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Visualising Lived Experience: Learning from a Master Narrative Framing

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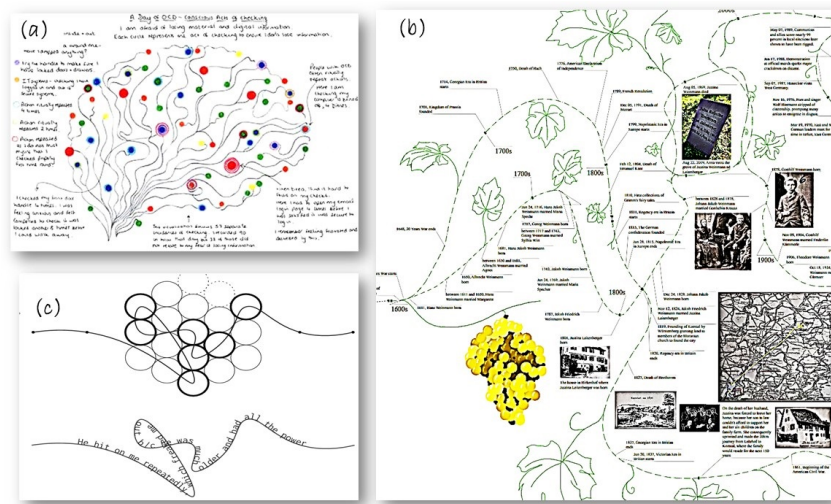
Figure 1: *(a)* Lived experience visualisations often rely on hand-drawn shapes as in Jill Simpson's *"Day of OCD"* [37]. *(b)* Tools enabling the creation of idiosyncratic timelines [30] are able to reveal individual-structural interactions over time. *(c)* When visualising cohort-level lived experiences, line shape can encode the unique features in each story [14].

ABSTRACT

Visualising personal experiences is often described as a means for self-reflection, shaping one's identity, and sharing it with others. In policymaking, personal narratives are regarded as an important source of intelligence to shape public discourse and policy. Therefore, policymakers are interested in the interplay between individual-level experiences and macro-political processes that play into shaping these experiences. In this context, visualisation is regarded as a medium for advocacy, creating a power balance between individuals and the power structures that influence their health and well-being. In this paper, we offer a politically-framed reflection on how visualisation creators define lived experience data, and what design choices they make for visualising them. We identify data characteristics and design choices that enable visualisation authors and consumers to engage in a process of narrative co-construction, while navigating structural forms of inequality. Our political framing is driven by ideas of *master* and *alternative* narratives from Diversity Science, in which authors and narrators engage in a process of negotiation with power structures to either maintain or challenge the status quo.

Index Terms: Narrative visualisation, lived experience.

1 INTRODUCTION

Visualisation research has made significant contributions to balance human stories with data-driven evidence in ways that can engage and inform lay audiences. However, the role that visualisation can play in influencing decision-making remains challenged by several factors, including poorly defined tasks of decision makers [11] and *"unmet needs"* for qualitative evidence to offer a nuanced understanding of real-world situations through data [12].

Qualitative participatory methods, such as co-design and co-production, have been significantly impactful in creating spaces where communities can actively shape person-centred public policies. For example, Hall et al. demonstrated the value of leveraging communities' voices through evidence-based co-production [19]. However, power dynamics and structural factors that contour individual experiences threaten to exacerbate inequities in these co-production settings [19, 17]. Technology-assisted formats are advocated as "a tool for inclusion" [32] but unless they tackle barriers, such as data illiteracy and technophobia, the design assumptions of such technologies risk furthering those inequalities. It is precisely that risk that led Pendse et al. [31] to highlight the importance of centering *lived experiences*, *power relations*, and *structural factors* in design. They argued that data insights alone risk reducing people's struggles to fit into inflexible categories and cause-and-effect narratives that reinforce colonial legacies and unjust power dynamics.

It is, therefore, critical to ask the questions: *(a)* how can visualisation design center the lived experiences of people rep-

resented in data in ways that can inform policy? and *(b)* what role can visualisation play to introduce a power balance between communities, researchers, and policymakers when co-constructing stories that center lived experience?

We present a critical reflection on visualisation design, from a sociopolitical perspective, to understand how values and assumptions embedded within the visualisation design and development pipeline are shaped by the interaction between individuals' lived experiences and the macro-political structures that surround them. Through four visualisation examples, we explore ways in which visualisation creators have presented aspects of lived experience for the specific purpose of negotiating with societal norms and power structures. The examples are selected to represent the four stages of visualisation creation (as defined by Thudt et al. [5]) during which subjectivity is introduced. Through a Diversity Science lens, we offer a subjective critique of the design choices made, and identify common patterns that have the potential to support similar individual-structural negotiations. We believe that understanding these design patterns can inform visualisation designers to create media that connect policymakers with the impact of policies on the lives of individuals. As we make progress in assessing this assertion, we offer three initial contributions:

1. We present a characterisation of *how* and *why* lived experiences are captured in data across disciplines (Section 3).
2. We advocate the use of a Diversity Science framework, called the Master Narrative Methodology [42], to critique the design space of visualising lived experiences (Section 4). We argue that this and similar frameworks can uncover design patterns that have the potential to empower minorities and tackle inequalities when shaping policy.
3. We reflect on common design patterns, found in our selected examples and the wider literature, and discuss their ability to make the master narrative negotiable, thereby empowering individuals to visualise how they internalise and either conform to or challenge the master narrative as they construct their own personal narratives (Section 5).

Through these contributions, we aim to guide visualisation designers on some key considerations as they create visualisations that act as a mediator between policymakers and members of society (Section 6). While a systematic mapping of the design space for visualising lived experience is outside the scope of this paper, we hope that our reported design patterns can be a first step in this direction.

2 RELATED WORK

Political rhetoric in visualisation has been a topic of discussion for a while. Hullman and Diakopoulos [20] presented a taxonomy of rhetorical techniques in visualisation design that can be used to direct interpretation in a certain political direction. They leveraged interdisciplinary evidence, applying concepts from critical theory, semiotics, journalism, and political theory, to critique narrative visualization examples from data journalism to political outlets. Other narrative visualisation techniques focused on understanding public discourse [6] and issues of marginalisation and misrepresentation in civic data that informs policy [4].

Specific focus on issues of diversity and equality in visualisation was highlighted by D'Ignazio and Klein's work on data feminism [10]. They examined how visualisation can challenge the status quo by featuring *"the voices of those who speak from the margins..."* [10]. Their work complements what is now a growing debate across disciplines on how emotional aspects of lived injustice can be expressed through vi-

sual means, from visual art relating to climate crisis [35], to ideas of art therapy tackling the impact of war [44].

Despite the growing interest in the overlap between visualisation design and issues of diversity, equality, and inclusion, the majority of personal data visualisation solutions were developed for other purposes such as self-evaluation [45], personal planning [1], or sharing one's stories with the world [33]. In this context, visualisation is promoted as a medium to evoke sympathy, approval, or trust. However, the role of visualising lived experiences for advocacy remains largely unexplored. This is in contrast with efforts in social and political sciences, where visual expression of personal narratives has been a tool for empowerment, documenting and countering colonial injustices [40] and co-constructing life histories and their interactions with political dynamics [38]. This paper brings this sociopolitical perspective and examines the emerging area of visualising lived experience through a personal-structural lens.

3 CAPTURING LIVED EXPERIENCES IN DATA

Definitions of data that capture and characterise lived experiences vary across disciplines. In HCI research, Sanches et al. distinguished the notion of *personal data*, which tracks aspects of daily life such as activities, health, fitness, sleep, menstruation, etc. from that of *lived data*. They explained that the latter *"foregrounds the physicality of tracking, the emotionality surrounding tracking, and ways in which tracking is often a social, rather than individual, practice"* [36]. Jo Wood's work on visualising cyclists' experiences falls in the latter category of *lived* data [45], where objective data metrics such as gradient, wind, and checkpoints are connected to individuals' experiences of a cycling route. The emotionality of data is linked to these metrics by connecting, for example, gradient to *"feeling of progress made"* and *"anticipation of future effort"*.

This view of lived data relies on the centrality of quantifiable measurements that underpin personal experiences. Such measurements are typically the result of an automated tracking process (e.g., via biosensors, GPS tracking, etc.). This objective component of lived data was excluded by Thudt et al. [5] in their discussion of visualising personal experiences. Instead, they highlighted the subjectivity of personal storytelling as a form of capturing "data portraits" and subjective perspectives that originate from the point of view of the narrator. While they don't specifically describe personal narratives as *lived experience*, their definition of *subjective data* aligns with the meaning-making process undertaken by individuals as they construct narratives of lived experience (e.g., [43]). In summary, the field of HCI and visualisation research characterises lived experience data as:

- **Subjective [5, 37]:** driven by the narrator's personal interpretation
- **Selective [5, 37]:** bound by *"active selection of certain data points and the omission of others"*
- **Situated [36, 45]:** foregrounding physicality and emotionality of surroundings
- **Reflective [36, 45, 37]:** intended for self-evaluation, self-exploration, and shaping identity
- **Communicative [5, 37]:** intended for sharing one's value system, evoking sympathy, and social connection
- **Multi-modal [20]:** including structured and unstructured data, in addition to video, photographs, and other media used by the narrator to capture snapshots of reality
- **Integrative:** capturing individual-level detail and a small number of variables [37], while sometimes contextualising it with cohort-level or big data [45]

While these data characteristics inform data collection and visualisation for the purpose of reflection, communication, etc., the role that such data can play in influencing policy and decision making is rarely investigated in this context. This role is perhaps more explicitly pursued in areas such as healthcare quality improvement, where Patients' Lived Experiences with Medicine (PLEMs), for example, are considered an essential source of intelligence to improve patient safety and outcomes [26]. In healthcare commissioning, we reported a need to understand the lived experiences of service users and to *"look at the pathways through services from the perspective of a child going through the journey, rather than an outside perspective"* [15]. In this context, lived experience data constitute narratives that are often captured through patient surveys, online forums, and qualitative participatory methods such as interviews, co-design and co-production sessions -where patients express their experiences to define problems and propose solutions (e.g., [16, 19]).

Other fields such as geographical study on lived experience and visual storytelling, rely heavily on multi-modal lived experience data, captured through methods such as community-based visual articulation [41]. In this context, lived experience data are captured for such purposes as surfacing subjugated knowledge [8], supporting community-relevant action [27], and understanding Indigenous populations' experiences of "solastalgia" (i.e., the mental distress caused by the transformation and degradation of someone's land) [2]. The focus on visual means for eliciting and presenting lived experiences in this domain is driven by a rising interest in both researchers and participants to direct their aesthetic and socio-geographical intentions toward subverting status quo power relations that are often found in media narratives (for example in research addressing lived experiences of highly marginalised populations in border regions; e.g. [28, 3]).

A common growing trend across the above disciplines is to call for more explicit attention to the ethics, goals and social relationships formed around visual storytelling on lived experiences [39]. In this sense, aspects of affect, aesthetic choice, and how visual representations circulate with different meanings to capture different narratives can matter significantly. The subjectivity at each stage of the process -from data collection to presentation- and the structural factors that surround it must be carefully studied and understood.

4 A DIVERSITY SCIENCE PERSPECTIVE OF LIVED EXPERIENCE: THE MASTER NARRATIVE APPROACH

Diversity science expands the characterisation of lived experience to include structural factors that influence patterns of selectivity, subjectivity, reflection, and communication of personal narratives. It sets the focus on how individuals make meaning as they reflect on their own autobiographical memories and/or recorded events, and the social and political structures that influence their reflection. Syed and McLean advocated a shift away from an individual-level focus of personal narratives, and explained that more attention needs to be given to the *"culturally shared stories that guide the construction of personal stories"*, or so called *master narratives* [42]. Such master narratives are typically established by societal power structures that maintain a status quo. Individuals engage with narrative construction in ways that either conform to or push against the master narrative, sometimes ultimately creating *alternative* narratives.

Two components of the framework (Content and Process) were suggested by Syed and McLean to enable re-
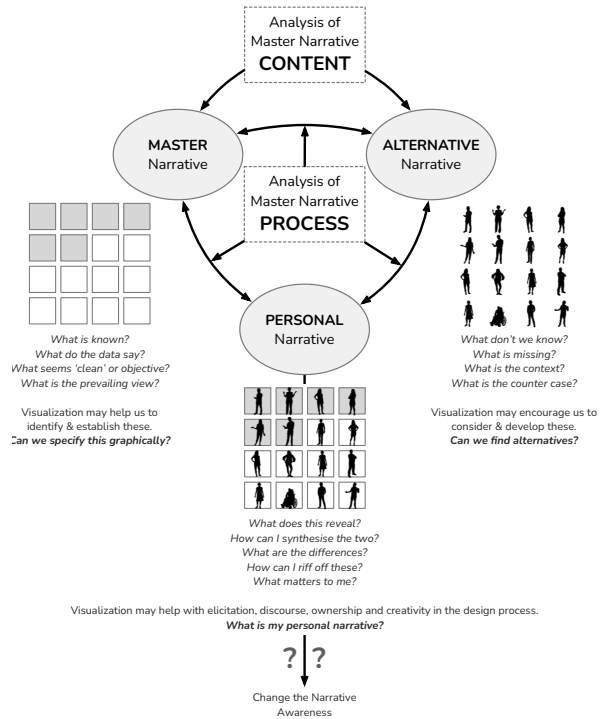

Figure 2: The Master Narrative Framework for Visualization, which may be useful for exposing Master narratives, developing Alternative narratives and establishing Personal narratives in visualization design, critique and education. Adapted from Syed and McLean [42]. We use Wee People, a typeface of people silhouettes https://github.com/propublica/weepeople.

searchers to study individual-structural relations and how they manifest in narrative co-construction and interpretation [42]. Content refers to the static components that make up master and alternative narratives. It offers means to examine the notion of selectivity and subjectivity of personal data, as defined in [5]; i.e., it presents an opportunity to dig deeper into *how* data components are conceptualised and included/excluded in a story. The framework defines four types of content to be examined in people's stories: *(i)* cultural products presented in media, literature, and other forms of communication perpetuate commonly valued stories of a particular culture; *(ii)* personal events or lifetimes capture common events that occur at a certain time and in a certain order that we would expect to see in the life story of a narrator; *(iii)* cultural events incorporate historical events (usually global events, such as 9/11, COVID-19, etc.) which may play a particularly powerful role in individuals' identities; and *(iv)* life scripts offer structural templates for how a story should be told and how events are expected to occur in the life of an individual from a specific culture.

Process captures the dynamics of how individuals navigate (e.g., through negotiating, resisting, internalising, or perpetuating) the master and alternative narratives. It enables researchers to *"gain insights into how structural inequities and marginalisation become part of an individual's everyday existence"* [42]. Four types of master narrative process are characterised: *(i)* deviation concerns examining individuals' ex-

plicitly stated position of whether they are conforming to or deviating from the master narrative. It requires an acknowledgement from the narrator that the master narrative exists. *(ii)* `Conversation` examines how individuals implicitly adopt different positions vis-a-vis the master narrative in natural conversation. This can be reflected in how they negotiate power and oppression without explicitly stating that they exist. *(iii)* `Group reflection` examines individuals' ability to explore their social identity through hidden comparisons between their demographic group and other groups; and *(iv)* `evaluation` examines how individuals respond to hearing or seeing representations of the master narrative.

Figure 2 presents an adaptation of Syed and McLean's framework [42] and suggests new opportunities to understand how authors of lived experience visualisation may construct personal narratives through visualisation, and how these narratives can be interpreted by their audiences. We are especially interested in the ability of the framework to characterise the relationship between individual experiences, group relations, and societal power structures. This ability offers an excellent theoretical foundation for examining how visualisation creators navigate the status quo. For example, do they explicitly visualise the prevailing view of a certain subject (perhaps using `cultural products`) to then `deviate` from it? do they conform to societal norms when selecting and visualising `life events`? and do they weave `content` from both master and alternative narratives and use them as a substrate for a personal view, that adds embellishments or annotations to develop a critiqued or interpreted view?

Understanding how narrators of visual stories make choices, either consciously as part of their design philosophy or unconsciously as part of their implicit negotiations with master narratives, enables the extraction of design patterns for visualisation to challenge norms and empower marginalised communities. It also enables situating elements of personal small-scale data reflecting personal events (e.g., failing an exam) with population-level or global-level data (e.g., numbers reflecting poor mental health during the pandemic) to inform policy. This componentised approach can augment the narrative elicitation and construction processes in qualitative research in ways that empower participants to sketch their own life histories and sociopolitical processes and contextualise these with global watershed moments (e.g., [38]).

5 CRITICAL REFLECTION: APPLYING THE FRAMEWORK

We engaged critically with four example visualisations of lived experience to study: *(a)* how they connected the 'personal' to the 'structural' through design, and *(b)* how the creator's involvement in stages of visualisation development have interacted with their negotiation with master narratives. Thudt et al. defined four stages of visualisation development where creators' subjectivity gets introduced [5] during: *data collection, data processing, visual mapping, and presentation*. Our examples are carefully selected to examine design decisions -driven by the subjectivity of visualisation creators- as master and alternative narratives are introduced in each of the four stages. Creators' relationship to the data varies across the examples from a slow intimate personal process (as in Example 1) to a distant interpretative process (as in Example 4).

Our 'critical' process follows the definition of critical visualisation by Dörk et al. [13], where researchers reflect on design practice while being aware of the values and assumptions embedded in their discipline. We expand this idea through engaging in critical reflection from an interdisciplinary lens. Specifically, we use the structure provided by the master narrative framework from structural psychology (see Section 4) to examine the intentions, practices, and reflections of the designers / narrators behind the examples. We draw connections between choices made along their design journey and the elements of `Content` and `Process` they used to convey meaning. This interdisciplinary lens offers an opportunity to examine individual-structural interactions and manifestations of this interaction in visualisation designs. In Section 6, we report on common threads across the components of this structured approach to identify recurring patterns of design. These preliminary patterns can be further developed into a design space for visualising lived experience.

5.1 Example 1: Lupi's *Life With Long COVID*

In her New York Times essay, Giorgia Lupi visualised her lived experience during 1,374 days of long COVID [22]. Lupi's engagement with her individual story and structural issues begins in the *data collection* stage of the visualisation creation pipeline. She started with a long, slow process of manual data collection, recording `life events` (e.g., symptoms' appearing or intensifying, treatments or supplements being tried, daily activities, food and drink, etc.) in addition to automated measurements including biometrics from her smart watch, and scans and results from her medical records. The multi-faceted nature of data collected was revealed in her visualisation through mixing brush strokes (encoding her manually recorded symptoms) with lines, crosses, dashes, and dots representing events in her medical record (Figure 3(a)).

Lupi's narrative uses `cultural products`, including research evidence (e.g., *"Over 200 symptoms related to long Covid have been recorded in patients"*), and testimonial-style commentary from patients and prominent physicians. Her narrative is organised around `cultural events` during the COVID-19 pandemic, including anchor points such as lockdown and vaccine roll out. She made references to `life scripts`, capturing expected daily activities such as cooking, cleaning, etc. and expected blood results from someone other than her. When making choices for visualising the `Content` of her lived experience, Lupi included `life events` as brush strokes and hand-drawn marks (Figure 3(a)), `cultural products` and `cultural events` as text and annotations (Figure 3(b)), and `life scripts` text as well as in visualisations of blood sample images comparing her sample with a healthy sample (Figure 3(d,e)).

The dynamics of negotiation in Lupi's visualisations reveal an interesting master narrative `Process`. This process bears some similarity to Jill Simpson's "Day with OCD" visualisation (Figure 1 (a)). Both creators relied on a slow process of collecting data manually. Simpson explained that this process enabled subjectivity and emotional motives behind her choices of which data to include to become visible. Lupi and Simpson made design choices that enable viewers to connect with their emotive and embodied experiences of collecting data. First, both creators showed the scale of `life events` captured in their data to implicitly converse with master narratives that downplay or deny the debilitating effects of long COVID and anxiety disorders. Simpson chose shape to reveal that scale, while Lupi showcased the longevity and scale of her symptoms across several years through juxtaposition and superposition of life events (Figure 3 (a,b)).

Lupi claimed ownership of this personal process of capturing `life events` through visual encoding, using hand-drawn lines and brush strokes. Simpson further elaborated the "pol-
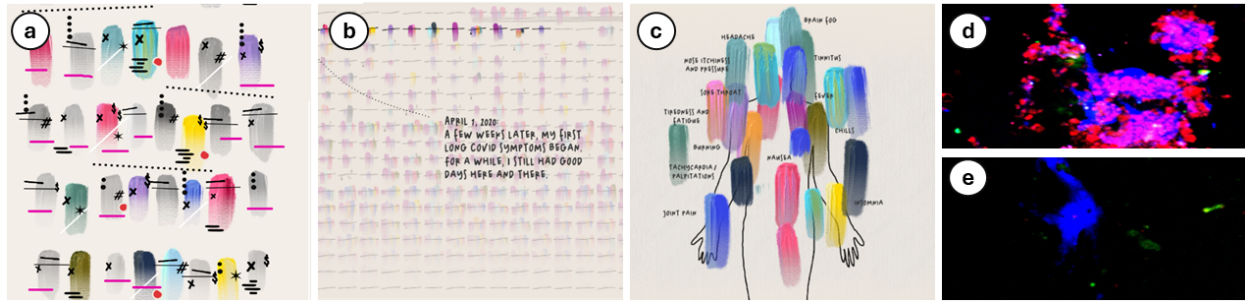
Figure 3: Giorgia Lupi included life events as brush strokes and hand-drawn marks *(a)*, cultural products as annotations *(b)*, life scripts as a visual metaphor *(c)* and group reflection using visual comparisons of her blood sample with a healthy sample *(d,e)* [22].

itics of hand drawing" and explained that they enabled her to explicitly `deviate` from a master narrative where data are expected to be objective, complete, and neutral [37]. She acknowledged the master narrative and mentioned cultural products (such as public dashboards) from which her alternative narrative `deviates`. In addition to hand-drawn visualisations, both artists included handwritten notes to disclose their choices of leaving some details out of the visualisation or highlight anchor points for the story.

Aesthetic choices reveal other aspects of negotiation with master narratives. The use of a bright colour palette was advocated by Simpson as a way to `deviate` from a master narrative where mental illness is viewed as sad and depressing. Lupi also used bright colours but did not explicitly state her intentions, which may have been similar.

The use of metaphors to bring physicality to the authors' lived experience was manifested in Lupi's use of a body silhouette with brush strokes representing symptoms all over and around the body (Figure 3 (c)). This allowed her to show an implicit deviation from narratives where long COVID symptoms are poorly understood, at times downplayed and/or assumed to affect only localised upper body areas. A 'scrollytelling' technique in her presentation (see [25] for a definition) allows the user to experience the emergence of new symptoms, hitting new areas of the body, as they navigate. Simpson used a brain metaphor and drew lines that mimic the surface of the brain to reveal a `group reflection` as she contrasted her experience from what would have been perceived as a 'normal' brain. Lupi also presented `group reflection`, by comparing a normal healthy blood sample to her own (Figure 3 (d,e)).

5.2 Example 2: TimeSplines for *Family History*

TimeSplines is a tool that enables users to draw personal data in the form of idiosyncratic timelines [30], enabling visualisation authors to capture temporal sequences in ways that convey subjective meaning. Examples in the Timesplines gallery range from personal memoirs to reflections on non-personal material, such as the film 'Forest Gump'. We selected one example from the gallery that shows an author's view of her family history in light of global historical events (Figure 1(b)). Unlike Lupi's slow process of *data collection*, this example focuses on the visualisation creator's design choices as she *processes* and reflects on data that capture lived experience.

The narrative includes `life events` and `cultural events` and displays a visible negotiation between the two. It makes implicit references to `life scripts`. For example, in Figure 4(b), the author aligned a significant hardship ex-
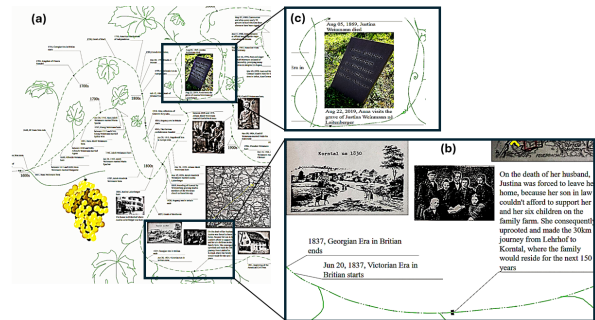

Figure 4: TimeSplines [30] Gallery example showing an interaction between a family history and historical events.

perienced by a family member (displacement due to lack of income) with cultural events like the end of the Georgian era and beginning of Victorian era in Britain. Without an explicit statement of `deviation` from the author, it is difficult to conclude what her intention was as she positioned these events along the same line, despite using separate lines in other parts of the visualisation to separate what is structural from what is personal. One possibility is that position was chosen as an item of conversation with a master narrative that typically describes the Victorian era as a time of relative economic prosperity.

Perhaps the most eye-catching element of the family history visualisation is the intertwining of lines around a photograph of the author's ancestor's grave, used to connect two life events: the death of her ancestor in the 1800's and the author's visit to that family member's grave in the 2000's (Figure 4(c)). It is easy to see that position and shape were carefully chosen for this part of the narrative. The centralised position reveals a negotiation with assumptions that family events from hundreds of years ago don't carry significant weight on life course today. The circular intertwined lines reveal a crossover between the past and the present, and the photograph in the middle connects the physicality of the lived experience to history. These visual encodings reveal a `process of evaluation` as the author responds to her own as well as her ancestor's lived experience. Finally, a hand-drawn vine metaphor glues together personal and cultural events and reveals occasional alignments and crossover between them.

5.3 Example 3: *Academia is Tied in Knots*

Visualisation authors may not be involved in the collection of lived experience data at all. The examples in this and next

If Gaza were 100 people... **25 would be starving** **85 would be displaced**

Figure 5: Chalabi overlaid what would be expected in the lived experience of Gazans on top of quantitative data that reveals a different reality [7].

section present cases where the role of visualisation authors gets introduced later in the visualisation development pipeline. This role is focused on giving voice to others, empowering the individuals represented in data, by ensuring that the personal and structural components of their lived experience are adequately represented. The *Tied in Knots* visualisation presented by Elli et al. [14] in the 2020 IEEE VIS Arts Program (VISAP) is a good example of empowerment as a purpose of visualisation design. It represents the lived experiences of victims of sexual harassment in academia, Several forms of master narrative `Content` and `Process` can be found in the creators' workflow, from *data processing* to *presentation*.

Subjective decisions were made during the `Content` generation stage, as creators engaged in careful and lengthy data processing, using both manual and automated methods. A personal connection to the data was established through deep reading, followed by automated aggregation and visualisation (using treemap-like diagrams) to further their understanding of patterns in the data. This careful exploration was aimed at ensuring that the final visualisation does not lose sight of the unique and diverse categories of `life events` and the consequences of those events on data subjects. Specifically, the creators defined the following criteria for content selection: the event must correspond to *"a behavior that negatively affects academia and that ought to be avoided (pedagogical choice), it is heartbreaking (rhetorical choice) and it helps in remembering the story and in differentiating it from the others"*. `Life scripts` were visible in the pedagogical choices made by creators as they revealed variations in consequential events both from the perspectives of the victims (e.g., leaving academia as opposed to the continuation of their expected academic career) and perpetrators (e.g., whether or not they faced Title IX related action).

One possibility to define a master narrative in academia is to think of a prevailing view that academic institutions are safe spaces where equality, diversity, and inclusion are respected and protected. Power hierarchies in this master narrative are not considered to be a threat to the integrity and fairness of applying the rules. The visualisation creators have opted to deviate from this master narrative through a parametric representation of "knots" (Figure 1 (c)). Each knot represents an excerpt from a victim's narrative. The shape of the knot is determined through positioning the story from specific aspects of the master narrative. For example, parameters that deter-

mine shape include whether the perpetrator is from a higher hierarchy than the victim, whether the incident was reported, whether it took place during business hours, whether the victim suffered consequences (e.g., had to avoid people or places, or had to leave academia).

In addition to `deviation` as a `process`, the creators also carefully considered `evaluation` in their design. They specifically catered to a process of self-identification by both victims and perpetrators in their reading of the narratives. Three modes of exploratory <u>interaction</u> were created to support this process. <u>Colour</u> was used to encode diverse views when conversing with the narratives. For example, they chose black text on white background for a victim perspective and white text on black background for a harasser perspective to *"stress out their diametrically opposed position"*. Finally, aesthetic choices such as <u>font</u> that looks like a typewriter (Inconsolata) and <u>voice</u> narration were chosen to emphasise the archival nature of the data and evoke an emotional response.

5.4 Example 4: Gaza Infographics

The war on Gaza has made headline news since October 2023, with several UN organisations warning against its unprecedented environmental and humanitarian impacts [24]. One master narrative, adopted primarily by media organisations and political elites, has largely downplayed and dismissed these impacts [18]. In response, some artists and visualisation creators have engaged in data activism to counter this narrative. A complete analysis of how visualisation has acted as a medium for activism during this major global event is outside the scope of this paper. Instead, we will focus on one compelling example and reflect on how the creator engaged with master and alternative narratives in her design. We examine how she connected the structural to the personal, despite being personally uninvolved in *data collection* and *processing*. Consequently, this example allows us to examine how design choices are made as the designer's involvement gets introduced in later stages of the pipeline, namely, during *visual mapping* and *presentation* of lived experience.

British data journalist and illustrator, Mona Chalabi, published a series of infographics collections on her website and social media accounts, that received tens of thousands of reactions from the public [7]. Figure 5 shows what can be considered a `deviation` from a master narrative that reduces war victims to numbers. Chalabi acknowledged the existence

Figure 6: Chalabi used `cultural events` and `group reflection` to present alternatives to a mainstream narrative.

Figure 7: Chalabi visualised data on `cultural products` to deviate from a master narrative.

of this master narrative through labels and a grid visualisation in the background, representing percentages of adverse `personal events`, such as starvation, displacement, etc. She then presented an alternative narrative that seeks to humanise those numbers by presenting facets of Gazans' lived experiences as illustrative overlays. In this narrative, `life scripts` are manifested as illustrations of what a normal life should look like, e.g., families dining together, children playing, etc.

Chalabi anchored some of her infographics around the `cultural events` of October 7th, 2023 (Figure 6), to negotiate with mainstream narratives about the duration of the crisis. This is another example where she explicitly acknowledged the existence of the master narrative and presented a `deviation` from it. `Group reflection` was used to present a visual comparison between items expected to be accessible to children anywhere (e.g., toys, musical instruments, biscuits, etc.) but not in Gaza. She presented these items in alphabetical order, using representations similar to a children's school book. This design choice reveals Chalabi's intention to `converse` with a new status quo, in which the `life script` of children in Gaza, including attending school and receiving education, has been disrupted.

`Cultural products` also appeared in Chalabi's work, where she relied on quantitative data characterising mainstream media reporting of the conflict. This time, she emphasised and even quantified the master narrative by presenting a timeline of mentions of Israeli and Palestinian deaths (Figure 7 top left). She contrasted this master narrative with an alternative one that presents the numbers of actual deaths on the ground (Figure 7 bottom left). Data on the specific language used in media descriptions of those deaths were presented in a tabular form, a design choice that reflects a 'cold' neutrality in the use of data in master narratives (Figure 7 right). `Deviation` is presented as illustrations of human beings' suffering on all sides surrounding the data.

6 DESIGN PATTERNS IN VISUALISING LIVED EXPERIENCE

While the examples presented in Section 5 are not sufficient to conclude a comprehensive design space for visualising lived experience, common patterns can be observed. This section summarises some of these patterns and outlines possible interpretations of their use in negotiating with master narratives.

6.1 Hand drawing for `conversation`

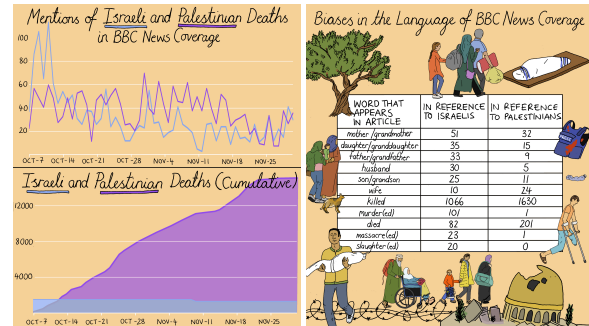The "politics of hand drawing" and their ability to support a `conversation` of personal subjectivity vis-a-vis master narratives was visible in three of the four examples in Section 5. For example, if one considers the master narrative in data visualisation to be that data should offer an objective view of reality, then the politics of hand drawing in visualising lived experience enable creators to contrast the apparent objectivity of digital data visualisations with the intentional subjectivity of hand-drawn illustrations. In her famous brain-shaped visualisation *"A Day of OCD"* (Figure 1(a)), Jill Simpson highlighted the subjectivity, authenticity, informality, and intimacy of paper-and-pen hand drawing. Similar to Lupi and Posavec's *Dear Data* [23], Simpson's depiction of OCD gained significant attention from the general public. One can see the influence of these pen-and-paper examples on design choices made for digital representations in examples 1,2, and 4 in Section 5.

In addition to the benefits of subjectivity and intimacy in engaging the public, hand drawings have been shown to enable the democratisation of narrative co-construction with lay audiences. Johanna Söderström's work on eliciting lived experiences through life diagramming interviews [38] democratises the authoring of hand-drawn visualisations through a process of equitable co-construction between interviewer and interviewee. This visual approach to participatory design has the potential to empower visualisation novices as *"the interpretation of their life story [...] is literally in their hands"* [38].

Finally, digital tools that support levels of sketchiness and hand-drawn input have been shown to empower lay users to critique visualisation design [46] and fill gaps in data [21]. What is currently missing in the literature on hand-drawn and sketchy visualisation is the role it can play in enabling co-construction of narratives of lived experience with lay people, and how much it can empower underrepresented communities to navigate and negotiate with master narratives.

6.2 Character orientation for deviation and evaluation

Dasu et al. [9] identified roles for 'data characters', including protagonists and antagonists in data stories. This character-oriented view of visualisation aligns well with how stories are captured and represented in visualisations of lived experience. In all of the cases we have examined, the person(s) behind the data is/are the protagonist of the story, whereas the data itself took different roles, depending on positionality of the visualisation from the master narrative. For example, in Chalabi's work, data took a clear role as an antagonist. Her opposing position to the master narrative, which glorifies the 'datafication' of human suffering, was visible in how she chose to `deviate` through illustrations that tell a different story.

In the *Tied In Knots* example, data took different roles. Three different views allowed different types of users (e.g., victims, aggressors, or casual viewers) to self-identify through their choice of data view, thereby allowing different approaches to conversing through data and `evaluation` of how narratives can be interpreted (see Section 5.3).

6.3 Shape and position for `conversation and life scripting`

Visual encoding of data and other narrative components varied across examples. The *Family History* example demonstrates an interesting case for the use of shape and position to draw attention to an important anchor point in the story. Shape was used to reflect alignments and intersections between the individual story and global circumstances that surrounded it. Idiosyncratic timelines are an excellent tool to enable the visualisation of `conversations` between personal and structural considerations in lived experience narratives. Similarly, in *Tied in Knots*, shape was used to convey the uniqueness of individual stories while drawing up more structural conclusions around similar patterns in them (e.g., where investigations led to no consequences for the perpetrator). Position and shape played a crucial role to identify those similar patterns.

In Lupi's and Chalabi's `conversations`, position played a critical role. Both designers used position to offer compelling alternative narratives. In Figure 3 (c), for example, Lupi introduced new brush strokes at scattered positions with every mouse scroll. The position of the brush strokes introduced an element of shock and surprise as it deviates from expectations of more localised symptoms of COVID-19. In Figure 5, Chalabi positioned her illustration of people's daily activities (or `life scripts`) at scattered locations to reflect a lack of structure in real life. None of the characters fits in any of the structured data squares. This design choice enabled her to challenge narratives where human life is reduced to statistics.

Drawing on these examples, one can conclude that shape and position are powerful tools of negotiation and expressing positionality when visualising people's lived experiences.

6.4 Visual metaphors for `group reflection and deviation`

`Group reflection` enables members of a certain demographic group to explore their social identity through hidden comparisons with other groups. Some of these comparisons are automatically interpreted from metaphors that are congruent with embodied experiences. For example, Simpson's brain metaphor (Figure 1(a)) enables a comparison with what would have been a 'clear' mind. The human body silhouette in Lupi's work (Figure 3(c)) serves a similar purpose. Both examples bring an element of physicality, enabling viewers to perform an implicit comparison, either by relating to or contrasting from the author's experience.

Visual noise is a metaphor technique that can serve to obscure information [20]. This technique was useful for `deviation` from a master narrative by obscuring parts of the data that conform to the narrative. Chalabi's illustrations of facets of Gazan life can be considered visual noise, which does not represent any data but is used to obscure quantitative data that conforms to a master narrative.

Metaphors can, of course, serve other purposes less relevant from a master narrative perspective. For example, the vine leaves and fruit shape in the family history visualisation (Figure 1(b)) are used as cultural artifacts, adding to the aesthetic and supporting viewers' understanding of where the family

tree begins. Leaves growing in a certain direction enable viewers to follow the chronology of temporal events.

6.5 Colour for `deviation` and `evaluation`

Both Simpson and Lupi challenged master narratives about mental and physical health through the use bright and appealing colours. In *Tied in Knots*, colour was used to explicitly reveal the `deviation` between a victim's view of narratives and a perpetrator view. The choice of colour was also considerate of viewers' ability to `evaluate` their own lived experiences as they relate to aspects of the visualisation. Care was given to not invoke trauma and cause distress for viewers who could self-identify through the visualisation in [14].

The emphasis on the affective impact of colour in these examples contrasts much of the wider discussion on colour design guidelines in the visualisation literature, which focuses primarily on perception (e.g., data categorisation, uniformity, order, etc.) in light of specific data types (e.g., ratio, interval, categorical) [29] and user tasks [34].

6.6 Additional techniques for Master Narrative negotiation

Hullman and Diakopoulos highlighted the nature of narrative visualizations as multimedia artifacts that shouldn't be reduced to visualization alone. The use of such multimedia artifacts is abundant in visualisations of lived experience. Images, text, and annotations were used with the smaller datasets in Lupi's and Simpson's works and the family history example. Voice narration was used in *Tied in Knots* and social media posts were elaborated in text captioning Chalabi's work.

Interaction varied across examples. Perhaps one notable pattern is that interactions supported `group reflection` in examples 1 and 3. In Lupi's work, the scrolling interaction enabled the users to slow down and appreciate the longevity and disruptive nature of the author's experience, while perhaps contrasting this with the viewers' own busy life and struggles. In *Tied in Knots*, interactions enabled a process of self-identification as discussed above. Finally, negotiations with the master narrative can be understood from patterns of use of gestalt principles of similarity, proximity, continuation, closure, symmetry and order in visualising lived experience. The use of such principles was abundant in all four examples.

7 Conclusion and Future Work

Subjectivity is an important feature of personal data visualisation. It enables a visualisation author to present their lived experience to a wider audience. To understand how such visualisations can play a role in influencing public opinion and decision making, we approached visualisation design from a master narrative perspective. This perspective allowed us to subjectively interpret creators' intentions of either conforming to or negotiating with societal power structures through design. Importantly, our observations reveal that visualisation can be a powerful tool for expressing the master narrative, depicting what is known, and what is the prevailing view? Such graphic expression of the prevailing view helps establish it, and gives audiences a baseline that requires critique. Alternative visual narratives then act as a tool for critique: What is missing, what don't we know, and what is the counter case?

Our interest in the framework is primarily driven by our ongoing work with healthcare stakeholders, where we aim to empower service users to build personal narratives that can shape policy and inform commissioning.

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