Visually Encoding the Lived Experience of Bipolar Disorder

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ABSTRACT

Issues of social identity, attitudes towards self-disclosure, and potentially biased approaches to what is considered "typical" or "normal" are critical factors when designing visualizations for personal informatics systems. This is particularly true when working with vulnerable populations like those who self-track to manage serious mental illnesses like bipolar disorder (BD). We worked with individuals diagnosed with BD to 1) better understand sense-making challenges related to the representation and interpretation of personal data and 2) probe the benefits, risks, and limitations of participatory approaches to designing personal data visualizations that better reflect their lived experiences. We describe our co-design process, present a series of emergent visual encoding schemas resulting from these activities, and report on the assessment of these speculative designs by participants. We conclude by summarizing important considerations and implications for designing personal data visualizations for (and with) people who self-track to manage serious mental illness.

CCS CONCEPTS

• **Human-centered computing → Visualization design and evaluation methods**; *Empirical studies in HCI*; *Collaborative and social computing design and evaluation methods*; • **Social and professional topics →** *User characteristics*;

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KEYWORDS

Participatory design; personal data visualization; bipolar disorder; quantified self; visual methods

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1 INTRODUCTION

"How well did I sleep last night? How relaxed am I right now? Will I feel better or worse tomorrow?" The expectation that questions about personal health and well-being can be answered with data is characteristic of the digital age [3]. Recent work in Personal Informatics (PI) has improved the instruments, methods, and algorithms that support self-tracking, strengthening connections between pervasive personal data and self knowledge. Because visualizations are the way that many PI systems make personal data available to end users [14], they play a critical role in this connection.

Personal visualizations offer "substantial opportunities to help individuals gain insight and knowledge about themselves and their communities" [72, p. 26]. Visual displays of personal information can support interpretation and use of what can be a dizzying amount of information by people not necessarily trained in quantitative analytic practices such as data science or statistics [6, 38, 45, 72, 78]. Further, design choices in the visual encoding of personal data can strongly influence how data-driven self-knowledge is shaped [19, 41].

To probe the limitations and potential biases of visual conventions in the representation of personal data and to identify alternative approaches that better align with lived experiences, we examined an "edge case" of personal tracking. Specifically, we worked with individuals self-tracking to manage bipolar disorder (BD), a serious mental illness (SMI) characterized by severe and unpredictable mood swings (i.e., episodes of depression, mania or hypomania, and mixed states). Previous work has shown that many bipolar patients

who track emotions and behaviors, such as mood, appetite, social contact, and physical activity [22], believe that tracking practices help them make a distinction between their "true self" and the extreme ups and downs of the disorder [55, 56, 61]. Self-tracking can also provide a sense of agency to patients whose BD makes them feel out of control [39].

In addition to hand-drawn graphs and charts, customized and manually updated digital spreadsheets, and forms and checklists provided by clinicians, many individuals managing BD also use self-tracking apps [55, 61]. In this context, how these PI tools visually represent personal data to users is critical for supporting healthy self-reflection, a sense of agency, and effective communication with care providers. However, popular applications like Fitbit offer a distinctly quantitative representation of an individual by displaying personal data though time-series graphs and line charts. In highlighting regularized patterns using standardized baselines, there is a risk that representations of self that emerge from these visualizations can foster unhealthy self-scrutiny and unrealistic normative expectations of health [51, 70].

In order to design personal informatics systems that more accurately represent lived experiences of a range of different types of users, it is essential to visually encode personal data in ways that are appropriate and responsible. This requires a deep understanding of factors that influence interpretation of behavioral and emotional markers, attitudes towards disclosure, and risks associated with expectations of what is "typical" or "normal."

Advocates for feminist approaches to data visualization [16, 32, 43] have critiqued conventional approaches to the display of data as disembodied and removed from lived experiences and have advocated for the potential of more inclusive and representative practices in the process of graphic knowledge production [19]. While greatly inspired by the spirit of feminist approaches to data visualization, in setting out to conduct research that embraces principles of inclusion, empowerment, and visibility [16], we recognized a dearth of methodological examples of this type of inclusive design practice in the information visualization literature.

To address this gap and to begin to establish more robust practical grounding for the collaborative design of personal visualizations, we offer an account of the process and outputs of a project that prioritizes participant voices and perspectives. We engaged individuals diagnosed with BD in a series of participatory design sessions focused on probing visual associations with lived experiences of SMI. Our presentation of this work is reflective and surfaces some specific challenges we faced in taking this approach. For example, as a result of a highly iterative and inclusive design process, traditional notions of "elicitation" and "finding" were confounded. Collaborative visual elicitation activities resulted in forms of knowledge production and synthesis [16, 19] that provided an alternative to conventional means for tracing the provenance of outcomes.

This marked an opportunity for us to think more deeply about the implications of developing research methods to support critical visualization design frameworks [18] such as feminist data visualization, including ways to present "findings" that do not exploit the contributions of vulnerable or marginalized participants. Here we settled on reporting "design process outputs" (rather than empirical results) as a way to signal 1) the collaborative, situated, and generative [16] nature of our research outcomes and 2) the role this methodology plays in our overall goal of producing personal informatics system that better align with lived experiences, especially those of marginalized populations [62].

In this paper, we describe the process and outputs of our collaborative design methodology, report on participant responses to speculative and exploratory visualization design concepts, and summarize implications for designing alternative approaches to visually encoding tracking data, especially for similarly vulnerable populations.

2 RELATED WORK

Personal data practices

PI systems enable users to engage with their personal data to optimize and maximize health and wellness behaviors. The self-monitoring or "Quantified Self" (QS) practices enabled by these tools encompass a range of tracking activities associated with self-knowledge, behavior change, and health management [79, 80]. While many QS activities resemble other types of data practices, they also embody a host of vernacular or context-dependent relationships with personal data. For example, Choe et al.'s examination of the data practices of quantified selfers [9, 10] showed that visualizations of personal data often share the same types of requirements as traditional information visualization (e.g., examining details, identifying trends, making comparisons) [5] but that quantified selfers are also interested in activities such as self-reflection that visual representations are often not designed to support directly [76]. Further, personal data users tend to be "more interested in being *inspired* and *engaged* by their data than completing a functional task quickly and accurately" [72, p. 26] (emphasis added), especially individuals using personal data to make decisions about well-being. In these cases, how personal data are represented and integrated into personal and therapeutic practices can cultivate—or counter—a sense of agency and identity [39].

Quantified self, visualized self, lived self

Many data-driven personal practices treat the user as a scientist; but what if one's end goal is not to perform scientific

analysis but to reflect, witness, empathize, describe, or synthesize self-knowledge in other ways? These activities are likely to require very different types of personal data representations [30, 68, 76]. From this recognition stems growing concerns that conventional graphic representations of personal data can, for example, make individuals susceptible to judgmental interpretations of themselves [74]. Standardized representations can privilege normative expectations about various aspects of one's body, behaviors, and overall wellness [51]. Dissonance between the "lived" self and the "computed" or "imagined" self can provoke distress or even shame [3]. In this way, personal visualizations have the potential to become "confronting" [2], with their metrics and reminders about what, how much, and when one is eating, sleeping, moving, and so on, which urge a user towards a more idealized version of self.

To respond to emergent and reflective QS practices, designers have begun to incorporate alternative visual configurations into PI interfaces. The wallpaper of the mobile application UbiFit [12] displays a garden where the number of flowers and butterflies reflects activity levels and attained goals. Gluballoon [17], a diabetes monitoring application that runs on a wearable device, uses an animated hot-air balloon to illustrate changes in blood-glucose levels. The smartphone wallpaper BeWell [44, 49] maps the number of animated marine animals to well-being scores, while the kiosk display Fish'n'Steps [48] maps size and facial expressions of animated fish to health goal progress. Such attempts to break from standardized approaches for displaying temporal data (e.g., line graphs or calendar depictions) are motivated by a recognition that experiences of time vary depending on contextual factors. They are not always perceived, remembered, or interpreted as linear; they can be abstract, and they can draw heavily on social and cultural metaphors [4].

Researchers have also explored avatar-based QS representations, using humanoid imagery to literally represent the person behind the data [1]. Others have used ambient displays, such as BioCrystal, which displays mood through biosensor data streamed to LED-embedded lanterns and crystal charms [65], and MoodLight [57, 70], which presents galvanic skin response data as a measure of mood through colored light. Plant-based displays, such as vines that receive water and nutrients based on human biometric data, have also been explored as a means of depicting health goals [8].

These alternative encoding strategies break from convention and mitigate some of the limitations of standardized representations. However, they are primarily driven by conventional models of interacting with personal data, including assumptions that: 1) progress towards an idealized and generalized goal is desirable (or even possible); 2) mapping external signals to internal states is viable, useful, and/or direct; 3) quantification of qualitative experience produces meaningful results; and 4) periodic sampling smoothed to represent the illusion of continuous measurement is desirable. Further, many are not developed in close collaboration with users, including those from vulnerable populations.

Critical approaches to personal data representation

In order to expand methodological approaches to the creation of personal visualizations beyond those typically employed by PI system builders, we explored data art projects involving the collection, curation, and display of personal data. We found that data art projects often engage more directly and critically with lived experience as a primary goal, inherently challenging many of the assumptions and conventions we have discussed so far [29]. For example, data artist Laurie Frick's projects focus on her daily rhythms, using hand-drawn elements and craft to reflect on notions of surveillance and the passage of time [23]. The hand-drawn aesthetic of this work, similar to Georgia Lupi and Stefanie Posovec's "Dear Data" project [50], draws attention to gaps between digital display and the material experience of life. There is a tension in these pieces between the display of personal data (often mediated by technology) and the embodied intimacy of a hand-drawn line (or a line programmed to appear to be hand-drawn). Narrative representations, also referred to as "autobiographical visualizations" [71], are another method deployed by data artists to scaffold situated engagement with personal data [33, 74]. For example, MyLifeBits [27] users can self-author stories based on logs of personal and sensor data. We drew from these critical perspectives along with traditional participatory design principles [60] to create a series of collaborative visual elicitations that would enable us to capture the voice, concerns, and expertise of participants.

3 METHODS

D'Ignazio and Klein highlight six conceptual design imperatives [16] for supporting inclusion and combating disciplinary bias in the creation of data visualizations: 1) rethink binaries, 2) embrace pluralism, 3) examine power dynamics and aspire to the empowerment of all individuals, 4) consider context, 5) legitimize embodiment and affect, and 6) make labor visible. Side by side with these principles, they identified a series of difficult and unavoidable questions related to both design process and design output that emerge as their conceptual approach is applied in practice.

Those that particularly resonated with the challenges we faced in our work included: *How can we leverage human-centered design and participatory design methods to learn about and with our end users, including learning more about their culture, history, circumstances, and worldviews? How can we let these insights shape our design practice and change our notions about what constitutes "good" information design?*

Whose voices are not represented on the design team but might be important for the conceptualization of the project? What might we learn if we were to visualize "messy" data? What kinds of embodied and affective experiences have meaning for end users? What kinds of expertise might we need on our design team in order to leverage and represent those experiences (e.g., fine art, graphic design, animation, communication specialists)? Can the visualization empower the end user and/or their community, group, or organization? We contribute to the emerging conversation marked by these important questions by responding in the form of an operational description of our design methodology, including outputs and impacts of this process on our PI research.

Participatory and iterative methods guided by D'Ignazio and Klein's principles [16] enabled us to explore the benefits and limitations of a series of speculative visual representations of personal data and experiences. We focused on four primary design inquiry activities:

- **Identify sense-making challenges** related to interpreting and using personal data in the context of BD;
- **Deploy participatory design techniques** that enable participants to share knowledge and insights and associate self-knowledge with diverse visual imagery;
- **Synthesize participant-generated imagery** to identify common themes including visual motifs reflecting participant experiences and sense-making challenges related to the interpretation of personal data; and
- **Create and assess speculative sketches** that build on these visual themes and draw on vernacular data practices to represent personal data in ways that are more akin to lived experiences.

These activities were performed through 1) two interviews with each participant, including a series of visual elicitation tasks, described below; 2) engaging with a professional graphic artist to transform common themes into exploratory visual encoding schemas[1]; 3) and a third interview in which participants responded to these visual encoding schemas.

Participants

Fourteen people took part in our study (9 female, 5 male; average age = 45.9; age range = 20–64). Participants self-reported 1) being over the age of 18; 2) having a diagnosis of BD (Type I N=9, Type II N=3, Type Not Otherwise Specified (NOS) N=2); and 3) not having been hospitalized for mental health issues within six months. Participants were recruited via community organizations (i.e., local chapters of the National Alliance for Mental Illness (NAMI) and the Depression and Bipolar Support Alliance (DBSA)) and via campus health care clinics and email lists. We also invited participants to share the study with their personal social networks. Our number of participants is typical of studies that use in-depth interviews of vulnerable populations (see examples in [46]). Furthermore, studies that employ multiple methods and longitudinal studies require fewer participants [53]; and with this number of participants, we were able to reach saturation [7].

All 14 participants completed Interviews 1 and 2 and 11 returned for Interview 3, marking a high retention rate throughout the study, despite this population's high risk of instability and rate of life transitions [13]. Interviews were scheduled for one hour, and most took place in a faculty office on campus[2]. The time between Interviews 1 and 2 ranged from two days to three weeks, depending on the availability of both researchers and participants. Average time between Interviews 2 and 3 was 7.75 months, due to the time needed to perform thematic analysis and work with the professional graphic artist to generate speculative visual encoding schemas. This longer gap also enabled us to gather longitudinal feedback from participants.

Visual methods for data elicitation

We used visual elicitation as a method to engage participants in the design process. In general, visual elicitation techniques include (but are not limited to): participant generated drawings, videos, photographs, collages; use of found or fabricated images as visual probes; and co-design activities such as speculative prototyping [58, 64, 69]. Visual methods have been shown to "have the ability to give voice to people and ideas that might otherwise go unnoticed or unnoted when eliciting and analyzing data" [69, p. 452]. Visual representations of concepts, prompts, and probes can be more accessible to a broader range of participants [54, 64], which is essential when working with marginalized populations. Further, imagery can be particularly effective in working with individuals diagnosed with BD [15, 34–36].

The visual elicitation activities described below were designed to be easy to perform, to encourage participants to expand on their experiences, and to probe visual associations with BD [25, 26, 69]. Activities did not require any special artistic abilities and were intended to be fun and thought-provoking. For some participants, thinking in images was a natural way of describing their condition; for others, articulating these associations was more challenging. Visual elicitation tasks provided opportunities for participants to invent and explain their own visual symbols or systems; adapt a flexible visual encoding system we suggested; and consider pre-existing images, removing the need to generate imagery on the fly. We also explicitly reassured participants that there was no "wrong" way of responding to prompts and that they

[1]See supplemental PDF for larger scale figures.

[2]At one participant's request, interviews were conducted in a private office at their place of work and in a public café.

could start over or revise their responses at any time. In cases where participants appeared uncomfortable when asked to produce imagery on a digital drawing tablet, we offered to do the drawing for or with them, following their instructions. The protocols, including visual elicitations, were reviewed and approved by the first author's university IRB.

4 DESIGN PROCESS

We conducted this study in three parts: 1) two sessions with participants to learn how they visualize and understand their experiences with BD; 2) design of visual encoding schemas based our analysis of these sessions; and 3) a third session with participants to assess the designs.

Part 1: Bipolar Experiences

Following a screening interview over the phone, we met with each participant for two successive one-hour sessions (Interviews 1 and 2), which focused on learning about participant experiences with BD, including formal and informal self-tracking practices. Each session consisted of a semi-structured interview and a series of visual elicitations, and was audio recorded with permission. We oriented participants to the 12.9-inch Apple iPad Pro tablet and Apple Pencil stylus and the GoodNotes[3] digital drawing app used for data collection. We recorded the iPad session using QuickTime running on a laptop connected to the tablet, allowing video capture of drawing activities.

Visual activity 1: Lines. The first visual elicitation activity, during Interview 1, explored the expressive capacity of a basic visual form: the line. We asked participants to draw a single line that represented their experiences with BD. We then asked them to add a second line to their drawing that represented someone close to them during the time represented by the first line; this could be a family member, a friend, a therapist, or even a pet. Last, we prompted participants to add a third line that represented what they would have considered an ideal state during that period. Notably, few participants drew a flat line in response to this last prompt. For most, an ideal state was marked by moderated (or "manageable") amounts of change within a set of boundaries. Examples of output from this activity are shown in Figure 1. We asked clarifying questions, including whether specific visual features had particular meaning (e.g., "I see this part of the line as really bumpy, but it straightens out over here. Does that represent a specific event? How would you describe the differences between those times?"). At times, this resulted in augmentations, additions, or corrections to the lines.

[3]http://www.goodnotes.com/

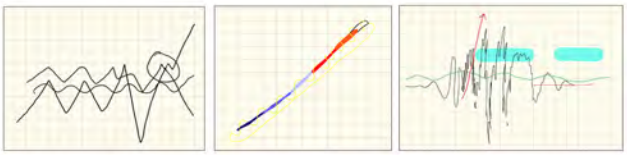

Figure 1: Examples of output from the line drawing activity. ©Authors. Image credit: De-identified participants.

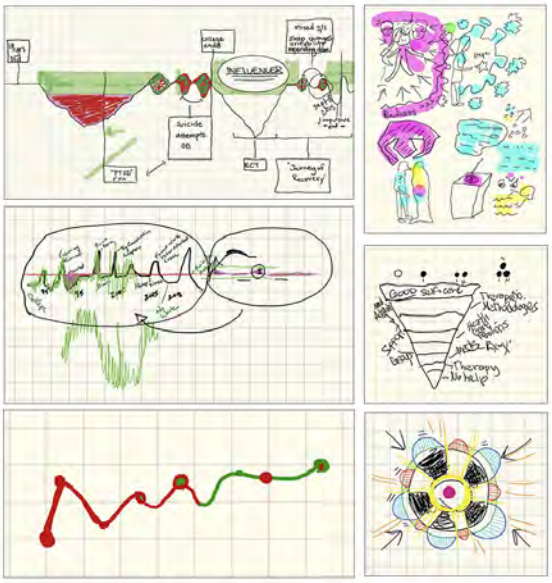

Figure 2: Examples of timelines. ©Authors. Image credit: De-identified participants.

Visual activity 2: Timeline. The second visual elicitation activity, also administered during Interview 1, required participants to think about their experiences with BD in terms of transitions and changes over time by creating a more detailed timeline. "Timeline" was defined as a diagram showing a sequence of events and how they relate to each other. Participants were encouraged to freely interpret this task. This activity explored how participants mapped complex notions like change over time to basic visual forms. A range of visual metaphors and encodings were used, some departing from linear representations entirely—for example, exploring circular or pictorial ways of illustrating change (Figure 2). We again asked clarifying questions and annotated a digital copy of each timeline to note specific intended meanings.

Visual activity 3: Icons. For the third visual elicitation, performed during Interview 2, participants were asked to use a set of five suggested icons (Table 1) to annotate the timeline diagram they created during Interview 1. These icons represented a merging of concepts derived from conventional approaches to visually encoding time series data [20] with ways that participants had talked about personally assessing their behaviors and moods over time during Interview 1. Participants were invited to modify or substitute these symbols

Table 1: Timeline icons

Name	Description	Symbol
Intensity	Moments with great or diminished intensity of experience	
Expectation	Periods when you knew what to expect or when you could recognize patterns	
Influencers	Factors, people, forces, circumstances, or events that influenced the unfolding of events	
States	Moments of positive, negative or uncertain valence	+ − ???
Change	Moments of radical change	

Figure 3: Examples of annotated timelines. ©Authors. Image credit: De-identified participants.

as they saw fit (Figure 3), with the symbol system serving as a probe to inspire reflection about how participants explicitly and implicitly assess their state of being over time, and to explore ways of visually documenting these changes.

Visual activity 4: Photo elicitation. The fourth visual activity introduced a photo elicitation task [11, 58, 63]. Participants used an "incognito" instance of a Chrome browser window to access the Google Image Search interface to find existing online images corresponding with their experiences of BD. Participants were prompted to think about concepts and descriptions that had surfaced during previous discussions, and to use associated words and phrases as search terms, for example: "boundaries", "split road", "fireflies", "ocean", "penguins huddling", "bear hibernating", "lichen", and "white noise." Images were downloaded for future analysis.

Part 2: Exploratory visual encoding schemas

Data generated from Part 1 included audio recordings, transcripts, PDFs of digital drawings, screen recordings of drawing activities performed on the digital tablet, and collections of online images. Some participants also shared examples of personal tracking documents and artwork, which we photographed with their permission. Between the second and third interviews, these materials were analyzed in collaboration with a professional graphic artist familiar with BD.

Analysis was inductive and followed social semiotic principles, focusing not only on what is represented in an image (the pictorial content), but also the communicative context in which it was created (the discursive meaning [67]) and what is and can be done with it by specific audiences (the cultural significance [75]). Social semiotic theory articulates the differences and similarities among these facets of meaning by distinguishing between the coded system representing pictorial content regardless of context or form (e.g., a photo of an apple, a cartoon of an apple, and an apple carved from wood are recognized as referencing the same object) and the ways that images of the same or similar things can have different social significance depending on the context in which they are viewed (e.g., the meaning of the Apple Inc. logo in contrast to someone being referred to as "a bad apple").

Social semiotic analysis surfaced a set of *visual motifs* associated with the pictorial content of images created and collected during Part 1 and a set of *sensing-making challenges* related to the practices of interpreting personal data. These themes are presented in more detail in our Design Outputs (see also Table 2). The first author worked with a professional graphic artist familiar with BD to use both sets of themes to create three speculative visual schemas for encoding personal data of people with BD. While these sketches are static and highly pictorial, they were created as vector-based graphics with the idea that various geometric forms, colors, and other visual features could be translated into data-driven visual encodings using one or more data visualization tools currently available such D3.js, Processing, or R. Technical feasibility will be established in future work.

Part 3: Assessment of design concepts

Interview 3 focused on determining whether and which parts of the visual encoding schemas represented in the professionally-developed sketches were useful or valuable to participants. Because several months had passed between the second and third interviews, the latter also provided insights about the stability of visual associations over time. We

Table 2: Results of social semiotic thematic analysis

Visual motifs	Water Tension and balance Circular growth and change
Sense-making challenges	Defining baselines within dynamic contexts Interpreting distortions Representing nonlinear experiences of time

began by asking if participants had experienced any significant changes or life events. We then revisited narratives and imagery from the first two interviews. All 11 participants who returned for the final interview clearly remembered creating and talking about specific images and, in spite of some variation in mental state (e.g., feeling more or less depressed or manic or being at different points in therapy), all participants confirmed that most images still carried substantial meaning.

Next, we introduced participants to the visual themes we identified using a set of representative images from data collected during Interview 2, selected and vetted by two members of the research team. These images were shown to participants during the interview, and participants provided feedback about their affinity for these images and concepts, providing informal validation for our social semiotic analyses. Last, we presented each participant with the three speculative design concepts and asked them to respond generally to all three, but in the interest of time, to select one to evaluate in more detail. Participants were prompted to imagine how the visual schemas could or should change in response to their personal self-tracking practices. Following our social semiotic approach, we encouraged participants to not only respond to the pictorial elements of the schemas, but also to consider how each visual encoding system enabled different relationships to be surfaced and different types of comparisons to be made among potential personal data points.

5 DESIGN OUTPUTS

We first focus on the thematic output of our iterative social semiotic analysis (Table 2), then present the exploratory visual encoding schemas, including summaries of participant feedback drawn from all phases of these research[4]. In reporting participant responses, we default to paraphrasing statements rather than offering verbatim quotes for practical reasons: our interactions with participants spanned a number of modalities, including verbal, gestural, visual, and indexical expressions. While verbatim quotes can provide valuable access to participant voices and perspectives, here they can be difficult to parse out of context [67].

[4]See supplemental PDF for larger scale figures and URLs of Googled images.

Visual motifs and sense-making challenges

In the following, we discuss participant responses to the participant-elicited and research team-curated sets of images representing each visual motif and sense-making challenge. Visual motifs capture common pictorial themes (shown in Figures 4, 5, 6). Sense-making challenges highlight common challenges for interpreting personal data (shown in Figures 7, 8, 9). Descriptions reflect both the associations made by the person who originally identified the image and the feedback provided by fellow participants.

Visual motif: Water. The visual motif of water (Figure 4) took on a range of forms and referenced aspects of uncertainty, danger, fluid change, and submersion or suffocation. The image of a stormy sea was discussed in terms of opacity, lack of control, ominous feelings, and being pushed back and forth in the waves. In contrast, some participants described the idea of "surfing" the uncertainty of the ocean, and the constant work and vigilance needed to try to stay balanced. They also noted a sense of beauty when that balance was successfully achieved. The third image of water reflects the feeling of being submerged, drowned, or muffled, as well as emotions and thoughts under the surface that are often difficult to parse or decipher, especially those related to identity.

Visual motif: Tension and balance. Participants spoke about the day-to-day vigilance required to maintain balance and stability (Figure 5). The person who initially selected the tug-of-war image highlighted both the feeling of being pulled off balance (e.g., by bipolar itself, by inner demons, by the expectations of loved ones) and the damage done by the resulting constant tension, represented by the fraying rope. The image of the bowels was selected by a participant because of its association with an internalized sense of constriction. For

Figure 4: Visual motif: Water. Image credits: Fair use. See supplemental material for source URLs.

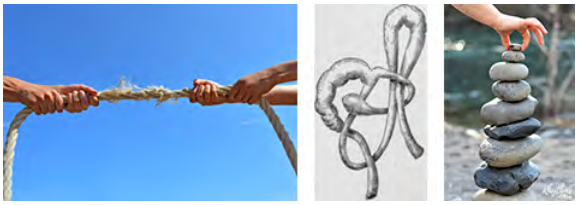

Figure 5: Visual motif: Tension and balance. Image credits: Fair use. See supplemental material for source URLs.

Figure 6: Visual motif: Circular growth. Image credits: Fair use. See supplemental material for source URLs.

some participants, emotional tension was felt in this type of visceral way. The stacked rocks illustrated a third type of tension: attempts to balance hard, seemingly immutable and irreconcilable elements of one's life, knowing that they will only fit together in certain ways. Participants who responded strongly to this image during the assessment portion of the study also spoke about being aware that stability might be fleeting—the stack of rocks might topple at any moment.

Visual motif: Circular growth and change. The idea of circular or cyclical, as opposed to linear, change over time appeared throughout the study (Figure 6). An image of a fractal was selected by a participant to describe how a tiny change can produce significant effects throughout a form. It can be difficult to establish cause and effect in such a dynamic system. One can also become absorbed with details and miss overall patterns. In the assessment phase, participants reflected on the mathematical nature of a fractal, with some having trouble reconciling it with their experiences in spite of its beauty. The explosion was another image of circular growth. The person who originally selected this image associated a sense of self with the bright light at the center, burning so hot that it is difficult to contain. However, on the explosion's outer surface, smoke and debris obscure the inner energy, reflecting a tension between internal and external appearances. Last, the image of lichen was used to discuss a growth edge, or a part of an organism where progression or expansion is happening; growth might not happen at the same rate for all of its parts. During the assessment interviews, the lichen also came to represent the interdependence of a biological ecosystem (discussed in more detail later).

Sense-making challenge: Baselines. With self-assessment of any sort, status or progress needs to be compared against something. Many self-tracking apps enable users to enter a starting weight or set a speed goal, and these initial points of reference are used as a basis for measuring success. However, for many of the participants in our study, the idea of a baseline or starting point was highly problematic (Figure 7). In response, one individual selected an image of a "DO NOT CROSS" sign on the road to represent the idea that rather than reaching for a singular goal of "mental health", they strove to just keep their behavior within a set of "acceptable" boundaries. This person was adamant that in order to be truly reflective of their experiences the image shown here should have *two* lines, delimiting an acceptable zone within which they needed to keep themselves. Of note, three participants bridled at this idea during the assessment interviews, describing their own reactive tendencies to cross over such lines just for the sake of being subversive. The hurricane prediction map was also associated with baselines, its concentric bands of color indicating the probable path of the storm. In another realization of the idea of *zones*, assessment interview participants talked about the need to control behavior and mood in order to stay within a predictable path. However, as with actual hurricanes, there is always uncertainty—a risk of being swept into uncharted territories. The last image of baselines shows a stack of Amazon boxes at someone's doorstep. For the person who selected this image and others for whom it resonated in the third phase of the study, it is not merely the stack of delivery boxes that is alarming; it is the ways that the repetition, the frequency, and the consequences of overspending represented in this image veer from acceptable behavior in varying degrees.

Sense-making challenge: Distortions. Perceptual distortions (Figure 8) were characterized in multiple ways. One participant (validated by others in the assessment interviews) associated distortions with the idea of a cloud of notations, marks, and scribbles hovering over one's head. For them, it was not about picking the *right* version of reality out of the din, but just figuring out *which* thread to follow and tuning out the other possibilities. The image of the pencils in the glass of water was selected by a participant to represent an awareness of inconsistencies in perceptions and the tremendous amount of energy needed to identify what is "real": that they are solid pencils, even if they consistently appear to be split. The last participant-selected image shows a similar type of distortion through water, contrasting the regular stripes in the background and the wavy pattern that

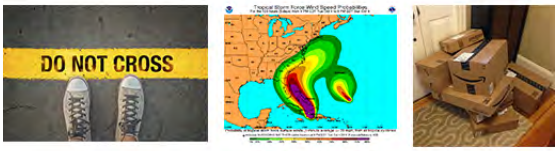

Figure 7: Sense-making challenges: Baselines. Image credits: Fair use. See supplemental material for source URLs.

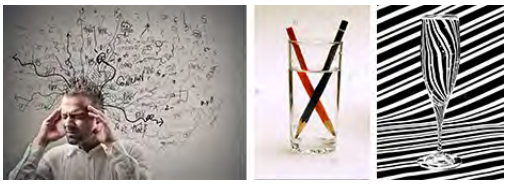

Figure 8: Sense-making challenges: Distortions. Image credits: Fair use. See supplemental material for source URLs.

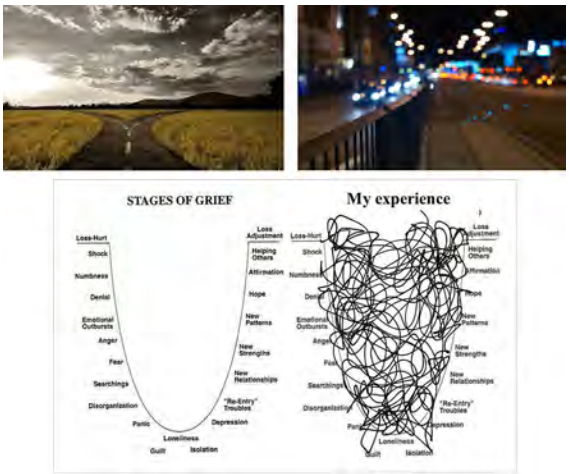

Figure 9: Sense-making challenges: Non-linearity. Image credits: Fair use. See supplemental material for source URLs

is caused by refraction. The regular stripes were referred to as what "normal" people see, and the wavy lines were used to illustrate what it is like to have BD. During the assessment interviews, one participant described seeing initially thinking the image was of an amazing zebra-striped wine glass, only to be disappointed upon looking more closely and recognizing that it was a regular glass made to appear special because of the distortions.

Sense-making challenge: Linearity of time. The experience of BD can be highly disjointed and difficult to grasp, especially when in the throes of a manic or depressive episode [21]. Participants described difficulties in piecing together the various moments, episodes, and periods of their lives in different ways. Asking participants to draw or extend a line indicating a future state (Interview 1, Visual Activity 1) was by far the most frequent activity during which participants exercised the option to decline to answer a question or forego a task. Some individuals chose to respond by representing their experiences using visual geometries that did not have such explicit beginnings, middles, or ends.

The image of a fork in the road was selected to express the feeling of being confronted with a choice and not having enough information to make a decision. When reflecting on this image during the assessment interviews, participants described feeling susceptible to false binaries and frustrated by ambiguity. The photograph of a street with a metal rail was chosen to reflect the challenges of using a crutch to provide stability, especially when one is unable to rely on it being there in the future—as represented by how the image blurs as the rail recedes into the background. Another participant selected the image of the tangled line in the diagram of the grieving process as an analogy for the ways that the process of managing BD was not always (or often) as linear as depicted in descriptions of therapeutic progress.

Speculative visual encoding schemas

The visual motifs and sense-making challenges above served as the basis for the design of three exploratory visual encoding schemas, a collaboration between members of the research team and a professional graphic artist. When providing detailed feedback about these schemas during the assessment interviews, four participants chose to discuss lichen and five chose water. Two had difficulty picking just one motif and chose to discuss both lichen and water.

Rope in tension. The image of the tug-of-war was the inspiration for this visual representation (Figure 10). Various aspects of the rope, including the tension between sides, the degree of twist in the braid, the amount of surplus available on either side, and the position of the hands, could all be used to encode personal data variables such as mood, social contact, anxiety, and adherence to medication protocols. Although participants understood the concept and could articulate how dimensions of their own self-tracking could be represented in such an image, all participants quickly dismissed this schema as being overly simplistic and most participants felt that it foregrounded an artificially binary primary relationship as the basis for bipolar experiences. A few participants mentioned that this dualism also evoked a feeling of hopelessness and inability to escape the constant tug of BD. Hope was a reoccurring theme with our participants; rather than a focus on tension, most wanted visualizations that could represent growth and incorporate both positive *and* negative experiences.

Water and sediment. The schema developed to show how water could be used to represent personal data included three distinct scenarios, drawing on the multiplicity of ways that water imagery was characterized in the earlier visual elicitation activity (Figure 11). First, we incorporated the idea of distortion, showing a pair of hands viewed through a clear plastic bag. We prompted participants to think about how their personal data might influence the type and degree of

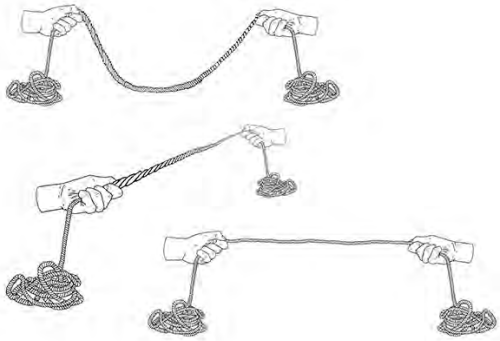

Figure 10: Rope in tension. ©Authors. Image credit: J. Snyder and I. Gottlieb.

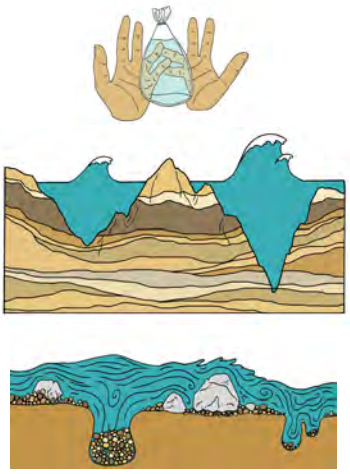

Figure 11: Water and sediment. ©Authors. Image credit: J. Snyder and I. Gottlieb.

distortion displayed. Second, we created an image of sediment and bodies of water. The layers of sediment could correspond to different personal variables, social relationships, or medications. These visual features might change slowly due to compression or decay. In contrast, the rate of flow, depth, and turbulence of the water could be used to display behaviors or moods that are more mercurial. The amount of land visible above the surface of the water could also be encoded based on factors that an individual tracks. Participants who positively responded to this schema noted the value of representing change as a geological shift. Participants also remarked on how they appreciated that, unlike the rope, the water was natural and beautiful (although not all participants felt bipolar was "beautiful"). However, the participants who chose to discuss the lichen over the water schema all cited their preference for an organic and living metaphor, over geological systems.

Lichen. The schema that developed from the idea of lichen (Figure 12) shows the evolution of a single organic unit to a more mature fungus growing on a log surrounded by other organisms. Many participants responded positively to the idea that different lobes of the lichen could be used to represent distinct parts of a person's life. The log and surrounding organisms were associated with how day-to-day care practices impact an ecosystem, such as the ecosystem of people in one's life or of different aspects of oneself. The lichen was described by some as potentially having "a life of its own" at times, much in the same way participants sometimes felt about their experiences with BD. When prompted to consider what it would be like to see the scene decay or wither on bad days, participants were quite uniform in their belief that this visualization would not be off-putting as long as the change was slow (as is the case with resilient organisms like lichen) and they had agency to make changes to reverse

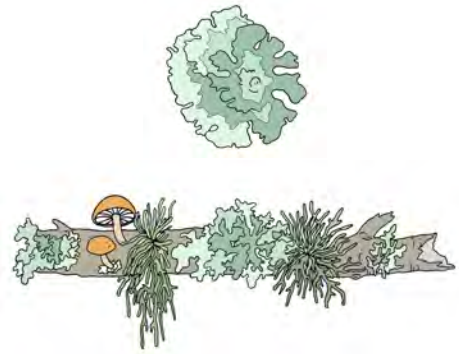

Figure 12: Lichen. ©Authors. Image credit: J. Snyder and I. Gottlieb.

the decline. While some participants expressed disinterest or even slight disgust at the idea of lichen itself, all assigned high value to the visual metaphors underlying this schema: growth edges corresponding to different parts of their lives changing at different rates; segmented but interdependent organisms within an ecosystem representing different facets of their relationships with themselves and others; and cycles of decay and resilience ensuring future growth.

6 DISCUSSION

Vernacular representation and situated expertise

As visual studies research continues to demonstrate, we have much to learn about the limitations and biases inherent in visualization conventions [24, 40, 42, 76]. Techniques like smoothing and data reduction have important roles in many types of data analysis. However, these same conventions can mask, occlude, obscure, or otherwise foster misinterpretations in other contexts [31]. For example, the uniform patterns common in time series diagrams support expectations of a normative (e.g., healthy, desirable, attainable, true) baseline periodicity in human biological rhythms. We engage with these normative expectations when we use heart rate monitors on a treadmill, see breathing rate and blood oxygen levels displayed on medical monitors, or curse stubborn line graphs built into weight-loss apps. However, in our interactions with individuals diagnosed with bipolar disorder, descriptions of regular periodicity were rare.

While terms like confidence interval, reliability, validity, or inferential reasoning do not appear in our transcripts, the tracking activities described by participants in our study reflected a deep understanding of the challenges, strengths, and limitations of personal data. The situated expertise and vernacular data practices shared by our participants [59, 77] spanned domains including the diagnosis and treatment of BD; risks and side effects of medications; evaluation of therapeutic interventions; restrictions and policies related to federal, state, and local health care and medical services; policies and procedures related to unemployment and disability

programs; and social and economic inequities disproportionately experienced by individuals with SMI. However, not all participants initially recognized the depth of their own expertise in these areas. By designing visual elicitations to cultivate a sense of agency—opportunities for participants to express themselves in scaffolded ways for those needing structure, but also flexible for those wanting to express their individuality—we built into our process a diversity of ways for participants to exercise their own judgment and creativity. For many participants, this experience was novel; many shared that no one had ever asked them to talk about their experiences outside of a medical setting.

Visualization as reflective practice

The visual elicitation activities that we designed were intended to help researchers and participants alike reflect on personal data practices. Similar to many approaches to co-design and participatory design used in sociotechnical research [28, 60, 66], visual elicitation methods prompt participants to *create* something when engaging with the research process. The act of making is inherently transformative: something comes into being or is changed [47].

In finding or creating visual representations of their experiences, participants were presented with opportunities to become more self-reflective and to move away from a mental health deficit model mindset. While many of the participants in our study shared stories that were marked by difficulty, frustration, confusion, isolation, and fatigue, many expressed that the interviews inspired them to consider their experiences in new ways, some of which helped them to explain their experiences more effectively to others.

For example, the interviews led some participants to reframe how they visualized the magnitude of their bipolar episodes. When asked to draw a timeline, early episodes that occurred before or at the time of diagnosis were often drawn at a greater visual magnitude (e.g., higher peaks for manic episodes, lower troughs for depressive episodes) than the more moderate cycling experienced after beginning effective treatments. However, when prompted to confirm that this visual difference reflected an experienced difference, many participants would clarify that more recent fluctuations, while visually less dramatic, were often more troubling because this type of cycling had occurred even though they had a treatment and maintenance plan intended to control the mood disorder. This point of clarification would often prompt the participant to introduce new types of visual encoding(s) to more accurately depict these differences.

In many cases, participants remarked that they had thought about how to better represent their experiences between interviews or had used images from the interviews as helpful analogies outside of the study. We consider this ability to support reflective practices to be an empowering aspect of this methodology [37], providing participants with tools, situations, and opportunities to have a voice in discourse around the representation of SMI.

7 CONCLUSION

In this study, we sought to understand how non-traditional visual encodings of personal data might better reflect lived experiences of SMI. The collaborative design activities that we developed for this work fostered candid conversations between researchers and individuals with BD about the challenges of managing a life-long mental health condition, the participants' existing self-tracking and data-reflection practices, and the strengths and weaknesses of several speculative personal visualization designs. The cumulative insights from this work will inform the design and evaluation of PI tools to support the long-term management of SMI like BD.

One of the common self-tracking challenges described by participants was reconciling an internal version of themselves (e.g., how the biochemistry of BD makes them feel) with external reflections of their behavior and actions in social contexts (e.g., how their actions are perceived by others). Participants created persistent, material representations of their experiences—either through drawing or photo elicitation—that served as concrete points of reference from which personal experiences could be probed and clarified [67]. This enabled more specific conversations about connections between personal data across time, magnitude of episodes, and complexities of interdependencies. Cultivating opportunities to clarify and confirm representations of self is critical for supporting vulnerable individuals who, like our participants, may have experienced doubt, scorn, or distrust from society over the course of their lives.

Personal data visualizations establish similar points of external reference in a myriad of contexts, from interactions with health care professionals to sharing symptoms and risk factors with loved ones to the exchange of progress in online affinity groups. It is therefore essential to reflect on assumptions embedded in visualization conventions and address potential biases. The exploratory sketches created during this study are not intended to be final products. Their value is in showing alternatives, pulling away from conventional and familiar methods for representing data to challenge our expectations about what a visualization should look like [19]. Building PI systems that incorporate even some of the feedback provided by participants regarding the benefits of these encoding schemas might require drawing more significantly on media art practices, techniques and tools that allow for more nuanced, lyrical visual expressions of data [29, 52, 73]. It will also surely require us to work closely with stakeholders to develop evaluation criteria that better reflects their needs, vulnerabilities, existing practice, and vernacular expertise.

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Visually Encoding the Lived Experience of Bipolar Disorder

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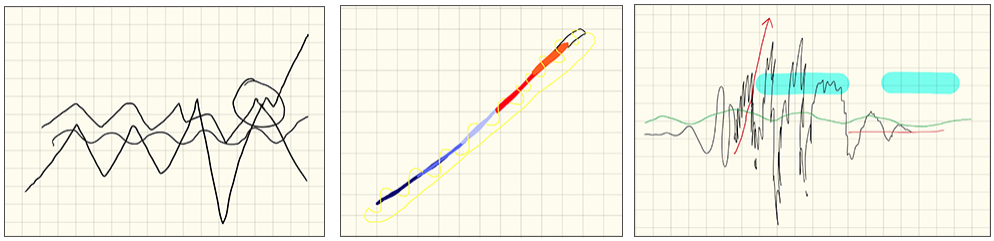


Figure 1: Examples of output from the line drawing activity. ©Authors. Image credit: De-identified participants.

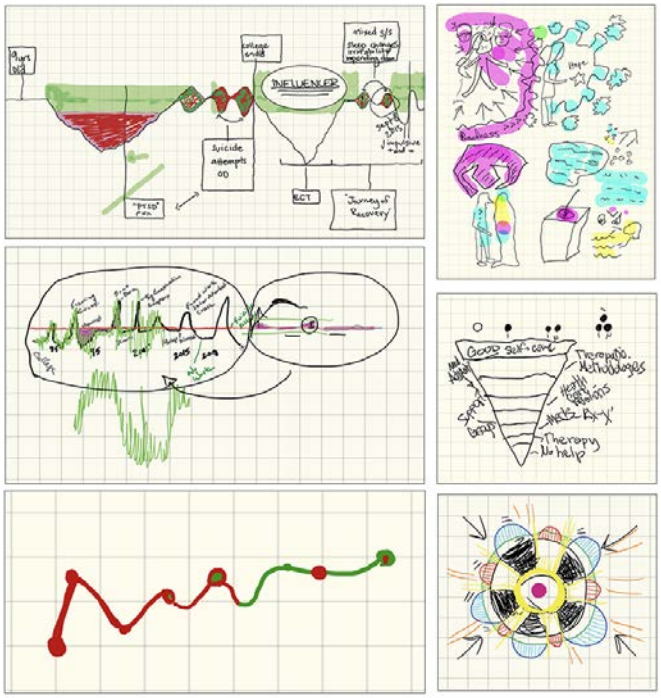


Figure 2: Examples of timelines. ©Authors. Image credit: De-identified participants.

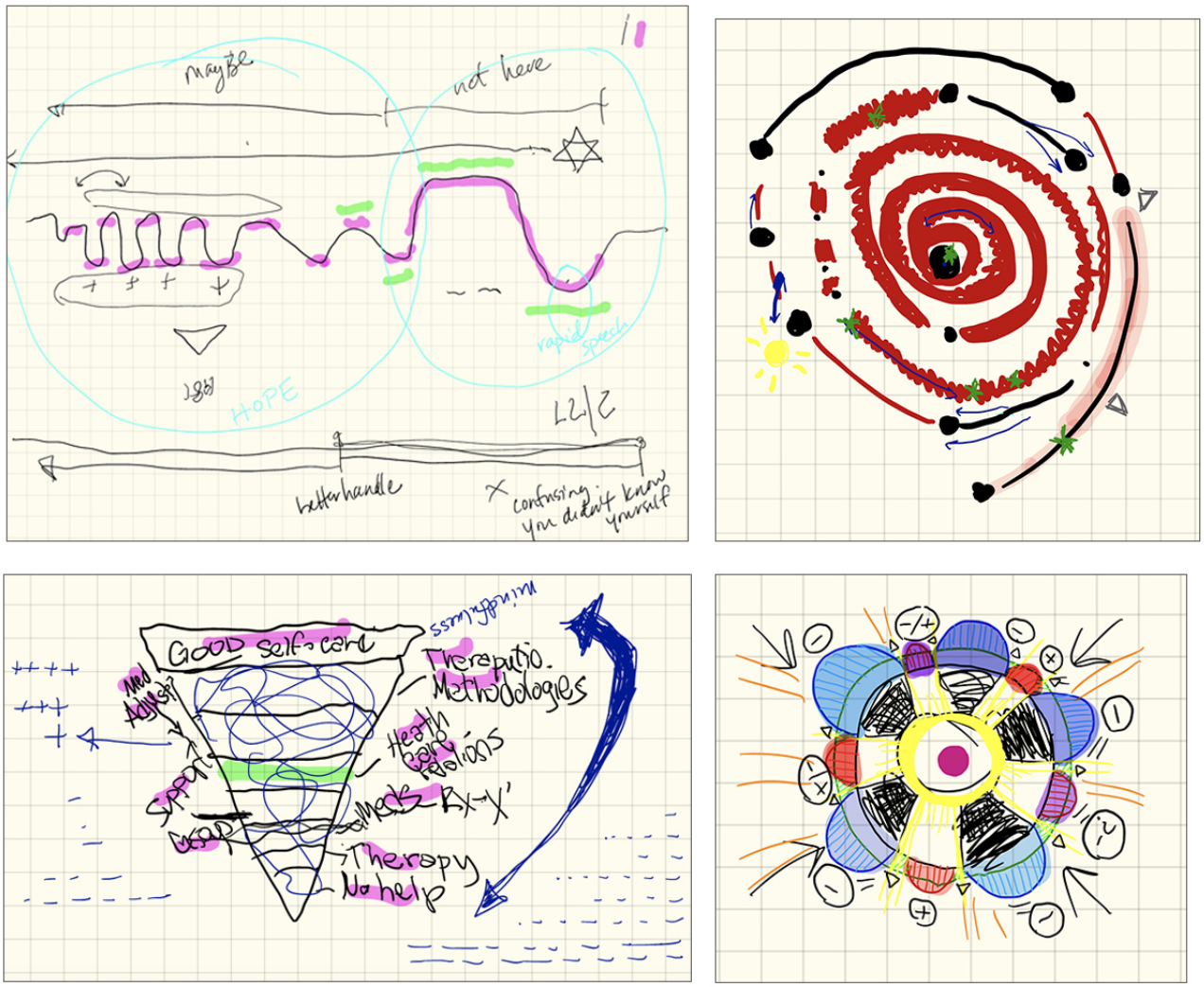


Figure 3: Examples of annotated timelines. ©Authors. Image credit: De-identified participants.

Figure 4: Visual motif: Water. Image credits: Google Image Search/Fair use.

Source URLs for Figure 4, from left to right (click to visit):

Fig 4– Stormy sea

Fig 4– Surfer

Fig 4– Submerged face

Figure 5: Visual motif: Tension and balance. Image credits: Google Image Search/Fair use.

Source URLs for Figure 5, from left to right (click to visit):

Fig 5– Tug-of-war

Fig 5– Intestines

Fig 5– Rocks

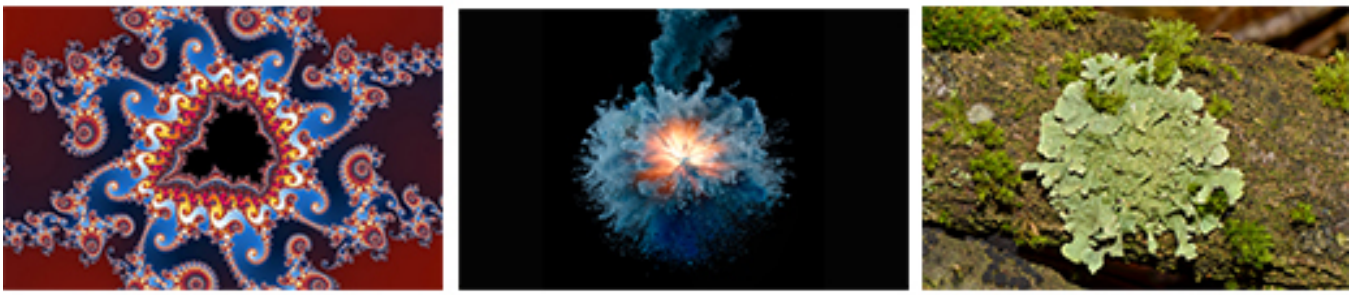


Figure 6: Visual motif: Circular growth. Image credits: Google Image Search/Fair use.

Source URLs for Figure 6, from left to right (click to visit):

Fig 6– Fractal

Fig 6– Explosion

Fig 6– Lichen

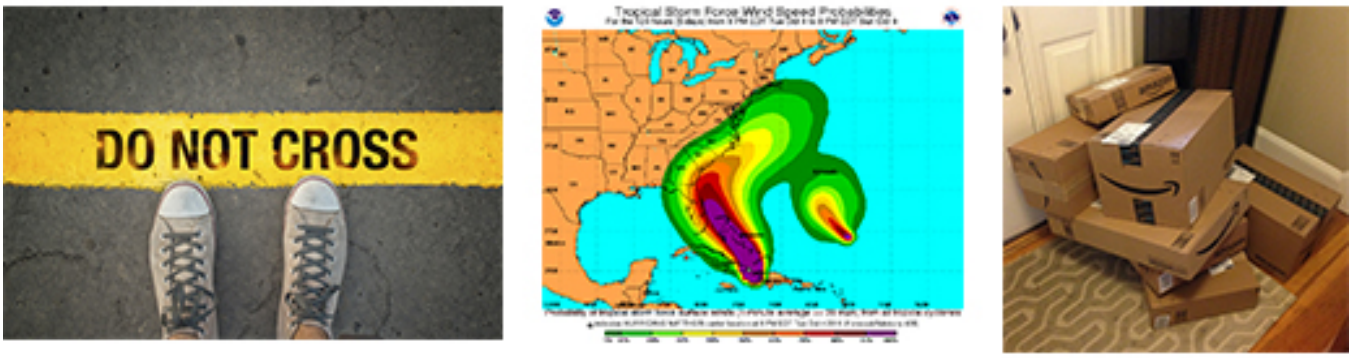


Figure 7: Sense-making challenges: Baselines. Image credits: Google Image Search/Fair use.

Source URLs for Figure 7, from left to right (click to visit):

Fig 7– Do Not Cross

Fig 7– Hurricane

Fig 7– Boxes

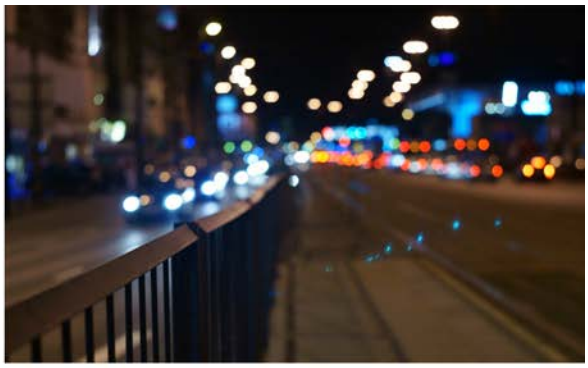
Figure 8: Sense-making challenges: Distortions. Image credits: Google Image Search/Fair use.

Source URLs for Figure 8, from left to right (click to visit):

Fig 8– Mental chaos

Fig 8– Pencils

Fig 8– Stripes



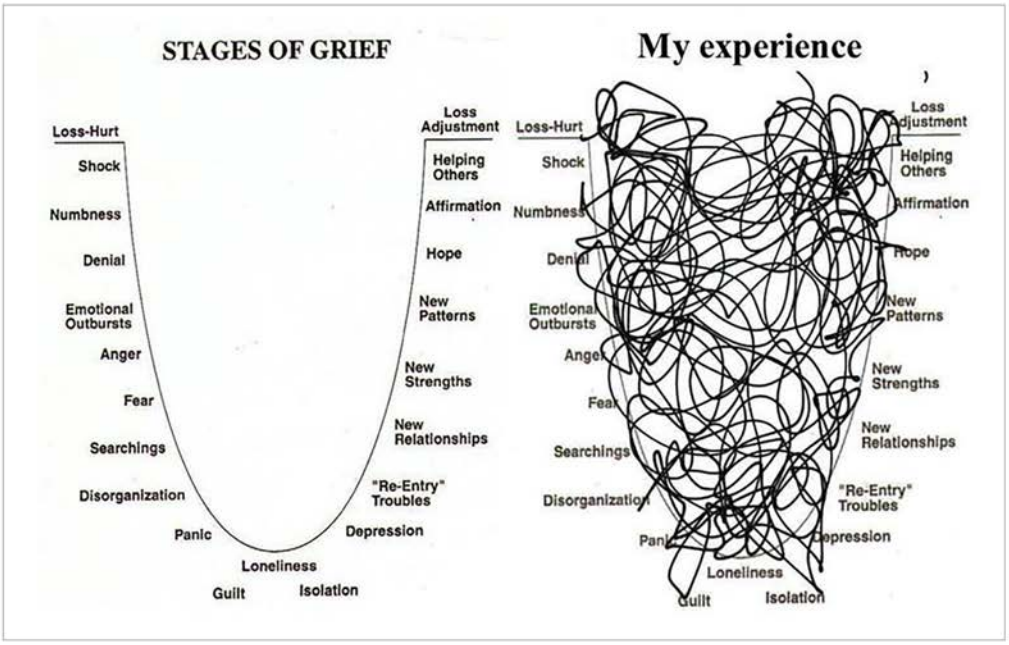


Figure 9: Sense-making challenges: Non-linearity. Image credits: Google Image Search/Fair use.

Source URLs for Figure 9, from left to right (click to visit):

Fig 9– Split path

Fig 9– Railing

Fig 9– Stages of Grief

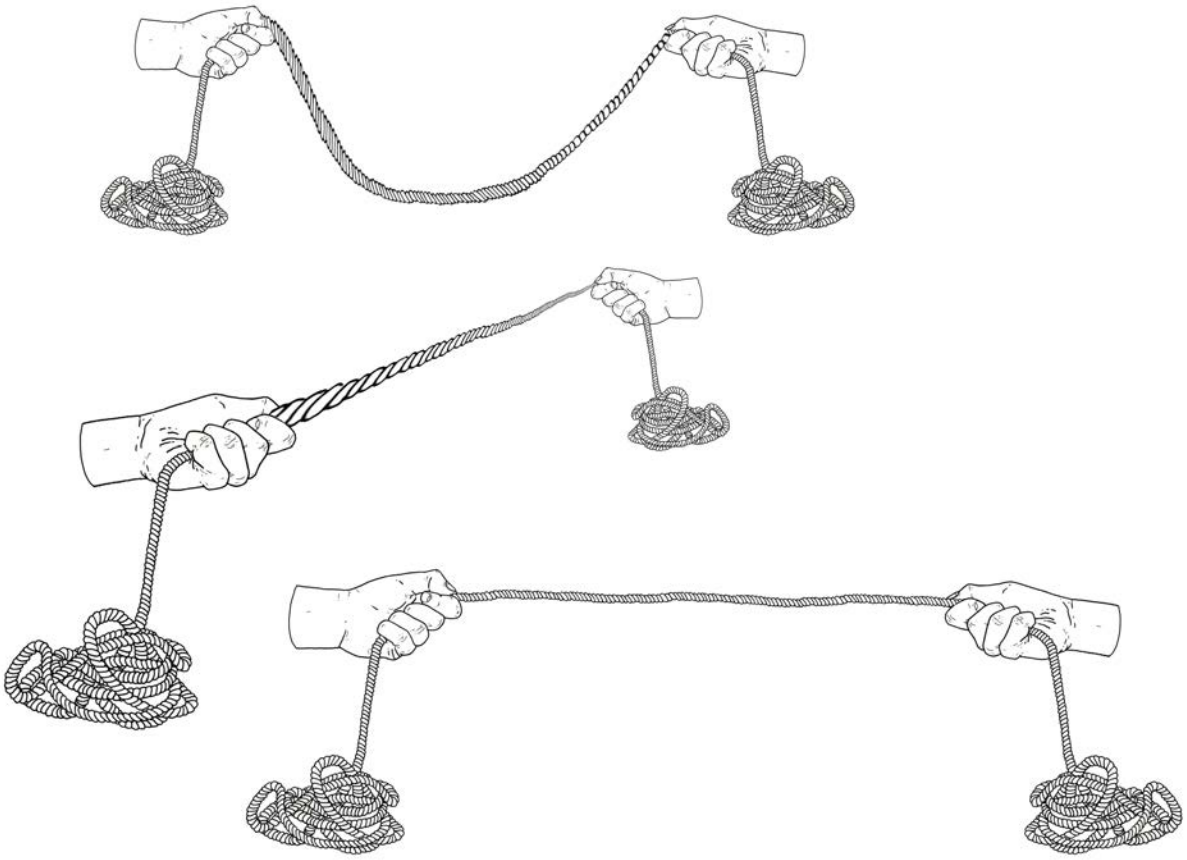


Figure 10: Rope in tension. ©Authors. Image credit: J. Snyder and I. Gottlieb.

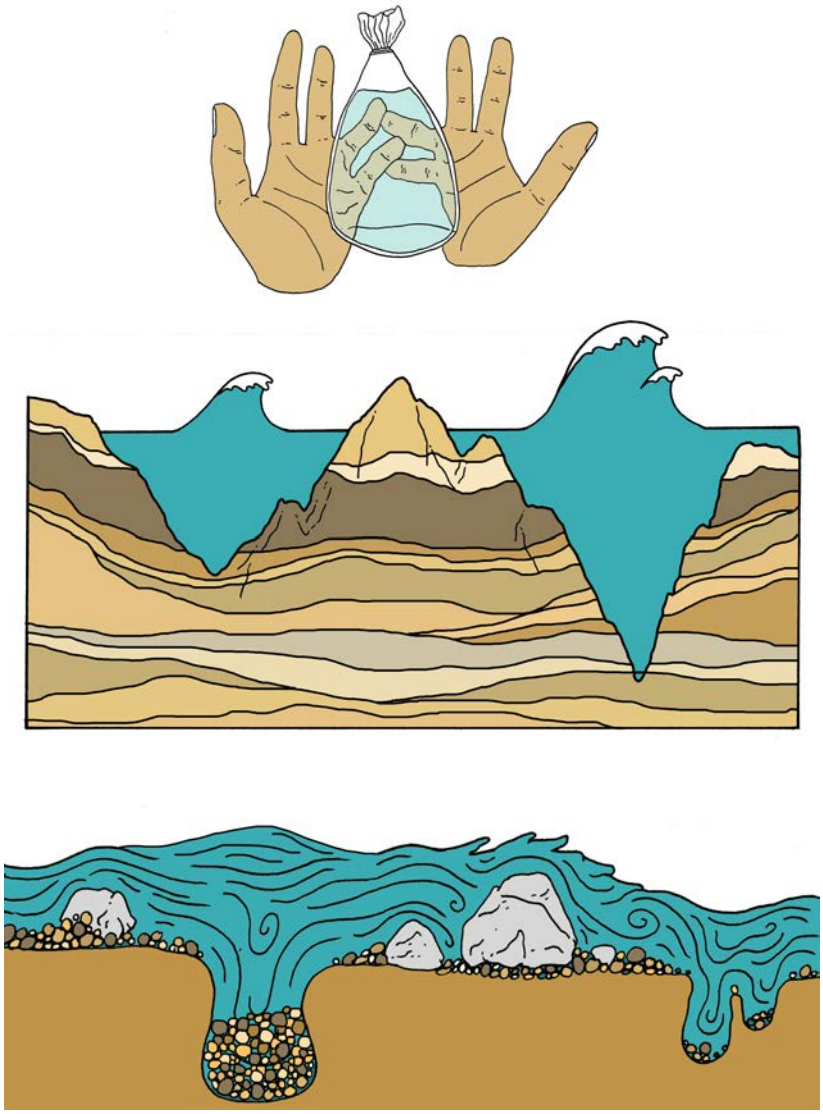


Figure 11: Water and sediment. ©Authors. Image credit: J. Snyder and I. Gottlieb.

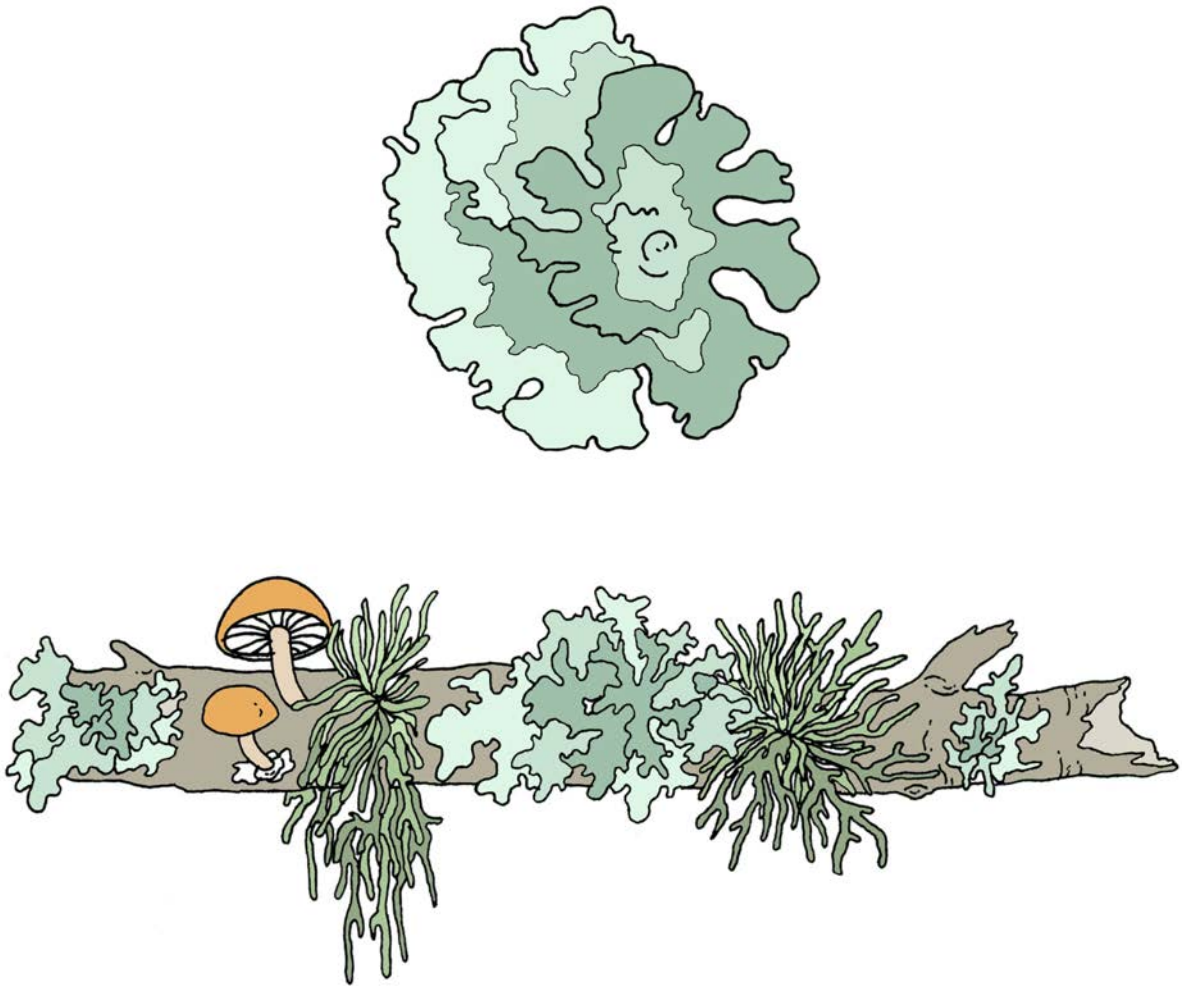


Figure 12: Lichen. ©Authors. Image credit: J. Snyder and I. Gottlieb.