# QUALITATIVE MEASURES OF WELLNESS

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## QUALITATIVE MEASURES OF WELLNESS ABSTRACT

"Physical pain has no voice, but when it at last finds a voice, it begins to tell a story"

- Scarry, Body in Pain

The highly personal nature of physical pain is challenging to communicate to others, which makes diagnosis and treatment difficult for those who suffer from chronic illness. Issues of the body are traditionally described in scientific language which overlooks the lived experience of those with this illness. This biological gaze of illness fails to include social and cultural influences on chronic disease. Despite the difficulty of expressing pain, metaphor and imagery can effectively articulate the invisible to one's self and others.

How might design create opportunities to consider a more nuanced approach to articulating symptoms of chronic illness? Currently, people who suffer from autoimmune arthritic conditions experience bias from health care providers leading to delayed diagnosis. In my thesis I will explore how design methods can give a voice to the daily pain of arthritis sufferers.

Health trackers such as Fitbit have grown in popularity in recent years, but such tools often reduce wellness to a number. My intervention borrows from self-tracking and builds on it by incorporating metaphor and visual storytelling. Early experiments showed that capturing embodied experiences through imagery and words allowed people to quickly identify their lived experience. This process also supports reflection and story-telling, inspiring empathy and better conversations.

Based on these experiments, I have prototyped a diary kit which enables health self-tracking while creating visual metaphors, empowering users to use their data to visualize barriers and limitations affecting daily life. Further testing will be conducted with people who suffer from arthritis to learn how the diary kit affects their awareness of pain and ability to articulate it to others. I predict this testing would show improved self-management which could result in better care

## INTRODUCTION

## **INTRODUCTION**

## How might design methods help people who have arthritis improve their understanding and communication of pain?

Pain's inexpressibility is a studied phenomenon. For instance, Elaine Scarry's book The Body in Pain explores the complexity of understanding pain. While one's own pain is effortlessly understood, for the observer misunderstanding the pain of another is effortless. The observer's best efforts to comprehend pain results in a small fraction of the sufferers experience. Thus the paradox of pain is its uncertainty to others despite its clarity to the sufferer.

According to Scarry, attempts to articulate pain are insufficient. She states, "Physical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned." (Scarry, 1987, p4) Pain's resistance to language limits clear doctor-patient communication.

Some physicians consider the patient voice an unreliable narrator, preferring to rely on imagery such as CAT scans or X-ray's to bypass the patient's verbal report. Conversely, physicians with great respect for the human voice have developed diagnostic questionnaires such as the McGill Pain Questionnaire, which helps patients better articulate the nature of their pain by choosing words such as as "throbbing" or "burning". Despite such advancements, the process of making one's pain knowable to others remains a challenge to doctors, writers, philosophers alike.

According to the American Autoimmune Related Disease Association (AARDA), people who suffer from auto-immune arthritic conditions see four different doctors and wait an average of three to four years for a correct diagnosis. An AARDA survey revealed "62 percent of autoimmune disease patients had been labeled as chronic complainers or were told that they were overly concerned with their health in the earliest stages of their illnesses." Since the symptoms are often confusing and unrelated, Doctors can get frustrated and exasperated with patients, especially ones with a difficult diagnosis. During this time of not being believed by doctors, irreparable damage is done to the body.

In recent years, self-tracking tools have helped people to understand their bodies by tracking daily symptoms and finding patterns. Self-tracking as a form of reflection can promote self-awareness and increased engagement. However, the approach of these tools is too mechanical to capture the complexity of pain.

Given the challenges in communicating pain, how can we help people to leverage their knowledge of self for more empowering conversations with providers? My thesis tests the hypothesis that applying design methods to self-tracking can help arthritis patients to understand their symptoms and improve self-care strategies. In my research, I explore how design can give a voice to the daily pain of arthritis sufferers.

After reviewing precedents, relevant literature, and conducting expert interviews, I designed a prototype diary kit which can empower people who have arthritis by helping them use their data to visualize barriers and limitations affecting daily life. My research shows metaphor and storytelling enriches the practice of self-tracking, provoking a richer dialogue about pain, inspiring empathy and better conversations.

## EXPLORATORY RESEARCH

## **EXPLORATORY RESEARCH**

### MAYO CLINIC TRANSFORM CONFERENCE

I was looking for an overview of existing challenges and innovations in health care systems to help ground my work in current and emerging practices and the state of the art in the field. So I attended the Mayo Clinic's Center for Innovation's Transform conference, a yearly event centered around technology and design innovation. Industry leaders are invited to share visions about the future of health care. The most interesting themes centered around the future of health care delivery, empowering patients to co-design their care, and the role of data in healthcare.

#### **EXPERT INTERVIEWS**

I was able to connect with experts, some of whom I met at the conference, to discuss my hypothesis in greater detail. It was important to interview a wide range of stakeholders – patient advocates, physicians, researchers and data scientists to gain a variety of perspectives on the challenges of this problem space. Below is a summary of the most relevant insights.

#### **Challenges of Arthritis Patients**

I spoke with Deborah Hartman, Executive Director of the Pittsburgh chapter of the Arthritis Foundation, about the challenges arthritis sufferers face in getting quality care. She explained that arthritis is trivialized. It is seen as something old people complain about. So, it is common for the symptoms of young people are commonly dismissed despite of the fact there are more kids with arthritis than muscular dystrophy or cystic fibrosis. When I asked about arthritis related tools, she spoke highly of the Arthritis Foundation's Live Yes! INSIGHTS. This assessment tool measures the symptoms and quality of life of arthritis sufferers.

#### Role of Data Visualization in Patient-Doctor Conversation

I interviewed Dr. Dave Pao to learn about the role of data in the doctor patient conversation. Dr. Pao is a practicing doctor in the field of sexual health and HIV medicine, with a clinical research MD from University College London. Alongside his medical work, he is undertaking a PhD-by-practice in Innovation Design at the Royal College of Art. His research acknowledges the critical influence of the medical record on the quality of the clinician-patient consultation. He is exploring the impact of the shift from paper to digital records, through the affordances inherent to these very different media.

He believes the current medical record inhibits doctor-patient interaction because it does not afford quick comprehension of patient's history and state. Data visualization is important because it can make comprehension instantaneous, and a doctor's first impressions have a profound effect on the quality and outcome of the patient interaction. If the doctor has to search for information too long, his cognitive load is wasted. For example, the red color of a stop sign provides a mental shortcut to the driver. If the color or shape changed and the driver had to read the type, this would increase the cognitive load which could cause an accident.

## **EXPLORATORY RESEARCH**

#### Data and Patient Self-advocacy

On the patient side, Increase in patient data empowers the patient to take a more active role in their care. I spoke with Gigi Kreibich, patient advocate and organic chemistry researcher at the University of Minnesota. In 2017 Krebich was diagnosed with hypophosphatasia, a degenerative bone disease. After a year of visiting specialists with no diagnosis, she became the first juvenile hypophosphatasia diagnosis at the Mayo Clinic.

According to Kreibich, there is an disproportionate length of time-to-diagnosis when the patients are of low-socioeconomic status, people of color, or women verses white male counterparts. In her case, her health had declined precipitously by the time doctors paid attention to her. She states that had she received treatment a year earlier, more advanced symptoms could have been avoided. Early in her search for a diagnosis, she was patient with doctors. Over time she became more assertive. Now as soon as a new symptom occurs, she tracks it right away and gets doctors to take it seriously. She believes self-tracking plays an important role in helping her validate her feelings and forming a support system. Currently, Kreibich does public speaking engagements for Research to the People, a group using artificial intelligence programs and research networking to analyze genetic information for complex disease patients. She says while it is easy to fall into despair and loneliness, public speaking gave a purpose which has helped her to move on the next chapter of her life.

#### The Future of Doctor - Patient Conversations

Dr. Summer Allen is an Assistant Professor in the Department of Family Medicine at the Mayo Clinic, in Rochester, Minnesota. She also serves as medical director of Patient Experience for the Mayo Clinic Health System. When she spoke at the Mayo Clinic's Transform Conference, she challenged the current paternalistic methodology of health care which prescribes solutions. The paradigm of the future will include flexible, responsive systems, collaboration and critical thinking.

I asked her about the role of patient generated health data in doctor patient conversation. She said the assumption is that people need more information. What they are looking for is advice from someone they trust. Patient expertise is not always welcome because it challenges the paternalistic mindset towards health care. According to Dr. Allen, a new approach to history taking is needed. One that considers patient context and biography. I asked her how patients can have more collaborative, less paternalistic conversations. Dr. Allen believes we need a tool that provokes curiosity between two experts: the patient and the doctor.

## **EXPLORATORY RESEARCH**

### **TERRITORY MAP**

I gathered the insights from the conference and interviews and began making a territory map to condense and clarify the direction for my research. I mapped five interest areas I could study further: patient led experiments, self-tracking, patient data, data and agency and health care delivery paradigms.

Initially, I was most interested in addressing the doctor patient hierarchy and empowering patients to have better conversations. I realized before this be addressed, patients had to better understand themselves. Since the rise in patient data is influencing patient provider dynamic, self tracking could be the most effective leverage point for intervention.



Having honed in on patient generated data as a direction, I conducted further research into self-tracking and how design can better support it. Here I discuss insights that emerged from selected literature on chronic illness, self- advocacy, visualizing self-generated health data, and metaphors. In addition, I discuss learnings from my review and experimentation with current self-tracking tools.

## Teaching Patients with Advanced Cancer to Self-Advocate: Development and Acceptability of the Strong Together Serious Game. Thomas, T. H. et al, 2019

Strong Together<sup>™</sup> serious game was developed to address the unique challenges facing cancer patients face when making decisions about their treatment. Research has found that female patients were more likely to prioritize keeping the peace over demanding better care, resulting in worse health outcomes. Study participants play a female patient with cancer and advance by making healthy choices for her. The character is asked to make decisions about accepting help and communicating symptoms. As healthy choices are made, the brighter colors and more upbeat music reflect the patient's growing strength.

I had the chance to ask researcher, nurse and co-author of the study Teresa Hagan Thomas about the reason games were chosen to teach self-advocacy. She acknowledged that games were not the only option but had the advantage of clear learning objectives, accessibility to those with low literacy, and high engagement. I was also curious as to why patients are playing a persona rather than themselves. Because women were better at advocating for someone else, playing a character was a more effective way to learn self-advocacy.

Because I consider self advocacy and health care to be serious topics, I think the concept of gaming as a tool for teaching self advocacy to patients is ingenious. The affordances of gaming are worth exploring. Could patients get in touch with themselves more effectively by playing a character? I had been exploring externalizing symptoms through making. It is possible that character narratives could also expand possibilities for expression. Acknowledged that games were not the only option but had the advantage of clear learning objectives, accessibility to those with low literacy, and high engagement. I was also curious as to why patients are playing a persona rather than themselves. Because women were better at advocating for someone else, playing a character was a more effective way to learn self-advocacy.

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## Uncovering self-management needs to better design for people living with lymphoedema. Kopanoglu et al, 2019

Lymphoedema is a chronic condition where progressive swelling of a body part is caused by excess lymphatic fluid. Maintenance of lymphoedema requires adherence to meticulous treatment routines. Systems designed to teach self management of this disease are focused on information delivery and fail to include user input. A user centered design approach was used to engage discussion and identify unmet patient needs.

Members of a lymphedema support group were interviewed about their feelings towards managing their condition. Then scenarios and personas were introduced. They were asked for suggestions on how to better support the persona. They also ranked her needs in a card sorting activity. The use of personas and scenarios helped participants to envision an ideal self-management support system.

From these interviews emerged three stages of self-management: novice, experimental and expert. At the novice stage participants were learning the skill of self-monitoring while developing essential self-management strategies. At the experimental stage, participants tested and iterated on strategies based on observations. At the expert stage, patients had developed sufficient awareness to adapt self-management strategies to their lifestyles. Consistent with all my sources, this paper calls for patients to be respected as proactive co-designers of their treatment plans rather than be expected to passively comply with prescribed routines.

Like in Strong Together™, personas are used to help participants communicate their own health care needs. The affordances of scenario based probes were effectively leveraged to help participants to discuss alternative futures and avoid focusing on their past treatment. The persona used in this study was someone recently diagnosed with lymphoedema. This allowed participants to recall and get in touch with their own anxious experience of being newly diagnosed. These user centered design methods can be used in participant interviews. This paper also illustrates the role of self-tracking in improved outcomes. Participants learn self-monitoring which evolves into greater awareness, and more confidence in the management of their condition.

## Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers. Hong, Matthew K., et al, 2020

Chronic illness can affect self-esteem, mental health, and social success. For adolescents still learning emotional regulation, tracking illness is an additional burden. While parents can support tracking, their reports are susceptible to observer bias. Family oriented diary probes were tested to investigate this gap.

Researcher led activities have mixed outcomes. For some, they can promote empathy and improve communication. But for patients still adjusting emotionally with illness, design activities can trigger unpleasant emotions. Another pitfall is that

the activities are conducted in a different context can discourage candid responses. Probes allow for data collection in context then allows participants to share what they want with others.

The goal of these probes is to provide scaffolds for reducing cognitive burden, allowing flexible expression and prompting reflection. The diary study contained pictograms of several activities, an emotion log and a template for patients to create a story of their day. The pictograms helped the adolescents develop language for emotional and physical feelings. They eventually began creating their own drawings.

Participants said the diary probe helped them see changes they wouldn't have otherwise seen. They started to become more attuned to small changes over time and understand how activities related to flare ups. Parents and adolescents were able to collaborate in the documentation process. While the parents helped to fill in the gaps, the adolescent's account was the most accurate. Many adolescents reported feeling more comfortable writing about concerns in a diary than discussing aloud with their parents. Ultimately, having a shared diary allowed mutual respect and communication to develop.

As discussed in other research cited in this section, design tools are effectively leveraged to improve patient awareness. For example, pictograms play an important role by improving patient comprehension, recall, and symptom expression. Storyboarding served as an effective scaffold to help patients draw connections between activities and symptoms. Researchers noted the limitations of structured pain scales and stressed the need for design tools capable of combining quantitative tracking with generative approaches such as diary studies.

#### T2 Mood Tracker, Daylio, Mood Notes, and Fitbit

My study of the Quantified Self movement inspired me to create my own selftracking experiment. I decided to study how my sleep habits affect my mood. I used a fit bit to record my sleep patterns passively. Then surveyed mood tracking apps currently on the market. Daylio asks the user to choose an emoticon to match their mood then add their most recent activities. The goal is to see a pattern of how activities affect their mood over time. Mood notes works similarly by asking the user to select from a list of positive and negative emotions add asking for specific thoughts at that time. The majority of mood tracking apps involve selecting emoticons.

Finally, I settled on T2 Mood tracker because it had a wide variety of emotional scales to choose from. There are 3 large categories: anxiety, depression and stress. Each category has 10 emotion scales. For example, between feeling focused to distracted I can select which side best describes my feelings and to what degree.

At times I found it challenging to identify specific emotions as they were not always relevant to my circumstances. For instance, whether I felt lonely or involved depended largely on context. The rigid structure of these scales did not afford much nuance but did allow me to see patterns over time. Over the course of a week, my ability to identify my emotions had improved. When I analyzed this data along with my sleep habits, I could clearly see the correlation between the two.

When testing these tools, it was important for me to track at the time of the event rather than reflecting at the end to the day. This decision was influenced by my interview with Deborah Estrin, associate dean and professor of computer science at Cornell, who spoke about the role of patient generated data in the future of health care at the 2019 Transform Conference. In our interview, I learned about the problem of retrospective recall bias when self-tracking. The longer one waits to recall an event the less accurate the recollection is. Unfortunately, if someone has to stop what they are doing to track an event, they are less likely to record and if they do the quality may be lower than if they had waited. This paradox makes reliable self-tracking elusive.

From this experiment, I was able to experience the benefits of daily tracking. It provided a scaffold for my daily reflection. I was more in touch with my emotions and identified gaps in my self-care routines. Quantified self-tracking is efficient, yet limiting. It would be interesting to see if a more engaging and visual tool could expand opportunities for self-awareness. Expand opportunities for self-awareness.

#### Quantified Self, Sociology and SelfTracking. Lupton, D., 2016.

*Quantified Self* describes the theories and influences driving quantified selfmovement. One influence is the digitization of society and social life. This digitization of human actions, or socio-materialism recognizes the role of material objects in the development of self-hood and embodiment. Building on socio-materialism is the concept of assemblage which is the configuration of humans, non-humans, practices, ideas and discourses combined into a complex system. Human usage of health trackers is one form of assemblage. Lupton describes how smart phones embody the user by encapsulating personal messages, photos and appointments. Self-tracking devices further embody the user through archiving bodily functions and movements.

Self-tracking can spark increased engagement and sense-making, which helps to sustain self-care routines and activities. By externalizing wellness, users have increased opportunities for deeper conversations with others. Some share discoveries and new found awareness with their providers. These conversations can promote a better support system which can lead to improved outcomes.

One criticism of self-tracking is that wellness is often reduced to a number. Also, navigation and sense making of the large quantities of data produced is challenging. Can the affordances of self-tracking be leveraged in a way that is more nuanced? In my intervention I will be borrowing from self-tracking but building on it by incorporating metaphor and visual storytelling.

## QUANTIFIED SELF JOURNEY

How does self -tracking change one's relationship with their health?



#### Visualizing symptoms, sensations and stories. McCurdy, 2017

Kate McCurdy is a user experience designer who also suffers from auto-immune disease. She has founded Pictalhealth, a service for creating visual time-lines for complex diagnosis. A history is taken of relevant dates and symptoms. From this history, time-lines, charts, summaries are drawn up to accompany the patient to doctor's appointments. Also available are worksheets with outlines of the body and set of visuals which can be placed where symptoms are occurring. She has observed from this practice how visualizations can improve doctor's appointments by aiding conversation and comprehension.

#### Dear Data. Lupi, G., & Posavec, S. 2018

In the book *Dear Data* a data drawing project conducted by Giorgia Lupi and Stefanie Posavec. These women wrote their data on a large postcard and mailed then too each other. Topics ranged from "week of clocks" to "week of complaints" they observed being changed by this visualization practice. They argue that data can be used to help us connect in a deeper way to ourselves and others.

*Observe, Collect and Draw*! is a visual journaling companion to *Dear Data.* Authors Lupi and Posavec have created a crash course in personal data visualization, teaching the reader how to observe data in their daily lives and draw inspiration from nature and art. Each exercise prompts the reader to reflect and visualize an aspect of their lives. Examples range from "How music makes me feel" to "Things I buy". The simple framework they have proposed can be an effective guide for creating visual vocabulary for wellness.

#### Metaphors we Live By. Lakoff, G., & Johnson, M. (2003)

Through my research I hope to address the challenge of expressing the experience of chronic illness. Since, this experience is personal and invisible, the question is how to clarify what is largely unknowable to others.

Lakoff demonstrates the power of metaphor to expand our understanding of abstract concepts by allowing one to experience it in concrete terms. He describes the various conceptual systems used to form metaphors. Within these frameworks we can discover new ways of understanding concepts and iterate on them. For example the phrase "time is money" defines time as a finite resource. Other phrases "I invested a lot of time in her "or "You need to budget your time" build on this concept.

Other conceptual systems are ontological metaphors, which are based on our experiences with objects. For example, "Fear of insects is driving by wife crazy"Orientational Metaphors are associated with our sense of space. For instance, "happy" is associated with "up". Some are based in idiom, referring to one thing as another. "I'm crazy about her" is based on the ideas that "love is madness" Metaphor an effective way to make our experiences coherent to others. They also create social realities and direction for future action. With respect to expressing illness, it can be an effective tool for making the invisible symptoms concrete. Recognizing that it is impossible to collect metaphors for all experiences. Understanding the mechanics of metaphor can inform the development of systems to create metaphors to describe individual experiences.

## Framing Chronic Illness: Fatigue Syndromes, Metaphor and Meaning. Bowditch, J., 2006.

*Framing Chronic Illness* investigates how women with Chronic Fatigue and Fibromyalgia use language to describe an invisible illness to others. Issues of the body are traditionally described in scientific language which overlooks the lived experience of those with this illness. A biological gaze of illness fails to include social and cultural influences on chronic disease. Women with Chronic Fatigue and Fibromyalgia regularly face skepticism from providers as well as social stigma. Given the difficulty of expressing pain, metaphor and descriptive language can effectively articulate the invisible to others and to one's self.

The metaphors used by the participants can be broken down into a few categories. Environmental or weather related metaphors such as "living in a fog" described the heaviness and confusion often experienced. Metaphors of fracture such as "coming apart" or "cracking up" were used to describe the feeling of not being whole. Metaphors of invasion described illness as a predator attacking from within. Participants used phrases like "dull like a knife" and "it works against me".

My artifact review of health trackers showed mostly a biomedical approach to tracking illness. Both metaphorical and biomedical language both express truth about the body. Yet, biomedical and scientific perspectives are considered to be a superior way of knowing the body. Bowditch makes a compelling case for elevating metaphorical expression in health care contexts.

### **INSIGHTS**

From these readings and artifacts, I have learned of the role of self-tracking in creating a reflective practice. A reflective practice of any kind aids in externalizing wellness and having a deeper connection to one's self. Design has the ability to create scaffolds for reflective practice in a number of ways. Personas and scenarios can help patients to better articulate their own needs. Visualization can be leveraged to improve comprehension and expression of symptoms. Metaphorical language helps to express abstract ideas and mental models. Each of these tools have been used separately to depict illness, typically to describe singular health event. In my research to date, I have not found a tool which combines the benefits of self-tracking, metaphor and design tools.

#### Limitations of current tools

Current tools reduce wellness to a number. Ridged systems only consider a scientific perspective and focus in information delivery.

#### Data Collection

A reflective practice supports having a deeper connection to one's self by helping to draw connections between activities and symptoms. Over time users become more attuned to changes on their body.

#### Externalization

Externalizing symptoms can happen through visualization or through language. Through this process users can identify and articulate experiences. This has the ability to create scaffolds for reflective practice.

#### **Co-Creating**

Having an artifact to interact with allows for deeper understanding. These artifacts can be shared with others to create opportunities for conversations with others

#### Role-playing

Through taking on alternative roles, users can express needs in an engaging manner. It also allows them to experiment with options in a safe environment.

Monday	Exhausted but deter- mined to finish project no matter what	Swimming against the current	
Tuesday	Unable to think about or do anything	Floating along	
Wednesday	Guilty about canceled appointments	In the weeds	
Thursday	Finally recovering from sleep loss	Rising above	
Friday	Too much time alone and overthinking are having a negative affect	Floating along	
Saturday	Difficult time switchinig context. too much time away from work.	Lost at sea	

## AUTO-ETHNOGRAPHIC STUDY

These insights emerged from my literature and practice review, revealing unexplored opportunities in design for self-tracking. I wondered how a more qualitative approach to health journaling might impact wellness. I conducted a series of design experiments to explore the affordances of self-tracking through metaphor and visualization.

Researchers typically act as neutral observers of their subject of study. However, in auto-ethnographic research, researchers turn the focus to their own perspectives and experiences. Recently, there has been an increase in auto-ethnographic design research, which may be inspired by the rise of self-tracking tools. (Lockton, 2020, p1). Inspired by this trend, I decided to test my concept on myself by creating an auto-ethnographic study of a hectic week.

I diagrammed a series of events and was able to see clearly how lack of selfcare early in the week resulted in burnout later in the week. Of the metaphors I discovered, nautical ones seemed to allow for the most diversity. I decided that obstacle would be the current direction and speed while my energy would be represented by swimming. So a hectic day would be shown by swimming against the current. Burn out would look like someone sinking. I created one simple sketch to illustrate my wellness for each day of the week. Through these sketches I was able to explain my week more comfortably and with greater depth than usual. Other were able to relate to the metaphors in my drawing more easily than a detailed description. The universality of metaphors allowed each drawing to serving as an icon for my wellness.

Figure 3: Chart and illustrations of auto-ethnographic experiment



Figure 4: Colleagues participating in research study

## **DESIGN RESEARCH WITH COLLEAGUES**

I created a vocabulary of visual metaphors based on previous research and placed them in sets along a the bottom of a white board near the entrance of the design studio. Along the top of the white board I wrote "How are you doing today? "and invited 25 colleagues to use one or more of the drawing below to tell their wellness story.

#### Choosing a Metaphor vs Drawing your own

Only one participant chose to draw her own metaphor, A fish in milk. I asked her about the origin of this expression and why she chose to draw it. Here is her response: "I made it up. Yesterday, a classmate asked me how I was doing. I told him I felt like a fish swimming in milk, I'm swimming but it's uncomfortable. It's not a good thing."

#### One Drawing vs. Many Drawings

I added examples showing how multiple drawings could be used to create a narrative. For example "on the right path" followed by "Falling through the cracks" No one chose a narrative approach however some chose two drawings to express simultaneous feeling such as "Painted in a corner" and "in the clouds" Most chose one drawing which told me they were mostly concerned with their current wellness without reflecting on the past. One student followed up on her previous choice "lost at sea". She had chosen this because she was confused about her project. Since then she has gotten direction from her professor but has little time to execute so now she is "weighed down".

## **CONSIDERATIONS FOR FUTURE STUDIES**

#### Limits of metaphors as a form of expression

It was not possible to include all metaphors in the study. This may have biased participants to choose the most applicable metaphor even if it is not accurate.

#### Metaphors are not universal

Some students asked me to explain the meaning of some metaphors. I realized metaphors were all are western in origin. Some are specific to certain regions or social classes. Moving forward I would like to consider cultural inclusivity.

#### Conclusion

This experiment took place near the end of the semester, when everyone is experiencing a great deal of stress. This exercise allowed us to visualize our shared experience. I can compare the outcome to how friends share how movies or songs describe life events. The media references become a shorthand for past experiences. The difference is this is a media representation of our wellness as we are experiencing it.

From this study I learned that capturing embodied experiences through imagery and words allowed people to quickly identify their lived experience. This also allows for a shared understanding of the experience with others. Having this artifact to interact with does indeed encourage further and deeper conversations about wellness.



### **CREATIVE MATRIX**

After completing my secondary research, I was inspired yet overwhelmed with ideas. I used a Creative Matrix to add structure to my concept generation. This tool promotes divergent thinking while providing constraints. Across the top of the creative matrix are insights from my exploratory research, while categories of solutions are listed vertically. At the intersection, a concept is generated that meets both criteria. The result is a wide range of solutions within the parameters of the research topic. Through this tool, I was able to generate a large amount of ideas in a limited time frame. I clustered the concepts with the most potential and looked for common themes.

#### Futuring for self-care routines

Patients prototype current self and future self. Then the actions which would support transition.

#### Generative toolkits for self-tracking

Combine storyline, cognitive, emotional toolkit elements. Images, words and prototypes tell story of health over time.

#### Board games for improved self care routines

Choose different personas, overcome self care obstacles and explore multiple paths to improved outcomes

Narrative collage Create a collage with symbols, words, photos every day.

Metaphor toolkit Range of symbols and words to create metaphors for each day.

#### Video auto-ethnography

Videos or photos of doll house toolkit prototypes of health experiences. Annotated with descriptions and audio.

#### Digital Garden

People often take better care of others than themselves. Plants in digital garden represent routines to be maintained. Seeing a physical object flourish or decay can inspire action and insight.

## **CREATIVE MATRIX**

	Data Collection Reflective practice supports connection to self. One becomes more attuned to changes in the body	Externalization through visualization or language, patients learn to identify and articulate experience	Co-Creation Having artifacts to share with others promotes conversation and shared understanding.	Role Playing Affords a safe space for expression, experimentation and perspective taking.	Iterative Self-care Reflection supports the creation of self care strategies which can be iterated on	Wild Card
Gamification	Earn points Mole a pues for about commitment consciones to self-tracking activities	Choose your change own scenarios to adventure of explore health different autcomes characters		Secury Registries Pay your failure characters to section games, Patients says gets empetyy settlements characters to settlements characters and settlements characters settlement settlements settlement sett		
Data Physicalization	Tack Symptoms through basis or other indential	Physical Structure that Chargets with symptoms		A digital A digital grows of dies based on set care care difference difference care difference di difference difference difference difference difference diffe		
Toolkit	Tool that back is what is toppen you and to prove that that prove when you and only that when you when you	Closes textures	Doffhores tools allow are to protope with body with body with body with body	Collaborative Mink taphysip of Annes. Colema a physical South and Annes. South and Annes. South and Annes. South and Annes. South and Annes.		Provocations Apply design binning Constructions (Apply design research on one side binning bin
Workshop	Group data synthesis		Weety waveshops to crose water.it         Scattor safet Discourse videous n results		Workshop on how to breate on set care strategies Routines	
Tech	Mood tracker	App the motion ammitten based on weeks and ammigrer second	Oreste Hearth stances to shake booted graderom, (Jubinotge)	Create VR simulation of health experience.		We impained too it servers an and/or can certain an and/or can be an an an an an an an an an an an an an an an an a
Wearable	Fit Bit		Clothes communicate symptom changes			Masseum of you. Gallery of antitic representations of wellness
Digital Media	Asia incodes of point of deng cases by expension, cases by expension, cases to make this a dong terms	Music that expressed bymainments composition correlation over time				
Metaphor		Metaphon that express symptoms and humin tells policy wave time	Metaphro toxica, Bongo et rumolo, casae negativo, (Convival Toxico)			
Diary - Activity log - Symptom log	Audio Diary Photo Diary Photo Diary Activity did you do? How did you feel?	draw on body outline daily to create tip book	Diary Probe w pictograms and scenarios		Diary to support creation of self care strategies	
Persona		Create a persona to represent daly heatth		Booose a raw Which Pick from Dataction revy version of Dataction wethous are you? approaches		
Scenario		Create Health Scenarios for each day Create Health		Scone Create changes Sconarios of based on Sconarios of Wellness health future	Create scenarios of self-care strategies	
Narrative		Create Narative from Photo of Video diary			Figure 5: Creative ma	rix chart of possible concepts



#### Ability to Participate in Social Roles and Activities

	Never	Rarely	Sometimes	Usually	Always
I have trouble doing all of my regular leisure activities with others	0	0	0	0	0
I have trouble doing all of the family activities that I want to do	0	0	0	0	0
l have had trouble doing all of my usual work (including work at home)	0	0	0	0	0
I have had trouble doing all of the activities with friends that I want to do	0	0	0	0	0

#### Physical Function

Please rate your ability to do the following activities.

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
Are you able to do chores such as vacuuming and yard work?	•	0	0	0	0
Are you able to go up and down stairs at a normal pace?	0	0	0	0	0
Are you able to go for a walk of at least 15 minutes?	0	0	0	0	0
Are you able to run errands and shop?	0	0	0	0	0

Figure 6: Arthritis Foundation's Live Yes! INSIGHTS

## **FEATURES**

While any of these concepts could create an exciting final product, I prioritized daily usability because consistency is key to successful self-tracking. Another important theme throughout the concepts was self-discovery through creation. While user experience designers conduct generative research activities to yield insights about user groups, people can do this for themselves. My goal was to show users how to leverage the affordance of the creative process towards their daily self-discovery. Finally, I decided to develop a diary kit with which would use metaphor and imagery to create daily collages which would form a personal health narrative over time.

#### Inspiration from Live Yes! INSIGHTS

I revisited the Arthritis Foundation's Live Yes! INSIGHTS tool the learn more about how quality of life was measured. Most questions pertained to how symptoms affected quality of life. For example, how does arthritis affect one's physical function or ability to participate in social activities. What I liked was the focus not on the symptoms but the context in which the symptoms occurred. Inspired by this approach, I decided my intervention should inquire about the context of the users symptoms. In what setting are they experience symptoms? What activities trigger these symptoms the most?

#### Prototype Format

When considering the format this tool should take, I considered the affordances of digital and physical prototypes. I envisioned my solution as a form of art therapy. A physical diary kit would provide an opportunity for making while engaging in self reflection. It would also provide a reflective escape from screen based activities. However, while still in an experimental phase it was important to be open to changes. Creating physical prototyping requires commitment to features and assets. Conversely, digital prototyping is flexible and low commitment. I decided to create a wire frame of a digital diary kit for testing and remain open to possibility of a physical diary kit at a later stage.

### **METAPHOR CREATION SYSTEM**

As I developed the diary kit features, I practiced metaphor creation became more adept at it. In order to make metaphor creation easy for the user, I referred to previous research on metaphors to inform a reliable process.

#### New Metaphors. Lockton, D., et al, 2019

Dr. Dan Lockton's *New Metaphors Toolkit* is a set of cards designed to help generate new approaches to concepts by expanding conceptual vocabularies. By mapping similar characteristics between two cards, which contain words or images, the user can find inspiration for new metaphors. He refers to anthropologists Mary Catherine and Gregory Bateson's Syllogism in Grass as a source of structure for generating metaphors. In a conventional syllogism, logical reasoning is drawn between two premises. For example, if people will die and Socrates is a person then Socrates will die. A more metaphorical approach to a syllogism can generate new metaphors. For example, if people die and grass dies, then people are grass.

#### Metaphors to Live By. Lakoff, G., & Johnson, M., 2003.

Lackoff describes the various conceptual systems used to form metaphors. The structure of many metaphors are formed by idioms which refer to one thing as another. This idiom can refer to experiences, objects, orientation, or actions. For example if love is war, an apt metaphor may be "He is know for his rapid conquests". If love is madness, "I'm crazy about her" is more fitting.

## Marketing Metaphoria: What deep metaphors reveal about the minds of consumers. Zaltman, G., & Zaltman, L. H., 2008

Through thousands of in depth interviews across cultures and generations, Zaltman and Zaltman have uncovered seven giant metaphor systems on which all metaphor are based: balance, transformation, journey, control, resource, container and connection. Other deep metaphors are motion, force, nature and systems. There are three foundational concepts underly all metaphors: pattern recognition, categorization and archetypes.

## Metaphor Cards: A How-to-Guide for Making and Using a Generative Metaphorical Design Toolkit. Logler, N., Yoo, D., & Friedman, B., 2018

This paper describes the anatomy of a metaphor. Every metaphor has a tenor, the underlying idea or principle subject, and a vehicle, the secondary subject which describes the tenor. If we analyze the metaphor, "the mind is a machine," "mind" is the tenor and "machine" is the vehicle.

SYMPTOM	THINGS WITH THIS QUALITY	METAPHOR SYSTEM	METAPHOR
Stabbing Pain	Knives, Needles	Force	Being robbed at knife point
Swelling	Balloons, Tires	Object	My hands are swelling like balloons
Immobilized	Vice, Weight	Force	I am buried under a blanket of bricks
Dizziness	Being spun around in a dryer	Motion	I feel like my head is spinning around in a dryer

"When I woke up this morning I was in so much pain I could barely move. The pain was excruciating, my joints were stiff, I could barely get out of bed."

## Part 1 – Setting

### What kinds of physical activites did you do today?







### Chores

## Walking

Getting Dressed

Sleeping

## Part 2 – Symptoms

### Where did you experience symptoms?





Whole Body







Foot



## USER STORY PART ONE: SETTINGS AND SYMPTOMS

Using this system I created this wire frame prototype. The following pages show the wire frame used by a person with arthritis to describe three painful experiences through visual metaphor.

#### **User Story**

This is a modified except of a users description of how pain effect his morning.

#### Setting

First the I've inputed the setting and selects the activity that triggers the symptom. Based on the story above they are waking up so "sleep" is selected.

#### Symptom Location

The user does not specify where the pain is experienced. He does say he can hardly move. For that reason I have chosen "whole body".

#### Symptom Quality

Here the user can specify the qualities of their pain. Since the users refers to his pain as excruciating I have chosen "sharp"

## **USER STORY PART ONE: METAPHOR CREATION**

### Part 3 – Metaphor Creation



## Select a metaphor style

JOURNEY	FORCE	NATURE	OBJECT
Journey	Force	Nature	Object

## Select a picture that best describes this pain













0



Mallet

#### **Metaphor Creation**

Here the user sees his selections together then is guided through the process of creating a metaphor

#### **Metaphor Style**

Then, the user chooses the type of metaphor foundation that best fits the scenario. In the the story he states he feels prevented from moving I chose "force".

#### **Symptom Location**

Next the user can choose the image which best describes the pain which in this case is "knives". From these factors this metaphor is created.

#### **Final Visual Metaphor**

The end result is: "When I wake up I feel like my body is being held down by knives"



"When I try to walk and there is a searing pain in my heels."

## Part 1 – Setting

## What kinds of physical activites did you do today?







Sleeping

Chores

## Part 2 – Symptoms

#### Where did you experience symptoms?

Head





Whole Body

Hands



Foot

## Pain



## USER STORY PART TWO: SETTINGS AND SYMPTOMS

So continuing with this story by the same user. He tries to walk but feels a sharp pain in his foot.

#### User Story

This is a modified except of a users description of how pain effect his morning.

#### Setting

Here is clear the context is walking.

#### Symptom Location

I have chosen "foot" as the closest option to heel. A wider range of options will be available in futrure prototypes.

#### **Symptom Quality**

"Sharp" seemed the closest to searing pain.

30

## Part 3 – Metaphor Creation



## Select a metaphor style

JOURNEY	FORCE	NATURE	OBJECT
Journey	Force	Nature	Object

### Select a picture that best describes this pain





#### Razor Blade

Needles

### **Metaphor Creation**

Here the user sees his selections together then is guided through the process of creating a metaphor

#### **Metaphor Style**

Then, the user chooses the type of metaphor foundation that best fits the scenario. Since searing implies penetration, I chose "object"

#### Symptom Location

Next the user can choose the image which best describes the pain which in this case is "needles" .From these factors this metaphor is created.

#### **Final Visual Metaphor**

The end result is: "When I an walking it feels like ea giant needle is in my foot"





Thumb Tack

**USER STORY PART TWO: METAPHOR CREATION** 

## **USER STORY PART THREE: SETTINGS AND SYMPTOMS**

"To top it all off, I have a flare up. My hands are so swollen I can't even button my own shirt."

## Part 1 - Setting

## What kinds of physical activites did you do today?







Sleeping

Chores

## Part 2 - Symptoms

#### Where did you experience symptoms?





Whole Body





Foot

## Pain



Hands

**User Story** 

This is a modified except of a users description of how pain effect his morning.

#### Setting

It is clear in this case the user is getting dressed.

#### **Symptom Location**

It is also clear he is experiencing symptoms in his hands.

#### Symptom Quality

"Sharp" seemed the closest to searing pain.

## Part 3 – Metaphor Creation



## Select a metaphor style

JOURNEY	FORCE	NATURE	OB
Journey	Force	Nature	Object

## Select a picture that best describes this pain





Balloons





#### **Metaphor Creation**

Here the user sees his selections together then is guided through the process of creating a metaphor

#### **Metaphor Style**

OBJECT

Then, the user chooses the type of metaphor foundation that best fits the scenario. In the the story "object" seems the most appropriate.

#### Symptom Location

Next the user can choose the image which best describes the pain which in this case is "balloons". From these factors this metaphor is created.

#### **Final Visual Metaphor**

The end result is: "I can't button my shirt because my hand are swollen like balloons"

## **USER STORY PART THREE: METAPHOR CREATION**

### **VISUAL STORY OF THE USERS MORNING**

Finally the user can see the visualizations together which can tell a story of their health over time. Here you can see the story of this person's morning.



When I wake up I feel like my body is being held down by knives



When I an walking it feels like a giant needle is in my foot.



l can't button my shirt because my hand are swollen like balloons.

# **SCENARIOS**

## **SCENARIO ONE**

I envision this tool being used when new patterns of symptoms occur It could be as symptoms occur or at the end of the day as part of a daily reflection practice. The tool can provide a moment of reflection. The process of trying to articulate pain can provide clarity. The user can stop and think about the quality of the pain,"What experience, object best describes how I am feeling?"

## SUPPORTING PATIENT IN CONVERSATION WITH DOCTOR

Anna has had difficulty getting out of bed in the morning due to pain. She uses the diary kit to track and describe this pain. When she looks back she can see weeks of the same imagery of her pain. This motivates her to make a doctors appointment.



(Anna uses her diary kit when she experiences pain in the morning so she can capture it in the moment)



Anna: Lately it has been hard to get out of bed in the morning.

**Dr. Pratt:** Are you having trouble sleeping? Have you suffered from insomnia in the past?



```
Anna: It's not insomnia. According to the symptom
diary kit I have been using, It feels as though my body is
being held down by knives. Every day for a month it has
been physically hard to get out of bed.
```

**Dr. Pratt:** It is unusual to feel that way every morning. Lets run a few more tests.

## **SCENARIO TWO**

## DOCTOR RECOMMENDS DIARY KIT TO PATIENT

Dr. Rodrigues notices her patient William has difficulty articulating his leg pain. She needs additional information before suggesting solutions. The doctor suggests the diary kit so he can gain more clarity into his symptoms, then return for an appointment to discuss them further.



**Dr. Rodrigues:** So, this leg pain you are experiencing, is it soreness that could come from having banged it against something. Or is it stinging pain that comes from the inside?

William: To be honest, I'm really not sure.

**Dr. Rodrigues:** Knowing more about the kind of pain you are experiencing could help me find the root of this problem. If you use this diary kit every day it could help you to understand your pain better.

William: I've been so busy I haven't been able to give it as much thought as I could. Thanks, this could help.



(Throughout the course of the week, William pays more attention to his symptoms, stopping to reflect on its qualities and record them whenever he get the chance.)



Return visit:

William: This diary kit helped me reflect more, I realized it feels like a needle is in my leg

**Dr. Rodrigues**: Well, now that you've described it better, there are a number of options we could try....

## **SCENARIO THREE**

## **DURING SUPPORT GROUP FOR ARTHRITIS SUFFERERS**

Paul attends a support group for arthritis sufferers. In the past, he would over share while discussing his arthritis management, taking up more than his share of the groups time. Now, when it is turn to share, he uses his diary kit to help him summarize how his recent symptoms have made daily life unmanageable.



**Paul:** Things that used to be easy for me have become a chore. I'm not getting as much done as I used to.

Group leader: Can you give a specific example?



**Paul:** Well if you look at this diary kit, you'll see some days I can't even get dressed because my hands are swollen like balloons.



**Group leader:** Now I understand. That used to happen to me before I tried this medication. Let's talk more later.

## **FUTURE WORK**

## **FUTURE WORK**

### **USER TESTING**

#### Methods

Due to the COVID-19 pandemic, I was not able to do the in-person user testing I had planned. I was uncomfortable placing additional demands people with chronic illness, who are particularly vulnerable during this crisis, by asking them to test remotely. When the time is right, I will test the digital prototype with five to ten arthritis sufferers. I would ask them to use the diary kit at least once a day or whenever they experience symptoms for two weeks. Because I was not able to include every symptom or context, participants may find the diary lacks enough options for describing their symptoms.

For this reason, I would provide a section for free writing and drawing to the diary kit.

#### Learning Goals

From testing the digital prototype, I would like to learn how participants react to process of creating metaphors. How much background information should I include about how metaphors are created? Are they happy with the metaphors created or do they prefer to create their own?

In my literature review, I mentioned the problem of recall bias in self-tracking. Recording events the end of the day is less accurate than recording them when they occur. I am curious to learn how participants compare the benefits of journaling in the moment to reflecting at the end of the day. Since this diary might require more thinking than the average symptom tracker, it might be more effective when they have more time to reflect. However, documenting the true nature of pain is best done as to the event as a possible. In order to accomplish accurate self-tracking in the moment, it is important for the tool to be easy to use.

After using this diary kit over an extended period of time, users will need to make sense of the multiple images they have created. From my literature review, I learned most self-tracking data is rarely revisited and when it is sense-making of data can be challenging. What is the best way for participants to reflect on the images they have created? How often should they reflect and what format should these summaries take?

#### **Participant Benefits**

In my own self-tracking exercise, I noticed behavior changes as my awareness increased. I would like to learn how this study affected participants' understanding of their symptoms. Do they become more in attuned to small changes? How does it affect their pain management routine? To understand the effects of the diary study on participants, I would ask them do a survey before and after the study. The survey would inquire about awareness of pain and ability to articulate it to others.

In an additional form, I would request feedback on participant experience with metaphor creation. They can also give suggestions for additional categories for symptoms and contexts. It would be interesting to learn what part of the process was the most helpful to them: the act of tracking, creating the metaphors or reflecting on the images created?

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