Context Sensitive Health Informatics and the Pandemic Boost
A. Bamgboje-Ayodele et al. (Eds.)

doi:10.3233/SHTI230384

Humanizing Big Data and Detailing Social Determinants of Health via Information Visualizations

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Abstract. The pandemic has had devastating impacts on humanity and the global healthcare sector. An analysis into the social determinants of health, in particular racial and ethnic disparities may explain why certain population groups have been disproportionately affected by COVID-19. The objective of this study is to humanize and personify numerical data. Additionally, COVID-19 population data will be stratified via three data visualization tools (i.e., a persona, a journey map, Sankey diagram) to create a Visualized Combined Experience (VCE) Diagram to illustrate the micro, and macro, perspectives of marginalized individuals across the continuum of care.

Keywords. COVID-19, sankey diagram, journey map, persona

1. Introduction

As of April 12, 2023, the World Health Organization (WHO) has confirmed 762,791,152 cases of COVID-19, which has resulted in 6,897,025 documented deaths [1]. The pandemic has been a catastrophic and unquantifiable devastation on humanity and the global healthcare sector at large [2]. Initially poised to impact global citizens homogeneously, the data reveals that racial and ethnic disparities exist with respect to the burden of morbidity and mortality from COVID-19 [3]. Specifically with higher rates of death in Native American (3.3), Hispanic (2.4), and African American (2) populations when compared to white populations [4-6]. Contributing factors to these disparities may include: genetics, place of birth, lifestyle, place of residence, location of employment [6,7]. Thus, social determinants of health (SDOH), could reveal why certain populations are disproportionately affected by lower access to healthcare and chronic medical conditions that may portend worse COVID-19 outcomes [4]. Moreover, minority

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communities are more likely to experience working and living conditions that predispose them to environmental factors that could preclude positive health outcomes [4]. Thus, the pandemic has exposed the underpinnings of these disparities as long-standing structural, societal, and cultural factors [4].

Countless information visualizations (e.g., dashboards, digital media) were introduced to inform the public throughout the pandemic. However, people are notoriously poor at interpreting large amounts of numeric data [8]. More specifically, no one wants to be 'just another statistic,' yet the goal of information visualization is precisely that — to synthesize many data points to illustrate trends, inspire insight, and ideally improve decision making. Although important, this act of synthesis fundamentally dehumanizes each data point (i.e., human) and their experience. Indeed, researchers have described that increasing reliance on big data may lead to a "reductionist perspective of a situation" [9]. In contrast, others favor the context of narratives and stories [10]. By combining different visualization approaches, more compelling ways to display healthcare data may be achieved, whilst illustrating the unique experiences of individuals simultaneously. This study sought to illustrate a proof of concept offering the best of both worlds: a macro level summary paired with a micro level human experience. Specifically, the proof of concept was represented through visualized COVID-19 data using a persona (i.e., James), a journey map, and a Sankey diagram to illustrate the micro to macro perspectives of the care trajectory of marginalized individuals.

2. Methods

A Visualized Combined Experience (VCE) Diagram (Figure 1) was constructed comprised of a persona, journey map, and Sankey diagram. Firstly, a Sankey diagram was created using Data-Driven Documents (D3), a JavaScript library toolkit and novel approach to creating dynamic data visualizations [11,12]. Preliminary COVID-19 data from the Centers for Medicare & Medicaid Services in the United States (US) [13] was used to illustrate the varied trajectories and outcomes of marginalized populations. Sankey diagrams depict alluvial flows and therefore this visualization was well suited to proportionally illustrate the macro perspective of this data (e.g., which population groups were hospitalized vs. died from COVID-19). Following this, to illustrate the data from a micro lens a persona depicting the individual (i.e., James) [14], and an Experience Journey Map [15-17] to illustrate the four phases of his journey were created. Data derived from the lived experiences of African American men in the US who died from COVID-19 [18] was used to create the micro lens narratives.

3. Results

A holistic perspective of a marginalized individual was represented across the care continuum via a combination of three varied visualization techniques (Figure 1). The diagram begins with a persona to provided context into James' humanity, in that he was a 37 year old father, husband, and Masters student. Next, the Experience Journey Map [15-17] illustrated James' lived experiences and emotional state during the four phases of his journey: symptoms, testing, treatment, outcome. Lastly, the Sankey diagram provided a macro perspective of the COVID-19 care pathways of marginalized groups

(i.e., African American, Hispanic, Native American) in the US. James' journey in relation to the broader population [13] was represented by the red line in Figure 1.

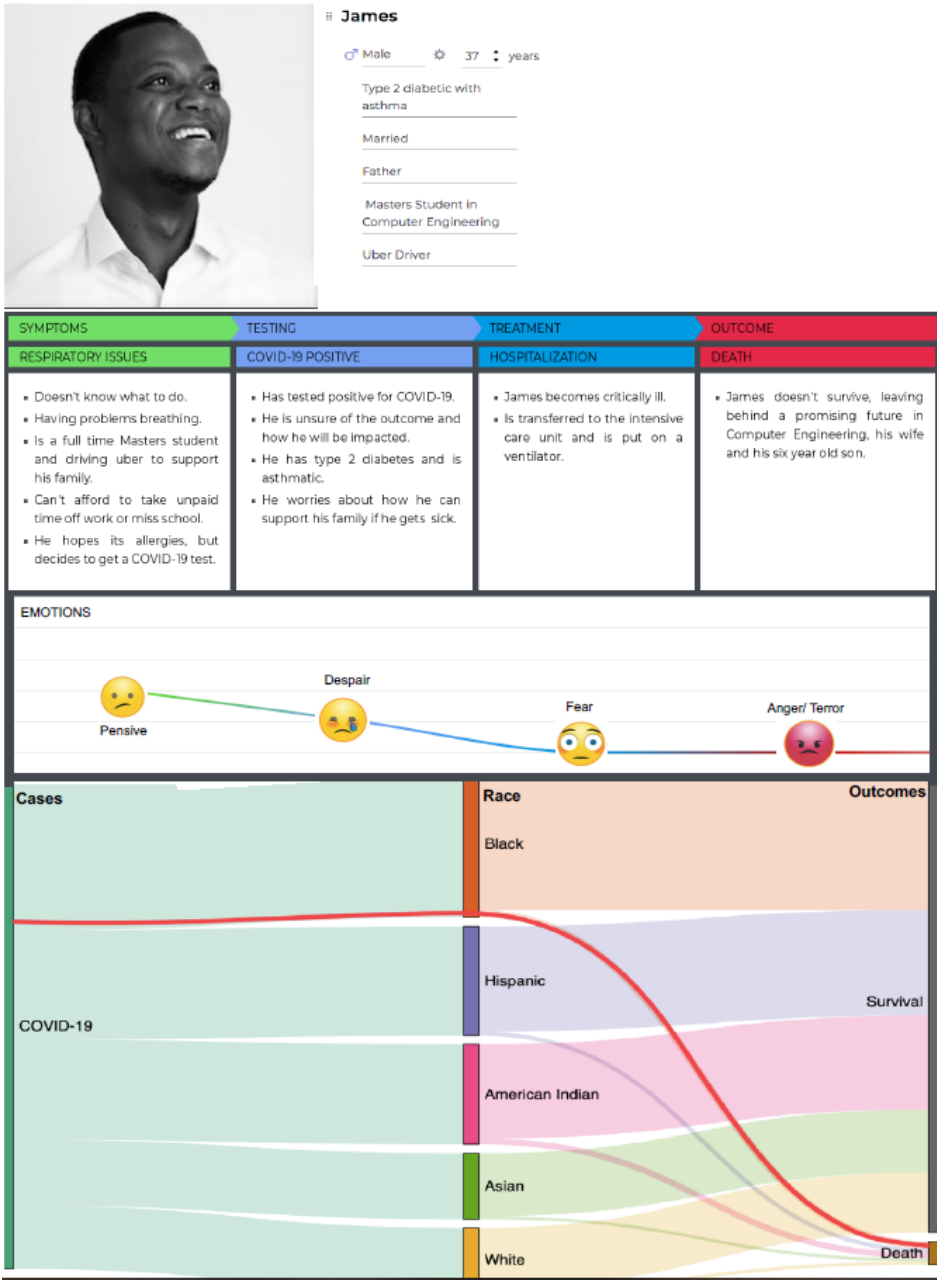

Figure 1. VCE Diagram illustrating James's patient journey in relation to US COVID-19 population outcomes data [13].

4. Discussion and Conclusions

This study personified the numerical data of a COVID-19 dataset sourced from the US Centers for Medicare & Medicaid Services [13]. James' patient experience was illustrated by the VCE Diagram (Figure 1), a novel approach to holistic data visualization combining the following elements: a persona, a journey map, and a Sankey diagram. The persona was created as a visual compliment to a high-level Experience Journey Map [15-17] to present the micro lens of James' trajectory and emotional state across the care continuum. Following this a Sankey diagram was used to depict streams of differences and similarities between the population data from a macro perspective. By combining the three visual tools, the illustration (Figure 1) effectively depicts how SDOH can impact marginalized individuals. Furthermore, these tools could be applied simultaneously to display information from various vantages and perspectives as vignettes of human journeys through other systems and industries.

Some limitations of the study include that the dataset was curated based on preliminary and static data [13], as such the data does not reflect current or real time COVID-19 statistics. Further, the global mechanisms for data aggregation and scientific reporting were heterogeneous at the inception of the pandemic, and often missing key SDOH factors. Moreover, medical avoidance is common among members of marginalized communities due to discrimination concerns (i.e., racial stigma, socio-economic status) [19], and therefore individuals may have avoided getting tested or seeking healthcare services, and thus may not be adequately represented in the dataset. Additionally, laboratory capacity and access to testing varied largely at the beginning of the pandemic, and thus individuals may have been sick but unable to get tested [20]. Notably, mortality as a result of COVID-19 infection has range from weeks to months, thus, given lack of testing at the inception of the pandemic, the death counts during that time period may be greatly underrepresented [20]. Further, the international classification of disease (ICD) codes (i.e., global standard for documenting global health information) have progressively changed throughout the pandemic [21]. Thus, the variability of coding practices of global healthcare systems, has rendered the true number of COVID-19 associated mortalities [22] difficult if not impossible to report.

More investigation is needed to ensure that evidence-based practices occur and that individualized data is collected equitably and is truly representative of the population. The limitations of the global COVID-19 data reporting and collection methods revealed an urgency to adopt a common data model (CDM) to aggregate health data into a standard structure that could be used across: networks, geographies and health systems [23]. Global standardization of disease state measures can assist healthcare providers and researchers compare institutional and population healthcare data [24]. Thus, coordination of healthcare services and data standardization is essential for closing the gaps in care, often driven by SDOH [25]. Thus, complimentary visualizations (i.e., personas, journey map, Sankey diagrams) could assist in creating a humanistic and standardized approach to display public health data. Streamlining the dissemination and availability of data could support the evolution of a cohesive, global learning health system [17].

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