Visual Disease Stories: Empowering Health Literacy and Promotion

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Abstract

Narrative medical visualization bridges the gap between limited health literacy and the need for health communication. We explore disease stories to promote preventive behaviors, educate patients about their conditions and treatment options to foster informed consent, which is embraced by clinicians for its potential to alleviate the burden on healthcare systems and providers. We integrate data visualization with storytelling to make scientific information more accessible to diverse audiences. However, the expansive design space presents significant challenges, as design choices can greatly influence levels of engagement, memorability, and comprehension. Our work investigates the fundamental dimensions of the narrative design space – conflict, content, character, and structure – with the aim of maximizing its impact on disease communication.

CCS Concepts

• ***Human-centered computing*** → ***Scientific visualization;*** • ***Applied computing*** → ***Life and medical sciences;***

1. Introduction

Narrative visualization integrates data, visuals, and storytelling to make information accessible to lay audiences. Narratives guide users through data, enhancing engagement and comprehension. In the medical domain, clinicians highlight the potential of using narrative medical visualization to improve patient education and public health initiatives, addressing challenges such as limited patient education time and low health literacy. The computer science community's efforts align with health communication research, which focuses on crafting messages that encourage health-promoting behaviors [MPM24]. Segel & Heer [SH10] identify key components of narrative visualization, i.e., story elements (e.g., text, images, audio) to create scenes, genres (e.g., slideshow, annotated chart) to arrange them, and transitions (e.g., animation, interaction) to connect elements, and story paths (e.g., linear, elastic) to define a sequence. These components are used to frame the data shown, reflecting the author's narrative intent to shape the audience's opinion [HD11].

We focus on communicating medical data through disease stories to convey information about diseases to lay audiences, focusing on preventable risk factors. This aligns closely with research in public health and health communication, which explores how to design health messages that encourage behaviors that improve personal and community well-being. Health message design focuses on the message content (*"What to communicate?"*) and message execution (*"How to communicate?"*) [NIYM22]. Audiences generally prefer narratives to didactic communication, where employing a relatable protagonist further enhances engagement and effectiveness [DSP*23]. Visuals are an effective means of improving health communication and combating the infodemic, i.e., oversaturation of the public with information [KL20]. For instance, pictorial warnings on cigarette packs are particularly engaging when they include realistic and personal elements, such as images of diseased anatomy, real people, or personal testimonials [NRB*20, OBMC19]. This underscores the importance of using authentic and relatable content and motivates our data-driven approach. Our contribution focuses on the design of disease stories, driven by a clear narrative intent, and structured based on the four story ingredients – conflict, content, character, and structure – defined by Brent Dykes [Dyk19], see Fig. 1. We further discuss the collaboration with clinical partners and the effects of data storytelling on the audience. We structure our findings according to our disease story design process, which highlights the interplay between author, story, and audience, see Fig. 1.

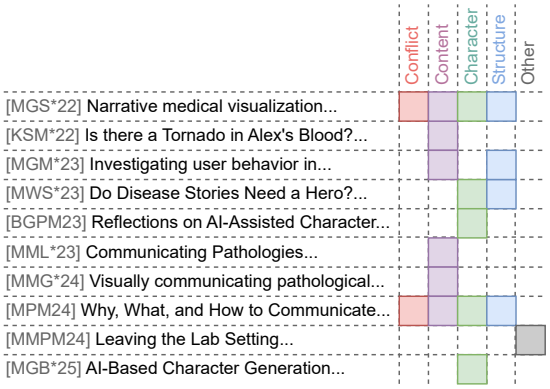

Table 1: *We focus on narrative design, as categorized by Dykes [Dyk19] into conflict, content, character, and structure.*

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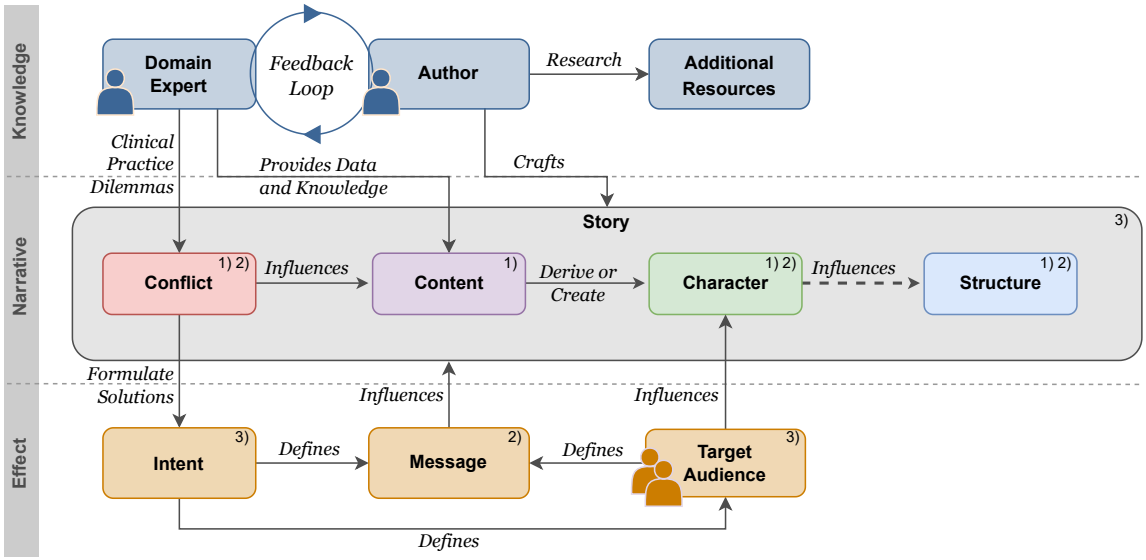

Figure 1: *Narrative medical visualization design process based on the theoretical foundations of (1) Brent Dykes [Dyk19], (2) Fog et al. [FBMB10], and (3) Bach et al. [BSB*18]. Dashed lines depict optional dependencies. Image from Mittenentzwei et al. [MPM24].*

2. Disease Stories Design Process

Based on our research, we discuss the general design process of disease stories, a subfield of narrative medical visualization, supported by application examples and case studies that explore various design choices. Web versions of our disease stories can be found at https://visualstories.cs.ovgu.de/dirk-bartz-prize. Derived from *health message design* research, our design process is divided into three stages: (1) the thematic background *knowledge*, (2) the creation of the *narrative*, and (3) the story's *effect*, see Fig. 1.

2.1. Knowledge Stage

The knowledge stage answers the question *"Why to communicate?"*. It describes the interaction between the story author and the domain expert, as well as the resources for the story content.

Author and Domain Expert. The domain expert introduces a problem that has the potential to be addressed through storytelling. Our expertise is based on cooperation with clinicians in cardiology, neurology, radiology, and epidemiology with many years of practical experience. For disease stories, these problems center around (1) inadequate prevention due to low health literacy, where people are unaware of conditions or their risks, (2) inability to give informed consent to treatment options due to lack of health literacy and complexity of medical topics, (3) lacking resources for medical research due to a lack of cases, and (4) the need to promote specialized treatment methods to attract relevant patients [MPM24]. While the last point addresses commercial concerns, the first three address *clinical practice dilemmas*, our clinical cooperation partners face, such as: (1) Clinicians at the University Hospital Magdeburg's neurology and cardiology clinics report that many patients do not take hypertension and its treatment seriously, leading to long-term complications such as cognitive decline and vascular dementia [MWS*23]. (2) Diseases like cerebral aneurysms and liver tumors require highly individualized treatment. However, physicians from the radiology and nuclear medicine clinic at the University Hospital struggle to convey risks and treatment options to patients with low health literacy [MML*23, MMG*24]. Similarly, the Heart Center Leipzig, specializing in cardiovascular diseases, faces difficulties communicating concepts like blood flow patterns and heart anatomy to patients [KSM*22, MGM*23]. (3) Cerebral small vessel disease (CSVD) is poorly recognized by the public, leading to missed early diagnoses. As a result, the University Hospital's neurology clinic lacks sufficient early-stage research data [MWS*23]. The University Hospital Greifswald, which conducts the SHIP epidemiological study, has also faced challenges in recruiting new participants [BGPM23, MGB*25].

Resources. Data and domain knowledge are provided by domain experts, such as imaging data from individual patients or cohort data to derive generalized insights. These materials can be enriched with additional resources, including scientific literature or reputable web sources [BGPM23] such as websites from the World Health Organization, the National Health Service, or hospitals. Incorporating supplementary data or contextual information is common, e.g., data from larger, representative studies can be used to present statistics on risk factors and prevalence, see Fig. 2.

2.2. Narrative Stage

This stage explains *"How to communicate?"* and focuses on story design. According to Brent Dykes [Dyk19], a story is split into four ingredients: (1) a central conflict, (2) the content, (3) the characters, and (4) the structure of it's content.

Conflict. The conflict arises from *clinical practice dilemmas* (Sec. 2.1) and can be mapped to the individual level, e.g., instead of presenting statistics linking hypertension to dementia, depicting a character who develops dementia due to hypertension [MWS*23].

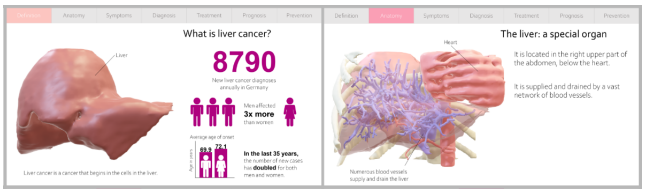

Figure 2: *Excerpts from a story about liver cancer from Meuschke et al. [MGS*22]. In addition to the volume visualization, statistics regarding prevalence are derived from external sources.*

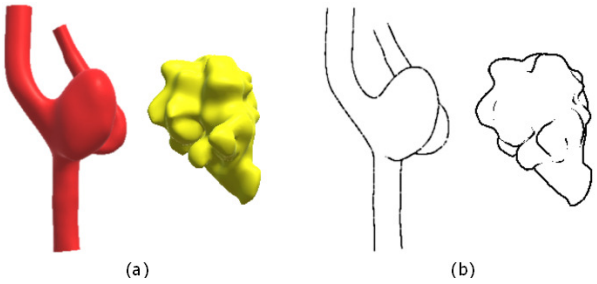

Figure 3: *Visualization techniques for aneurysm and tumor models: (a) Phong shading; (b) inverted hull outlines, offering better accessibility for users with color vision deficiencies [MMG*24].*

Content. Based on the initial conflict, the author must determine which data and general information are essential to effectively portray the conflict. For disease stories, we identified different types of content: *data-driven content* (e.g., data visualizations such as MRI volume renderings), *context-driven content* (e.g., explanation of a procedure or list of symptoms), and *character-driven content* (e.g., name, photo, character description) [MWS*23]. In two user studies (n=60, n=40) we investigated which visualization techniques lay people preferred for anatomical surface models [MML*23, MMG*24]. Users' aesthetic preferences coincide with their preferred visualization technique for analyzing the data. While the illumination-based technique is generally favored, the illustrative technique shows potential for enhancing accessibility for users with color vision deficiencies, see Fig. 3.

Characters. A story can feature one or more characters, including various types such as protagonists (main character, e.g., a patient), side characters (e.g., a treating physician or relative supporting the protagonist), and antagonists (opponent of the protagonist, e.g., a disease) [MWS*23]. While a character need not always be a person (it can be a data point or an object), our experience shows that using a patient character as a protagonist is well received because it provides a relatable personification of the conflict. The design space for characters is vast; while photorealistic characters can make the story feel more authentic, artistic characters may be more memorable and offer neutrality in terms of age, gender, and appearance, making them potentially more appealing to a diverse audience, as shown in Fig. 4 (c and d). Characters can be derived from cohort data and augmented with fictitious names and images, ensuring both realism and patient anonymity [BGPM23]. More specifically, prompts can be formulated using cohort data and used to generate AI images, ensuring that the visual representation of the characters is consistent with the underlying data. We have derived the following prompt scheme to generate a character [BGPM23]:

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<character name> <textual description from data>
<image style> <additional features, e.g., visual
appearance, emotional expression>
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Structure. Disease stories can follow the structure of professional health blogs, using the seven stages: (1) definition of the disease, (2) explanation of the affected anatomy, (3) symptoms, (4) diagnosis, (5) treatment, (6) prognosis, and (7) prevention [MGS*22]. While this template provides a logical progression of information, its effectiveness in engaging audiences has not been extensively tested. Therefore, story structures designed for entertainment media may be more engaging to audiences. There are different story structures, some of which are character-driven, such as Campbell's Hero's Journey, while others, such as Freytag's Pyramid, depicting the tension level of the story, see Fig. 5. The Hero's Journey provides the most guidance on determining which information to present at specific points in the story, making it particularly valuable for novice storytellers. We developed a template for disease stories inspired by the original Hero's Journey (Fig. 5).

2.3. Effect Stage

This stage centers on the intended effect of the narrative on the audience answering *"What to communicate?"*.

Intent and Message. The narrative intent addresses the *clinical practice dilemma* by providing a solution. For example, if the dilemma is *"Patients often underestimate hypertension, leading to organ damage"*, the intent would be to educate about the risks and motivate lifestyle changes to prevent harm [MWS*23]. The key message of the story is derived from the intent and defines the story's content, summarizing what the author aims to communicate to the audience. Disease stories typically emphasize preventable risk factors and include a "call to action", encouraging users to reduce these risks in their own lives. The intention of narrative medical visualization lies between objectivity and persuasion and is aimed at health-promoting behavioural change, as emphasized in health communication and public health [MPM24].

Target Audience. The intention also defines the target audience, e.g., patients through whom the dilemma arises in clinical practice or are able to solve it. Discussions with domain experts have been invaluable for gaining insights into the target audience, such as identifying common questions and concerns patients raise during consultations with physicians.

Social media can be utilized to reach a large user base of a non-patient lay audience, making it an important tool for public health interventions. We curated a dataset of 76 YouTube videos featuring medical 3D visualizations and analyzed 14,550 comments across all videos using manual review and machine learning techniques, including natural language processing for sentiment and emotion analysis of user comments [MMPM24]. We gathered user feedback about visual health communication outside of a lab setting. A major motivation for watching the videos is personal dismay. Users valued the videos for simplifying medical topics

Figure 4: *Characters from our case studies. We used stock photos (a) [MGS*22], AI generated characters (b, c) [BGPM23, MGB*25], and illustrated characters (d) [KSM*22].*

through clear visuals, expressing a preference for simplicity, aesthetics, and human voiceovers. This work was recognized with the VCBM Best Short Paper Award in 2024.

In a between-subject study (n=85), we investigated different audience behaviors by comparing interactive slideshow (horizontal navigation via clicking) and scrollytelling (vertical scrolling) for presenting disease stories [MGM*23]. Unlike scrollytelling, slideshows offer a variety of interaction options (e.g., sliders, buttons, click and drag). However, some users found slideshow interactions cumbersome. This study also highlights the need to consider the audience's computer literacy to improve usability.

3. Discussion and Outlook

Narrative medical visualization has the potential to transform clinical practice and research by enhancing patient education, communication, and public health interventions. Disease stories can simplify complex medical information for a lay audience, addressing the challenges of engaging individuals who have limited time or health literacy. Since many diseases may be lifestyle-related, it is important to increase the public's understanding of preventable risk factors. Narrative visualization techniques personalize health risks by visualizing disease progression using narratives with relatable protagonists (e.g., hypertension to vascular dementia), and including expressive visuals of real data. By engaging audiences emotionally and enhancing their understanding of health-related issues, health and lifestyle behaviors can be effectively improved. In addition, narrative visualization can facilitate informed consent for complex procedures and high-risk treatments (e.g., cerebral aneurysms, liver tumors, and cardiovascular diseases) by educating patients about treatment options and associated risks, empowering them to make informed decisions. Disease stories have the potential to raise awareness, promote early detection, and encourage research for under-recognized conditions, such as CSVD, which is often not detected in its early stages. Some of our studies have methodological limitations due to a limited number of participants or the comparison of only a few visual alternatives. Much of our work is exploratory, focusing on identifying trends and gathering qualitative feedback through case studies, laying the groundwork for future research. Given the vast design space for disease stories, this field presents numerous opportunities for further exploration.

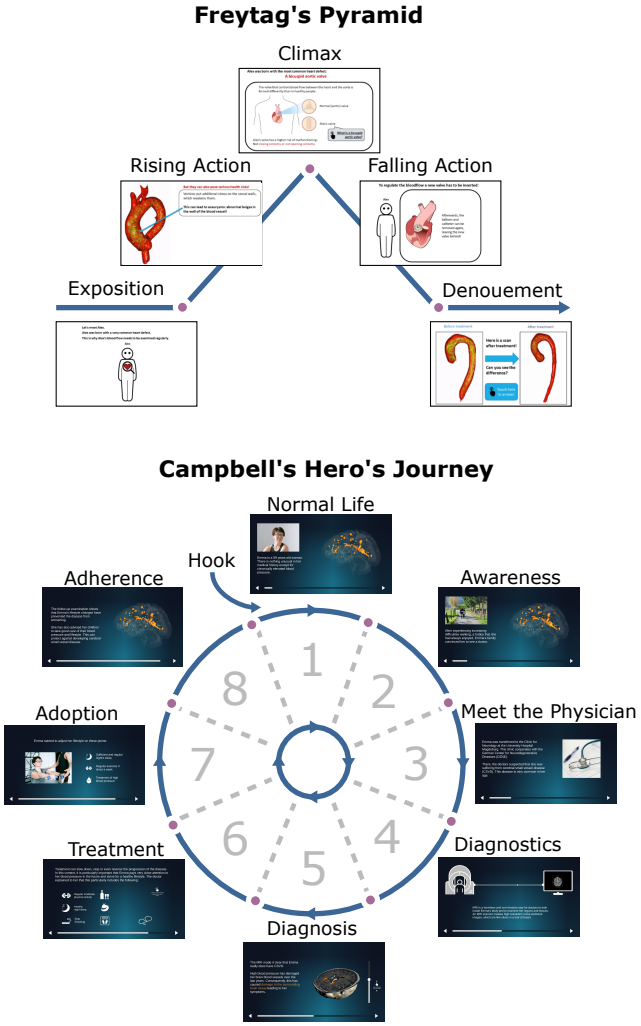

Figure 5: *We employed both Freytag's Pyramid (e.g., a story about aortic bloodflow [KSM*22]) and Campbell's Hero's Journey (e.g., a story about cognitive damage from hypertension [MWS*23].*

Future research directions include personalizing narrative content for audiences with special needs, such as language or visual impairments. We will continue to investigate emotional engagement and gaze guidance using sensory measures and eye tracking. Interactive story design studies can provide insights into the effective use of affordances and gamification elements. Longitudinal impact studies could examine the effects on patient outcomes, adherence, and preventive behaviors over time.

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