 1997.
- [25] H. M. Mentis, A. Komlodi, K. Schrader, M. Phipps, A. Gruber-Baldini, K. Yarbrough, and L. Schulman. Crafting a View of Self-Tracking Data in the Clinical Visit. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 5800–5812. ACM, 2017.
- [26] J. Niess and P. W. Wozniak. Supporting Meaningful Personal Fitness: The Tracker Goal Evolution Model. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, CHI '18, pages 171:1–171:12, New York, NY, USA, 2018. ACM. ISBN 978-1-4503-5620-6. doi: 10.1145/3173574.3173745.
- [27] D. Ren, M. Brehmer, T. Höllerer, and E. K. Choe. Chartaccent: Annotation for data-driven storytelling. In *2017 IEEE Pacific Visualization Symposium (PacificVis)*, pages 230–239, April 2017. doi: 10.1109/PACIFICVIS.2017.8031599.
- [28] R. M. Ryan and E. L. Deci. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. 55:68, 2000. ISSN 0003-066X. doi: 10.1037/0003-066X.55.1.68.
- [29] M. Simmond and J. M. Fleming. Occupational Therapy Assessment of Self-Awareness following Traumatic Brain Injury. *British Journal of Occupational Therapy*, 66(10):447–453, Oct. 2003. ISSN 0308-0226. doi: 10.1177/030802260306601003.
- [30] N. Sultanum, M. Brudno, D. Wigdor, and F. Chevalier. More Text Please! Understanding and Supporting the Use of Visualization for Clinical Text Overview. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, CHI '18, pages 422:1–422:13, New York, NY, USA, 2018. ACM. ISBN 978-1-4503-5620-6. doi: 10.1145/3173574.3173996.
- [31] S. J. Taylor, R. Bogdan, and M. DeVault. *Introduction to Qualitative Research Methods: A Guidebook and Resource*. Wiley, Hoboken, New Jersey, 4 edition edition, Oct. 2015. ISBN 978-1-118-76721-4.
- [32] E. A. Townsend and H. J. Polatajko. *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-being, & Justice Through Occupation*. Canadian Association of Occupational Therapists, 2007. ISBN 978-1-895437-76-8.
- [33] P. West, M. Van Kleek, R. Giordano, M. J. Weal, and N. Shadbolt. Common Barriers to the Use of Patient-Generated Data Across Clinical Settings. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, CHI '18, pages 484:1–484:13, New York, NY, USA, 2018. ACM. ISBN 978-1-4503-5620-6. doi: 10.1145/3173574.3174058.
- [34] S. Wheeler. Approaches to managing executive cognitive functioning impairment following tbi: A focus on facilitating community participation. In F. Sadaka, editor, *Traumatic Brain Injury*, chapter 19. IntechOpen, Rijeka, 2014. doi: 10.5772/57395.
- [35] S. M. Yeung. *The effects of a transitional care programme using holistic care interventions for Chinese stroke survivors and their care providers : a randomized controlled trial*. Thesis, The Hong Kong Polytechnic University, 2012.