



Current Approaches in Narrative Medical Visualization

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Abstract

In a world increasingly driven by data and technology, it is imperative to empower stakeholders across diverse backgrounds (scientists, policymakers, patients, the general public) to make informed decisions about their health with the information available. However, simply providing the information is often not enough. The key to sharing and communicating health and medicine is making the information relevant to the intended audience. This issue lies at the heart of effective science communication. Storytelling is an age-old practice, and arguably one of the most defining features of humanity. Stories enable science communicators to translate complex information from health and medicine into a narrative that is personally accessible and relevant to the individual. Many pieces

come together to craft what many would call a “good story”—one of these is *narrative*. Our work seeks to tease out the role of narrative, with its various components, in telling medical stories. This chapter discusses current approaches in narrative medical visualization, with an eye toward future opportunities in developing narratives for data-driven medical stories. We explore various strategies in narrative structure and character that may be unique to telling medical stories and provide an outlook on future directions in this space.

Keywords

Narrative visualization · Narrative medical visualization · Medical visualization · Data-driven medical story · Science communication

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4.1 Storytelling in Medicine

Imagine that you are in your doctor’s office, trying to understand the details of the surgical procedure that you are scheduled to undergo the following week. Your doctor roughly sketches out some confusing anatomy on stray printing paper, trying their best to answer your questions. However, you feel overwhelmed and leave the appointment feeling as if you have already forgotten most of what you and your doctor discussed. If this scenario is not familiar to you, then a friend or family member has likely

experienced feelings of confusion, lack of understanding, and feeling intimidated by visits to the doctor. This may have left you, or your loved one, inadequately prepared and unclear on the risks of the procedure or treatment they will soon receive.

The medical community is aware of this communication issue, and recent years have seen a focus on facilitating communication between health professionals and patients, along with the growth of an entire industry focused on patient and medical education. Many science communication materials developed for patient education couch the intended message in the form of a story. Storytelling is an age-old practice central to humanity and enables science communicators to translate complex information from health and medicine into a narrative that is personally accessible and relevant to the individual (Joubert et al. 2019). Software products like *EmmiEngage* (Wolters Kluwer 2023) support patient empowerment and provide reassurance through self-paced multimedia modules that can be prescribed to patients by their doctors. Medical comics, for instance, those crafted by *Artibiotics* (Kearns 2023) based in New Zealand, can engage patients and encourage them to advocate for their health with their doctor (Alkureishi et al. 2021).

Supporting visual science communication, medical illustration is a field dedicated to translating complex medical information into approachable visual stories tailored for, e.g., patient education, clinical training, and broad outreach, such as Fig. 4.1. However, while engaging, these stories are time consuming to create and are not easily tunable to the unique needs of the individual.

Narrative visualization, from the computer science domain, combines the study of traditional storytelling techniques with data visualization (Lee et al. 2015). Driven by data, narrative visualization explores the semiautomated crafting of stories for different topics that, unlike handcrafted visual stories, are more easily tunable to different goals and audiences. Narrative medical visualization may enable and facilitate more personalized patient education and outreach, with easily generated and reusable components. In the example that opened this chapter of a

patient–clinician interaction, a narrative medical visualization approach could allow the clinician to draw from the patient’s medical record to explain their upcoming procedure specific to the patient’s own anatomy. They could discuss the predicted effects and risks of the procedure according to the patient’s personal health information in a visual style that is clear and relatable for the patient. Rather than laboriously handcrafting a custom story, narrative medical visualization can provide a framework for the story crafter to prepare different versions of a story with different variants of a given condition that can be fine-tuned to fit a communication goal. Finally, while storytelling is inherently subjective, by incorporating data into the storytelling process narrative medical visualization may introduce a degree of objectivity preferable in certain situations. In the following sections of this chapter, we sketch the basic theory and elements of narrative visualization. We then discuss current approaches and challenges in adapting this study for medicine, known as narrative medical visualization. For the sake of clarity, our use of the terms *narrative visualization* or *narrative medical visualization* throughout this chapter refers to the conceptual or methodological approaches and frameworks within the field of visualization, while *data-driven medical stories* are the end products of the implementation of these frameworks.

4.2 Narrative Visualization: Theoretical and Practical Foundations

Narrative visualization combines traditional storytelling techniques with data. While not a particularly new area of study, its practical application has expanded in recent years with the advent of an increasing accessibility of the web and technology supporting Internet access from nearly anywhere. Data journalists, e.g., from the New York Times Graphics Division, and data visualization agencies, such as Fathom Information Design (Fathom 2023), often employ storytelling techniques when crafting visualizations about

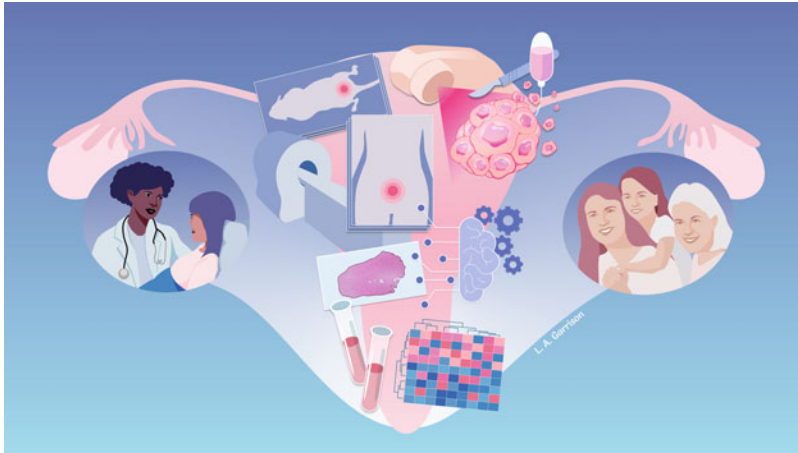


Fig. 4.1 Example of a hand-crafted medical illustration, created for broad outreach that visually describes the Mohn Medical Imaging and Visualization Centre's (MMIV) Gynecological Cancer Imaging research process and initiatives. The goal of this illustration is to visually

communicate the group's research focus on gynecology, its various methods, and to capture the notion of patient care at the beginning and end of the research pipeline. Illustration © Laura Ann Garrison, used with permission

data in order to attract and appeal to their intended audience.

Spanning practitioners and researchers, narrative visualization is an interdisciplinary area of study well-suited to collaboration. Visual and interaction design, as well as some programming experience and knowledge of the particular application area, are often necessary to craft a successful visual data story. In this section, we provide a brief overview of theoretical and practical foundations of narrative visualization, including:

- Narrative intent
- Story pieces: data facts and visualization techniques
- Narrative structure and genre
- Narrator and story personalization
- Evaluation in narrative visualization

From these foundations, we discuss applications of narrative visualization to the sciences which feed into the ideas central to narrative medical visualization.

4.2.1 Narrative Intent

The story creator(s) has two main objectives when telling a story: (1) engage the audience

and (2) hold their interest. Defining a *narrative intent* is arguably the most important aspect of story development, as this dictates nearly all other aspects of narrative construction. Narrative intent essentially is the take-home point or key objective of the story. As a story creator, what do you want your audience to understand, or remember, from your story, and how can you achieve that? Narrative intent can more formally be framed in the context of *narrative patterns*, which are low-level narrative devices that, alone or in combination, serve a specific intent in a story. Defined by Bach et al. (2018), these narrative patterns can be categorized into five high-level groups: argumentation (e.g., *compare*), flow (e.g., *repetition*), framing (e.g., *address the audience*), emotion (e.g., *humans behind the dots*), and engagement (e.g., *call to action*).

Having set the narrative intent, the story creator can then determine the necessary material to include in the story and the visualization techniques to use for this material. They can also consider how to group and sequence the story material, i.e., how to construct the story chronology), and determine their narrative strategy, i.e., how to tell the story through narrative genres, structure, and narrator perspective. These aspects of a story are illustrated in Fig. 4.2. Other issues, such as story personalization,

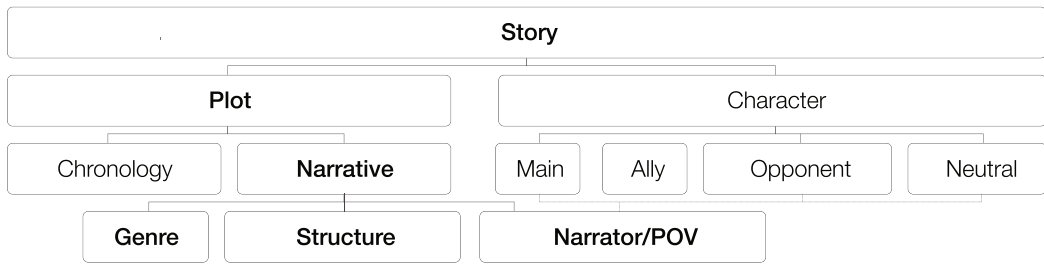


Fig. 4.2 Elements of a story, where *narrative* is the element that drives how the story is told. Narrative in turn is influenced by many elements. The three that we

focus on are: structure, genre, and narrator/point of view (POV). Image adapted from Beemgee GmbH (<https://www.beemgee.com/blog/story-vs-narrative/>) 2017

accessibility, and credibility, can also be considered. Depending on the domain, these issues have various degrees of importance (Böttinger et al. 2020; Ynnerman et al. 2020). For instance, credibility is vital for medicine, as medical information from a trusted source often means that the content and advice are vetted and safe to follow without detriment to one’s health.

4.2.2 Story Pieces: Data Facts and Visualization Techniques

The raw material used to construct a visual data story includes concepts, images, data facts, and textual descriptions (captions, labels), and visualizations derived from the data. Story pieces can be static or animated in cases where demonstrating temporality is key to the narrative intent. Interactivity is another important dimension to consider in narrative visualization. User interactions with various story pieces may include highlighting and filtering behaviors, or transitions between different events (Segel and Heer 2010). These interactions can serve as integral narrative elements that guide the user through the story.

The visualization technique chosen in narrative visualization should always be appropriate to the data it represents and align with the narrative intent or user task(s). This corresponds with standard practice in visualization design. Classic visualization design often tends toward widely used, unembellished techniques that are known to be safe and effective, such as bar charts. However, a

risk of using such simple or generic charts is that these are easily forgotten (Kosara 2016). Narrative visualization seeks to engage the audience and create memorable data stories. This means that there is greater use of charts incorporating specific visual aspects of the data for better recall. For example, disease incidence can be depicted with human isotopes to show disease occurrence as a fraction or percentage, rather than simply text. Annotation of visual elements is another important aspect of narrative visualization, tying in with important concepts such as data provenance and acknowledgment of uncertainty (Hullman and Diakopoulos 2011). Various storytelling techniques can be realized by means of annotation, e.g., labels, whereby annotations are revealed incrementally for different aspects of the visualization to guide the user through the story without being inundated with information.

Scatterplots appear often in data stories to compare variables against each other and to highlight possible correlations and trends. In narrative visualization, the story creator often adds a trend line to the data to send a clear message to the audience. Scatterplots can also incorporate a time dimension through animation. One of the most successful and well-known examples of an animated scatterplot telling a clear visual data story is Hans Rosling’s World Income Distribution plot from the Gapminder Foundation shown in Fig. 4.3. Rosling plots the health vs. wealth of all countries of the world, and then guides the audience through the evolving story of this relationship over the last few centuries. It is a

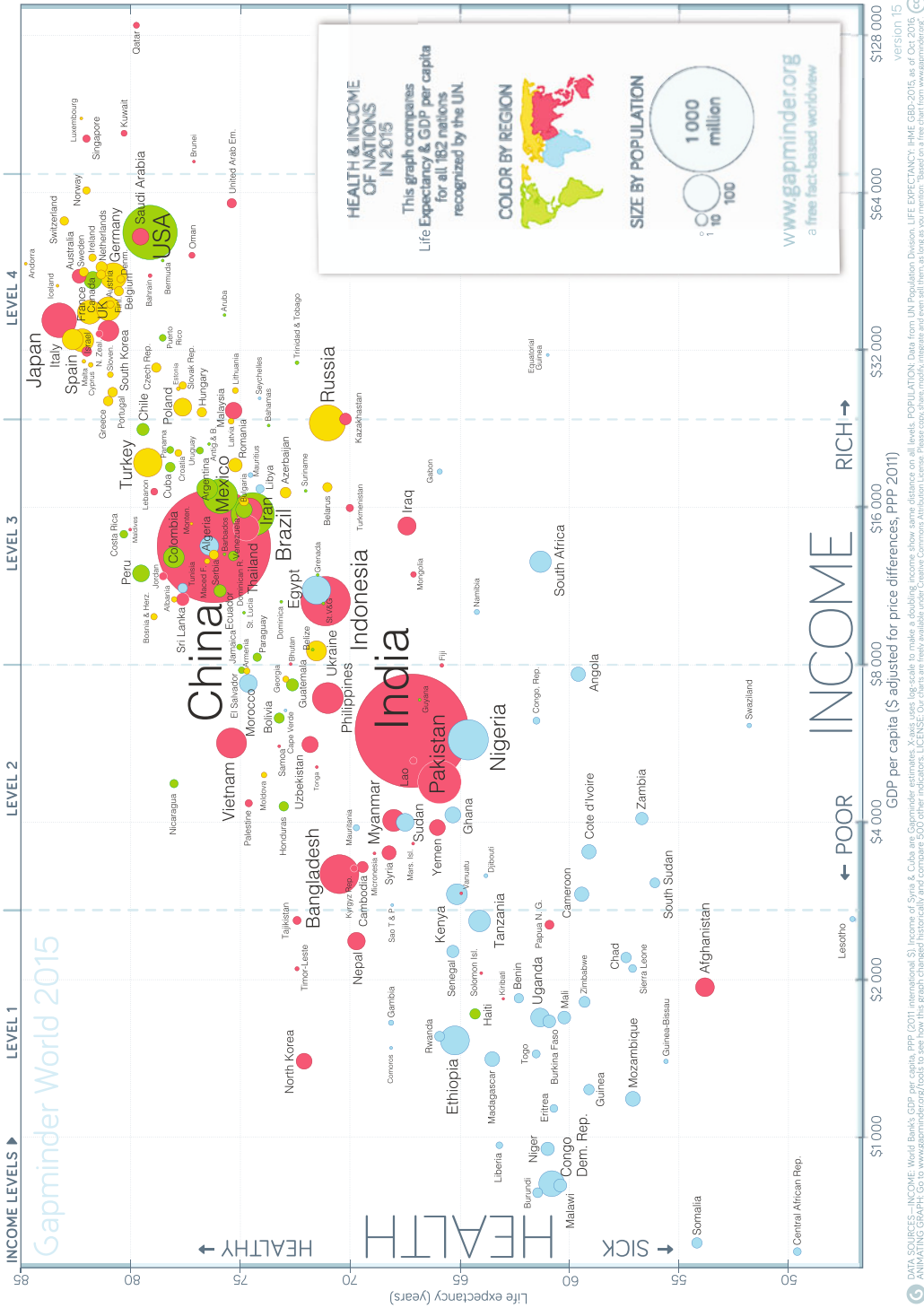


Fig. 4.3 Gapminder visualization of the countries of the world, plotted in terms of life expectancy (y-axis) and median income (x-axis). The colors represent the regions of the world, while the size of the circles indicates the population of the country in question. Image from Gapminder Foundation, reused under Creative Commons Attribution 4.0 International License (<https://en.wikipedia.org/wiki/File:Gapminder-World-2015.pdf>, <https://creativecommons.org/licenses/by/4.0/deed.en>)

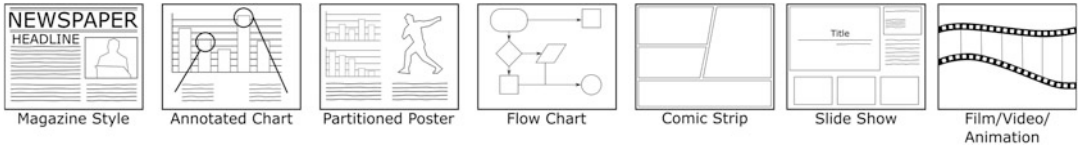


Fig. 4.4 Seven narrative genres for storytelling with data graphics, defined by Segel and Heer (2010). Image adapted from Segel and Heer (2010), reproduced with permission from Meuschke et al. 2022

fascinating and insightful story, where his narrative intent is to demonstrate that world development is not simply a division between rich and poor or developing versus developed countries. This visualization is complex. Rosling’s narrative guidance, paired with the animation, is helpful for the audience to follow the narrative thread. Absent animation or Rosling’s guidance, a story creator could consider incorporating filters into the visualization, e.g., by region, to reduce the amount of visible information at one time.

4.2.3 Narrative Structure and Genre

Following decisions on narrative intent and assembly of the story pieces, narrative visualization considers the structure and presentation of the story. The chronology of the story, and how it is presented, depends on the narrative intent and the target audience. We can borrow from ancient storytelling techniques like Aristotle’s suspense arc (Aristotle 2008) to arrange our story in a logical and engaging way. Aristotle’s suspense arc consists of three acts: after an introduction in which characters and a conflict are introduced, the story moves toward a climax in which the conflict intensifies. In the third act, the conflict is resolved; the characters succeed or fail. These three acts easily expand to five acts in Freytag’s pyramid, which includes an exposition, rising action, climax, falling action, and denouement (Madej 2008). Shakespearean plays, such as *Macbeth* and *Hamlet*, follow this structure. Another popular storytelling structure is Campbell’s Hero’s Journey (Campbell 2008). This is a character-driven structure that describes typical stages a hero reaches throughout a story. The Hercules story, for example, follows this narrative

structure. In Sect. 4.5, we include a detailed case study of the Hero’s journey in a data-driven medical story.

Whatever storytelling structure is followed, presentation of the story’s narrative is another consideration. Segel and Heer (2010) characterize the design space of storytelling with data graphics through an analysis of 58 visual data stories including content produced by news media outlets, blogs, instructional videos, and visualization and communication research. Their resulting classification of these visual data stories introduced seven visual narrative genres, which are illustrated in Fig. 4.4. These genres include (1) magazine style, (2) annotated chart, (3) partitioned poster, (4) flow chart, (5) comic strip, (6) slideshow, and (7) film/video/animation. These genres are distinguishable mainly by their ordering and number of frames. Much of our research in narrative medical visualization has explored the slideshow genre and the scrollytelling genre, a newer addition to the set of visual narrative genres. Scrollytelling is generally agreed to have been introduced by the New York Times in 2012 with their story, “Snowfall” (New York Times 2012), and has more recently been formalized in visualization research (Seysler and Zeiller 2018).

Genre selection can in part decide the linearity, or non-linearity, of the story structure. Stories may have branching events that return back to the main storyline, or that diverge in a “choose your own adventure” type of scenario. Our case study in Sect. 4.4 discusses a simple incorporation of storyline branches in the context of narrative medical visualization. Stories with branching structures naturally require a degree of interactivity with the audience, while more

One of the open questions in narrative visualization is the degree of influence that the identity of the narrator exerts on audience perception, trust, and subsequent behaviors after completing a data-driven story. Section 4.5 explores this question and considerations in a narrative medical visualization case study with three different narrators in a story about diagnosis and treatment of a neurodegenerative condition.

4.2.5 Evaluation in Narrative Visualization

Evaluation is critical to determine the success of a story, e.g., its narrative intent, story engagement, and story coherency. These aspects can be evaluated through baseline interviews or surveys prior to the story experience, and with follow-up interviews after the audience has experienced the story to assess story memorability, knowledge gain, and suitability of the narrative intent. Evaluation criteria often used in classical visualization design, such as user task speed and precision (Preim et al. 2018), are less relevant in narrative visualization.

4.2.6 Narrative Visualization in the Sciences

Research into applying narrative visualization techniques and strategies in climate research (Böttinger et al. 2020), astronomy (Ynnerman et al. 2020), and the biological and medical sciences are gaining traction. For instance, the World Health Organization incorporates narrative visualization techniques into their web content for public health education and outreach, such as the W.H.O. COVID-19 Dashboard (W.H.O. 2023). Semiautomatic authoring tools to tell visual stories are also in development. A notable recent example of applying narrative visualization to the life sciences is Moleculumentary (Kouřil et al. 2023), a tool for producing documentary-style content that renders structural models from molecular biology in real time. Artistic expertise is not necessary, and this tool is able to prepare a

story structure and construct a narrative from this structure. Text can be incorporated as narration, and this textual input may also guide semiautomated camera moves to guide the narrative.

Investigations into audience preferences when crafting biomedical stories are another growing branch of study from narrative visualization that can shed light on appropriate visualization techniques to use within a life sciences-oriented story. An early study in this space examined the practice and preferences of different audience groups for data-driven visualizations and medical illustrations of five well-known biomedical processes: signal transduction between molecules, constitutive activation of molecules, normal blood flow, aneurysm formation, and tumor movement in metastasis (Garrison et al. 2021). This study found that aesthetics, while important, is not the most critical criterion for topic experts to choose a visualization, and that, unsurprisingly, a degree of information abstraction is more often preferred by broad audiences relative to expert audiences. These audience-specific findings are useful to keep in mind when developing visual stories in the life sciences and other complex topics.

4.3 Narrative Medical Visualization

Narrative medical visualization takes and adapts the basic ideas and framework of narrative visualization and applies these concepts to the specific needs and challenges of the medical domain. Different flavors of these adaptations are likely true for any specific domain, e.g., adapting narrative visualization to stories for climate sciences. Adapting the concepts of narrative visualization to medicine is important because this framework can, for instance, provide an efficient and engaging means to educate patients and the general public about disease occurrence and, perhaps more importantly, disease treatment and prevention. Despite the wealth of medical data collected for every patient throughout their lifetime, understanding how to communicate real medical data encoding complex anatomical relationships and

diseases to a lay audience remains an immense and open challenge. Data-driven stories showing real medical data are promising in their possibility to allow nonartists, such as researchers, to create medical stories that visually communicate their science. Our discussion in this section of approaches for narrative medical visualization blends theory and concepts from narrative visualization with practical advice for crafting data-driven medical stories.

4.3.1 Expertise and Audience Involvement

The key to any successful story is ensuring that the right voices are heard and included in the story creation process. In narrative medical visualization, this means that the storytelling team should include a physician or medical expert with competence in the topic of interest. Involving members of the target audience or those in a position to sympathize with the needs and interests of the target audience is invaluable, but this is often where corners are cut in the story creation process. Continued engagement with these stakeholders, e.g., through interviewing and testing concepts, and sharing early sketches and prototypes of a data-driven medical story, will ensure a more effective and targeted end result.

4.3.2 Narrative Intent

Narrative intents for medical stories can focus on communicating preventable risk factors for a given disease that can leave the audience feeling empowered to make actionable, positive health choices. For example, smoking is a risk factor for numerous diseases, with multiple studies reporting probabilities of disease occurrence with smoking. A story creator can combine the *call to action* and *human behind the dots* narrative patterns (Bach et al. 2018) to achieve a narrative intent inspiring the story viewer to quit smoking.

This narrative intent could be realized by introducing a relatable story character who initially is a smoker, and reporting the higher risks of a given disease amongst smokers in comparison to non-smokers. The story can then wrap up with an outlook on reduced disease risk and other health benefits the story character has experienced when they quit smoking. Rhetorical questions to hook and engage an audience with a story can be useful narrative patterns to incorporate, e.g., *Why is cancer often curable today?* or *How can I strengthen my immune system?*

Human aspects are particularly important to consider for medical stories. Many data-driven medical stories focus on patients or loved ones of a patient. These people are often in a stressful, emotional situation where they are scared or overwhelmed by a disease or condition that they do not fully understand. Empathy at the outset can go a long way in ensuring that the message lands as intended, without painful repercussions.

4.3.3 Story Pieces: Data

Medical data are common story pieces in narrative medical visualization that can deliver a high personal impact. Clinicians use medical imaging data, e.g., X-ray, magnetic resonance imaging, ultrasound, or computer tomography data in diagnostics and treatment planning. If processed appropriately, these data can also form the basis of a medical story for broader audiences. Appropriate processing requires that any diseased or abnormal structures are delineated, highlighted in color, and provided with suitable textual information. Time-series data can be animated to help illustrate the progression or treatment of a particular disease. For example, if the data are available, a medical story can be crafted that shows the shrinkage of a tumor with successful therapy over time. Beyond medical imaging data, other medical data such as statistics on disease prevalence, disease burden, and commonly affected age groups are useful story pieces adopted for narrative medical visualization.

4.3.4 Story Pieces: Visualization Techniques

The visualization techniques available within narrative medical visualization are numerous and their selection depends on the data, narrative intent, and user tasks. Scatterplots, similar to Hans Rosling’s world health vs. wealth example that we discussed earlier, are useful for narrative medical visualization to show relationships between clinical variables, e.g., smoking and disease occurrence. This type of visualization can support a narrative intent of comparing and revealing patient-specific disease information.

Imaging data can play a decisive role in patient diagnostics and treatment and is an important facet to consider when crafting a medical story. Imaging data can not only provide a more tailored story to a patient by using their personal data but also means that artistic training or skills may not be necessary to craft a visualization. These data can be rendered and presented in different styles, from static abstracted 2D to interactive realistic 3D structures. The decision comes back again to the narrative intent and the target audience. While interactivity has been shown to engage users and

contribute to memorability (Richter Lipford et al. 2010), this may not be the right call for a patient audience with low computer literacy. Understanding when and where to leverage different visual representations of imaging data is an ongoing research question. We encourage incorporation of text labels and descriptions to accompany imaging visuals (Oeltze-Jafra and Preim 2014), as this information can help with identification and clarification of the structures, especially for audiences less familiar with anatomy and physiology (Meuschke et al. 2022). Icon-based visualizations, such as isotypes as shown in the far-right panel of Fig. 4.6, can also be meaningfully connected with imaging data visualizations.

Increasing data complexity necessitates considered approaches to story guidance and reduced information complexity. This can be achieved through thoughtful interaction and navigation techniques that are part of the visualization. In a 3D environment, e.g., a liver model with embedded tumor tissue, preset views, limited rotation capabilities, and/or preset parameters (Fig. 4.6, bottom left panel) can be helpful to restrict the exploration space and ensure that the audience

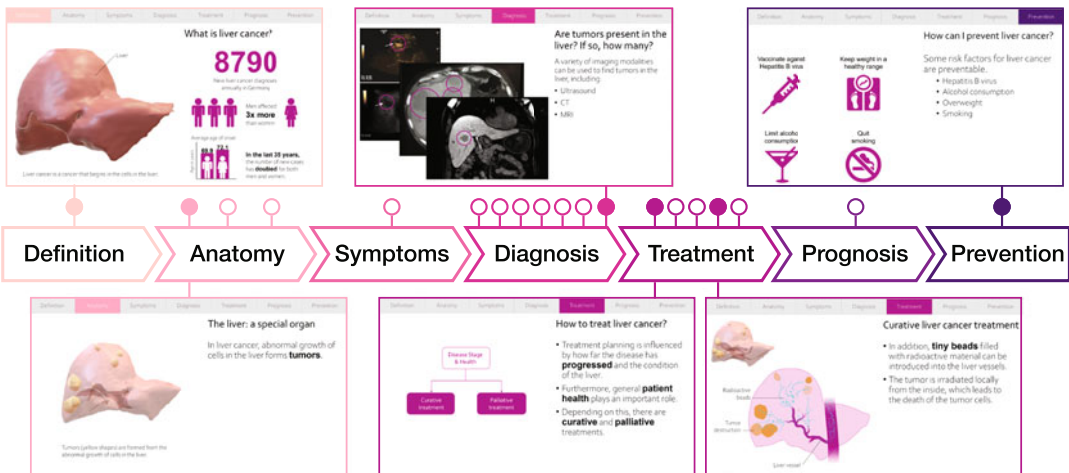


Fig. 4.6 Liver cancer story overview with scene excerpts using Meuschke et al.’s (2022) proposed seven-stage narrative structure for data-driven medical stories. Using the slideshow narrative genre, this story about liver cancer uses diverse story pieces including imaging data, 3D

models, medical illustrations, diagrams, free text, annotations, and isotype graphics. Image modified with permission by Meuschke et al. (2022). Illustrations created by Laura Ann Garrison

does not become disorientated (Ynnerman et al. 2020). “Hotspot” annotation mechanisms are another option to filter information or to facilitate transitions. On selection, these may trigger, e.g., movement to a new camera angle or reveal further contextual information about the region of interest.

Another consideration for 3D environments is managing occlusion. Elmqvist and Tsigas 2008 identify five approaches to manage object occlusion, including multiple viewports, virtual X-ray tools, tour planners, volumetric probes, and projection distorters. Virtual X-ray tools are especially exciting for narrative medical visualization, as the audience can be empowered by bringing them closer to the clinician’s perspective. They can investigate and reveal hidden information, like turning a liver to “x-ray mode” to localize the tumors buried within. Other smart visibility techniques, like ghosted views and cut-away techniques, are good options for such “invisible” structures (Lawonn et al. 2018).

4.3.5 Medical Narrative Structure and Genre

To date, narrative medical visualization has explored possibilities for a base narrative structure for telling data-driven medical stories. These efforts have centered on stories about diseases for broad audiences (Meuschke et al. 2022). Similar to the data story design space analysis conducted by Segel and Heer 2010, Meuschke et al. (2022) devised their medical narrative structure by analyzing health and medical online content

developed by hospitals and other health and wellness websites. Their narrative structure for disease stories, shown in Fig. 4.7, outlines seven steps that follow the path of Aristotle’s tension arc.

The narrative opens with (1) a definition of the disease and brief statistics on its incidence in the population. This serves as a hook to draw the audience into the story. An (2) anatomical overview follows, which orients the audience to the anatomical structures that are involved or affected by the disease. Tension is introduced to the narrative by (3) describing common symptoms of the disease, and tension reaches a climax with (4) disease diagnosis. The story progresses toward resolution with (5) a discussion of treatment options and their associated benefits and risks. Tension continues to drop with (6) disease prognosis, often presented as a 5-year prognosis, and the story finally concludes with an overview of (7) preventative measures for the disease that leave the audience with a sense of agency. This structure provides a logical framework for the grouping of data and other story pieces. For example, Fig. 4.6 shows excerpts from a liver cancer story that Meuschke et al. (2022) created following this template. Imaging data story pieces are used in (4) disease diagnosis, while 3D models and abstracted illustrations show (5) possible treatment options. While this template is linear by design, it can be easily extended with side branches to provide, e.g., more in-depth information on a certain surgical procedure in the treatment section before rejoining the main story line. From this basic structure, more complex branching structures may also emerge, e.g.,

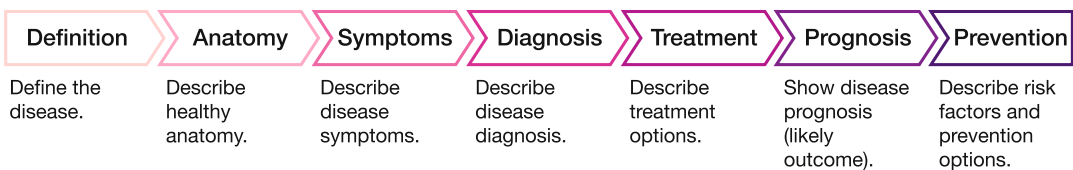


Fig. 4.7 Meuschke et al. (2022) proposed a narrative structure for visual disease stories told to broad audiences. The steps include (1) disease definition, (2) an anatomical overview, (3) symptoms, (4) diagnosis procedure,

(5) treatment options, (6) prognosis, and (7) prevention. Image was modified with permission from Meuschke et al. (2022)

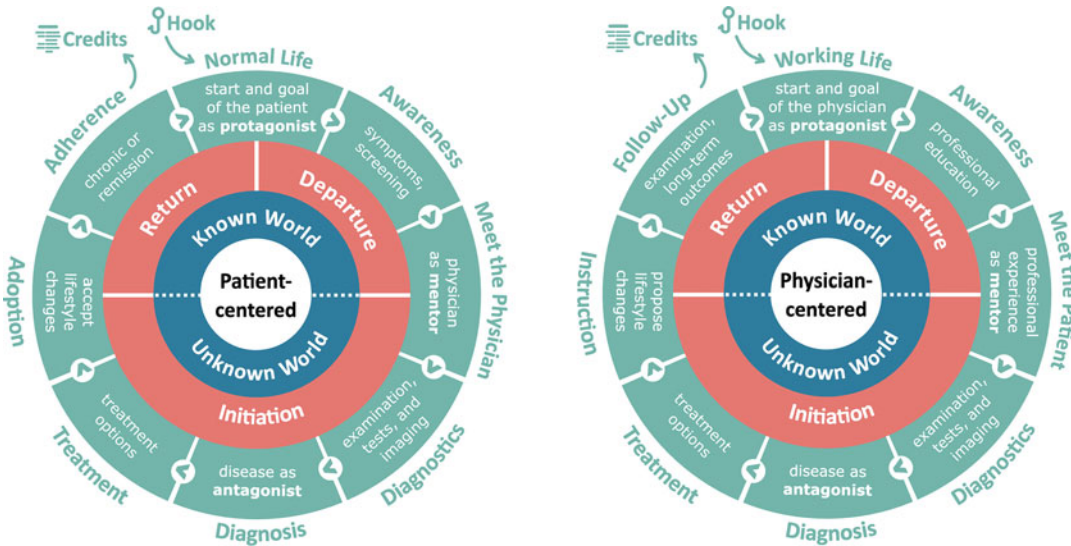


Fig. 4.8 The disease journey adapted from Campbell's Hero's Journey shows a structure for the patient-centered (left) and physician-centered (right) disease story. The structures depict the different stages (green) the protagonist must experience. These stages divide into three acts (red): departure, initiation, and return, which are split between the protagonist's known world and the unknown.

The story begins with a narrative hook, before showing the first stage of the disease journey. After the last stage, the story ends with a call for prevention and credits showing the story authors' affiliations for information transparency and credibility. Image reproduced with permission from Mittenentzwei et al. (2023)

the audience chooses a specific treatment, which leads to a diverging branching structure for each possible treatment option. Other structural variants may skip one or more steps altogether if not relevant to the narrative intent or the content of the story.

Campbell's Hero's Journey (Campbell 2008) is another story structure which can be applied to disease journeys that can be experienced by, e.g., a patient or clinician protagonist, as conceptualized by Mittenentzwei et al. (2023). Illustrated in Fig. 4.8, the disease journey crosses between the protagonist's known world of prior experiences and the unknown in three main acts: (1) departure, (2) initiation, and (3) return. In the first act, the protagonist, e.g., a patient, is introduced to the audience living their normal life, before an event, e.g., symptoms or diagnostic screening, alters their awareness and begins their journey. Meeting a mentor, e.g., a healthcare professional, builds to the second act: initiation. During the second act, the protagonist encounters the antagonist, e.g., the disease, and experiences the main conflict of the story, e.g., diagnosis of

the disease. In the final act, the protagonist navigates from the unknown back to the known world, e.g., through treatment and follow-up.

4.3.6 Personalizing Data-Driven Medical Stories

Narrative medical visualization can introduce personalization through the choice of narrator, or by including additional details about story characters to encourage relatability and empathy between the audience and the story. To facilitate broader relatability between story characters and a diverse audience, the story creator may represent characters as abstract and androgynous figures as shown in Fig. 4.9, such that characteristics like gender, body shape, hair color, or age are left vague and open to the audience's imagination (Kleinau & Stupak et al. 2022).

Many medical stories that are targeted to patient audiences adopt a patient character as the main narrator and protagonist of the story. The

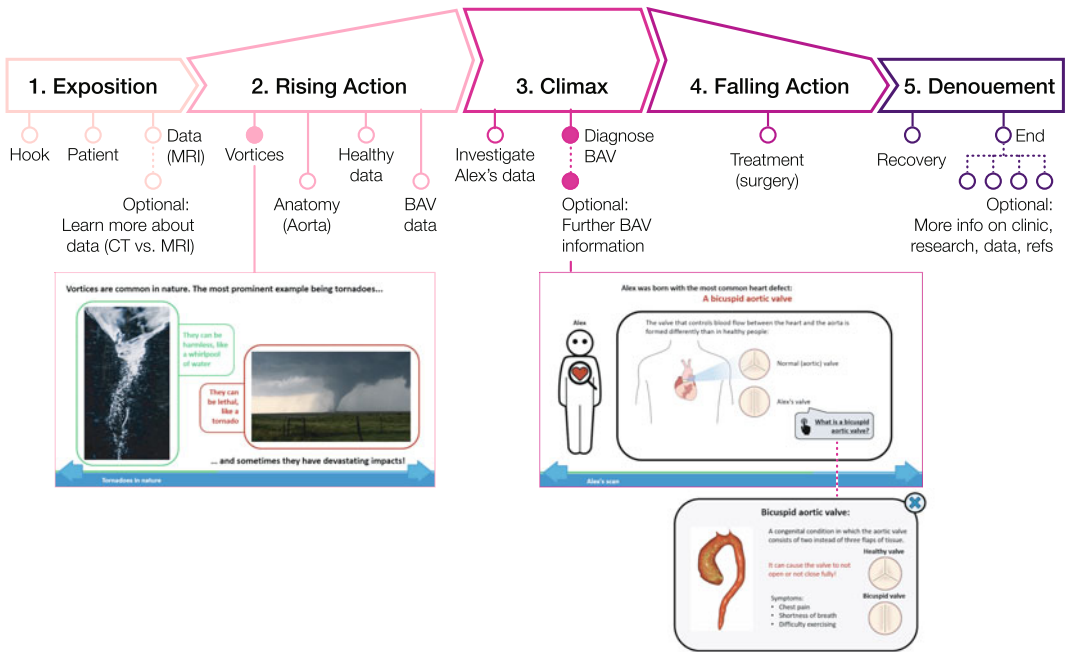


Fig. 4.9 Freytag’s Pyramid story structure (Madej 2008) in five acts as applied to a bicuspid aortic valve disease story. Image modified with permission by Kleinau & Stupak et al. (2022) under Creative Commons Attribution

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main conflict of the story is often the presence of a disease or other medical condition affecting the patient’s quality of life. Following the structures that Meuschke et al. 2022 and Mittenentzwei et al. 2023 describe, the audience joins the patient through their experience of disease diagnosis and discussion of treatment options, all while the disease continues to progress, building to a climax with disease diagnosis. The story tension begins to recede with our patient receiving treatment, their subsequent recovery, and their progressive return to normal life. Throughout the narrative, sharing our patient’s inner struggles and emotions can help the audience empathize with our patient in this journey.

Data-driven medical stories may, instead of patients, focus on the clinician as the main character and story protagonist. The case study we discuss in Sect. 4.5 explores a story variant where the narrative follows a clinician as the story protagonist (Mittenentzwei et al. 2023). The narrative intent of such stories may be to

garner sympathy and to promote cooperation with an overworked and overburdened health system in the face of public health emergencies, as experienced at the height of COVID-19. Personalization for this type of story can focus on a doctor or nurse who works long hours under intense time pressure, all the while wearing masks that leave deep and painful imprints on their faces. This can help the audience see that clinicians are not, as we may sometimes want to believe, superheroes—they are human, and are generally trying their best to help.

These personalization examples are in the spirit of positive emotional empathy, or to encourage choices for the advancement of public health, e.g., getting vaccinated. However, a critical perspective on stories triggering feelings of empathy from an audience may find that these approaches are deliberately manipulative and impact story credibility. Introducing counterfactuals or alternative viewpoints in a narrative can mitigate this perception of bias or

manipulation, and ultimately produce a more holistic and informative story.

4.3.7 Credibility in Medical Stories

Credibility is vital in narrative medical visualization. Regardless of their level of medical education, people can and should be critical of their information source and demand transparency when related to their personal health and medical records. The fact that the pharmaceutical industry, the medical technology sector, and the medical profession have not only the welfare of the patient in mind but also tangible economic interests is well-known in times of rampant hospital privatization. This means that a narrative intent to encourage patients to participate in vaccinations and screenings could be perceived as economically motivated.

To establish and retain credibility, it is important to avoid oversimplifying or providing only one-sided information on the benefits of medical interventions or any other aspect of medical care. The story creator should be careful to use data from reliable, high-quality sources, and to avoid bias in their interpretation. To allay concerns about data source or quality, data provenance should be retained and displayed where and whenever possible. It should also be clear whether the data has been altered for the preparation of the story and, if so, by whom and with what objectives. Does a renowned medical professional, e.g., a hospital director, vouch for this story? If so, this can help establish trust. This vetting by a formal health entity should be conveyed early in the story, and repeated at the end to remind the audience of this validation.

4.3.8 Evaluating Medical Stories

Evaluation in narrative medical visualization is challenging, as there are numerous ways to tell a story and evaluation can, on some level, become a subjective exercise. Audience engagement and memorability are meaningful objective measures of evaluation, with an early between-subject

study ($n = 90$) finding that a carefully designed narrative structure, comprehensible visualizations, easy-to-use interactions, and credible references contribute to more memorable data-driven medical stories (Meuschke et al. 2022). The following two case studies provide concrete examples of story development and evaluation in narrative medical visualization research, beginning with a case study exploring the process and various challenges of adapting complex medical data into a coherent and engaging data-driven medical story.

4.4 Case Study: Bicuspid Aortic Valve Disease

This case study illustrates an application of a narrative medical visualization structure presented in two different narrative genres. We also explore some of the complexities and challenges of translating medical data into a broadly-accessible visual narrative. The story describes a common type of congenital heart disease and its treatment (Kleinau & Stupak et al. 2022). This story was developed in close cooperation with clinicians and researchers affiliated with the Heart Center Leipzig in Germany, which often encounters and treats this condition.

The aortic valve is one of four valves of the heart, providing the connection between the left side of the heart and the aorta, which is the largest blood vessel in the body, and which carries oxygen-rich blood from the heart to the rest of the body. In healthy individuals, the aortic valve consists of three leaflets. With bicuspid aortic valve disease, two of the three aortic valve leaflets are fused at birth. Bicuspid aortic valve disease is the most common congenital heart defect, affecting up to 2% of the population (Masri et al. 2017). The fused valve leaflets may mean that the valve cannot seal completely, leading to a so-called “leaky valve,” or the valve may be narrowed. In either case, blood flowing through this valve becomes more turbulent. Over time, this turbulence can stress and weaken the wall of the aorta, causing it to bulge into what is called an aneurysm. Aneurysms are potentially life-threatening

and need careful monitoring. If an aortic aneurysm ruptures, survivability is low. Early detection and observation of this disease are critical to ensure patient health and mitigate risks of such a rupture.

The *narrative intent* of this story is to inform and engage a broad, non-expert audience on the complexities and risks associated with bicuspid aortic valve disease, and more specifically to help the audience understand the connection between turbulent blood flow and aneurysm formation from this valvular disease. Metaphor can be a powerful tool to give meaning and context to unfamiliar phenomena. For this disease, clinicians often use a tornado metaphor to describe turbulent blood flow in the aorta to their patients. Tornadoes are well-known extreme weather occurrences with varying degrees of strength and severity, similar to the varying strength and severity of flow vortices in the aorta. The story creators adopt this metaphor into the narrative of this story, shown in Fig. 4.9, to achieve familiarity and bridge gaps in medical knowledge.

The *story pieces* include clinical imaging data known as 4D PC-MRI (phase-contrast magnetic resonance imaging) that capture blood flow dynamics in the human body. These data are processed through software that detects and classifies the different types of blood flow turbulence (Köhler et al. 2019). Blood flow data are complex. At each point in space, what is known as a vector describes the direction and strength of the blood flow at that point. These vectors change over the course of a cardiac cycle. Common convention in medical illustration and in flow visualization is to place blood flow in an anatomical context, in this case, the aorta, to make the information less abstract. To reduce visual complexity, another common convention in flow visualization is to show flow vectors only in anatomical regions of interest, e.g., low-velocity regions where vortices may be more likely to occur (van Pelt and Vilanova 2013). These are areas where flow is especially turbulent, which is what the story creators want to highlight. To make the flow visualization more readable and more illustration-like, another convention is to integrate

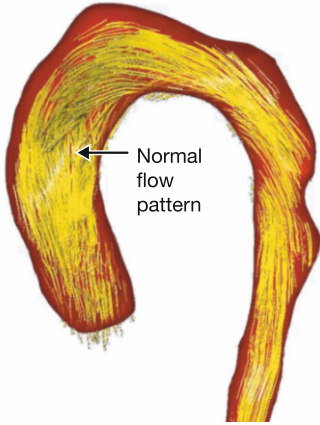
the flow vectors visually into pathlines that show the path of blood flow, rather than a single point in space. While the fluid mechanics community often maps the velocity of the flow to color, this mapping choice is not intuitive to an audience outside of this domain. To facilitate communication, the story authors instead represent the blood flow pathlines as one color, as shown in Fig. 4.10.

This story uses Freytag's Pyramid and follows the basic *narrative structure* for data-driven medical stories about diseases from Meuschke et al. (2022). Figure 4.9 shows a high-level overview of this structure, which consists of five acts: (1) exposition, (2) rising action (3) climax, (4) falling action, and (5) denouement. The story creators adopt a martini-glass story structure as in Fig. 4.5 (Segel and Heer 2010), with an author-driven opening that has limited interactions and a strong message in the form of a narrative hook before transitioning to a reader-driven experience with more interactive elements and limited optional story paths.

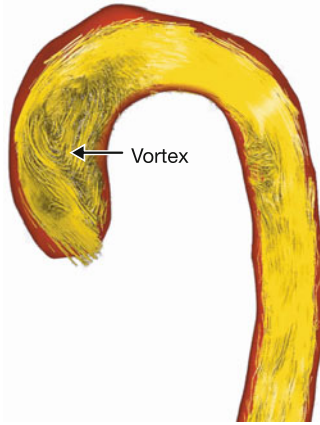
In the first act, the story opens with a narrative hook phrased as a rhetorical question, with different hook options and accompanying visuals that the story creators explored shown in Fig. 4.11. To establish credibility at the outset, the story creators place the logos of the involved institutions, which include universities and hospitals, on the opening screen of the story. The audience is also introduced to the main character, Alex, who is the patient experiencing this disease. The last segment of the exposition introduces the user to the blood flow data in the context of Alex's upcoming examination. At this point, the story pivots from a fully author-driven experience to a partly reader-driven experience, where the audience may choose an optional story path to learn about the difference between CT and MRI medical data, before returning to the main story path.

The second act builds story tension by reintroducing the tornado metaphor, shown in Fig. 4.9, which is referenced in the title of the story. The narrative continues, describing blood flow vortices as "tornadoes in the blood." While at first illustrated as a harmless case in a healthy person, the narrative escalates tension by showing

Normal, regular aortic blood flow. Any vortices present are small.



More turbulent blood flow, with large and clear vortex in ascending aorta.



Extreme vortex that has compromised stability of vessel wall, forming a bulge (i.e., an aneurysm).

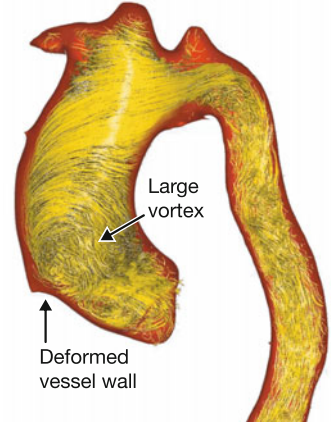


Fig. 4.10 Data-driven representation of blood flow through the aorta in three different levels of severity. The blood flow data are represented as pathlines. While fluid dynamics convention maps the velocity of these data to color, for the purposes of this story, the data are mapped to

a single color to minimize information complexity and audience confusion. Image reproduced and modified with permission by Kleinau & Stupak et al. (2022) under Creative Commons Attribution 4.0 International License (<https://creativecommons.org/licenses/by/4.0/deed.en>)



Fig. 4.11 Early variations of a narrative “hook” with different visuals to begin the data-driven medical story about bicuspid aortic valve, a common congenital heart disease, including What is wrong with your heart, Brian? (left), Is there a tornado in Brian’s blood? (middle), and Is

there a tornado in Alex’s blood? (right). Image reused with permission by Kleinau & Stupak et al. (2022) under Creative Commons Attribution 4.0 International License (<https://creativecommons.org/licenses/by/4.0/deed.en>)

a blood flow vortex causing serious health risks, with the possibility of aneurysm formation and subsequent rupture. The climax of the story is the point where the user investigates if Alex has blood vortices by comparing a 3D visualization of Alex’s blood flow against the normal flow of a healthy patient and the flow of a patient with an aortic aneurysm. On determining that Alex does indeed have vortices in their blood, tension begins to resolve when the narrative identifies

bicuspid aortic valve disease as the cause of the vortices. Often in medicine, having an answer to the cause of the symptoms that a patient is experiencing can already help relieve their anxiety. Another optional story path is available at this point for the interested audience to learn more about the signs and symptoms of bicuspid aortic valve disease, shown in Fig. 4.9.

The fourth act follows the narrative’s falling action by describing Alex’s surgical procedure,

which uses medical illustrations of the relevant heart and aortic anatomy in a clear and simple style intended to inform without intimidating the patient or their loved ones who may be following the story. In the fifth and final act, story tension is resolved by allowing a side-by-side visual comparison of Alex's aortic blood flow before and after the surgery, where the audience discovers that Alex's blood flow patterns are no longer life threatening. The story closes with Alex returning to normal life, with links to further reading for the audience who would like to learn more about bicuspid aortic valve disease.

This narrative is presented in two genres: (1) a PowerPoint-style *slideshow* and (2) a long, vertically structured “*scrollytelling*” experience. These genres produce different interactive and navigational experiences that require thoughtful user interface and experience design. While scrolling naturally initiates transitions between story acts and is generally intuitive on touch screens, slideshows still have a strong association with clicking to advance to the next slide, which can be unintuitive on tablets or other touchscreen solutions. Speed and smoothness of transitions between story pieces are another important consideration. Scrollytelling experiences set an expectation for a smooth and rapid transition between pieces. If the transition feels slow or awkward, the audience may disengage from the story. Some audiences may not understand that navigation forward and backward in the story is possible, or that alternative story paths are available. For both genres, graphical user interface elements that make these navigational options clear are integral to a complete user experience. In a preliminary evaluation with a broad audience ranging from older children to middle-aged adults ($n = 24$), Kleinau & Stupak et al. (2022) found that many users prefer the click interactions of a slideshow to navigate the story and that some users were unsure of how to move forward from the story opening with the scrollytelling genre. While this is just one case study, these findings demonstrate the importance of interaction and navigation experience planning in narrative medical visualization.

4.5 Case Study: Cerebral Small Vessel Disease

Our second case study explores the challenges and considerations of narrator and story protagonist choice in a data-driven medical story about cerebral small vessel disease (Mittenentzwei et al. 2023). Cerebral small vessel disease (CSVD) is a broad term for a variety of changes in small blood vessels in the brain that can cause further damage to surrounding brain tissue (Wardlaw et al. 2013). These vascular changes can have effects ranging from mild to severe, e.g., slight dizziness, dementia, or a life-threatening stroke. CSVD affects about 5% of people in their 50's, but this number increases to 100% of the population older than 90 years (Cleveland Clinic 2022). In spite of such widespread occurrence, most people have never heard of this disease. Awareness of CSVD, and an understanding of protective measures to mitigate severe effects later in life, can have a profound positive effect on public health.

The *narrative intent* of this story is to familiarize an early- to middle-aged adult audience with the possible causes and symptoms of CSVD, focusing in particular on the causal relationship between high blood pressure and CSVD. Through empathy and engagement with the narrative, a second intent is to motivate personal lifestyle changes and regular blood pressure checks to mitigate the more serious risks of CSVD later in life.

The story follows Campbell's Hero's Journey *narrative structure*, depicted in Fig. 4.8, which we discussed as a narrative structure for disease stories earlier in Sect. 4.3 of this chapter. In this structure, a disease story protagonist is the story character who is affected by a disease or its risk factors. Mittenentzwei et al. (2023) designed two human protagonist variations of the CSVD disease journey story, one with a patient protagonist and the second with a physician protagonist.

In the patient-centered variation of the story, we meet Emma, a 59-year-old patient with chronic high blood pressure. Emma's disease journey begins with her awareness of high blood pressure as a possible symptom of an underlying

disease. She departs her known world and enters the unknown, meeting her mentor in the form of an unnamed physician who helps and guides her through the next stages of the story. She undergoes diagnostic imaging, examinations, and tests, before arriving at a diagnosis where she finally meets her disease antagonist: cerebral small vessel disease. She is then exposed to and chooses from a set of possible treatment options, and re-enters her known world and adopts lifestyle changes, e.g., quitting smoking, to manage the disease. She visits her mentor, the physician, for follow-up to assess whether the disease is under control or in remission, or if further treatment steps must be taken. The story concludes with a call for prevention by Emma advising her family to take steps to manage high blood pressure before serious symptoms of CSVD could appear later in life.

The physician-centered story follows the same basic structure, but from the physician's perspective: the first act begins with meeting Dr. Schreiber in her position as senior physician in her hospital's neurology department. Her medical education leads to her awareness of CSVD and its signs and symptoms in her patients. Her professional experience on the hospital floor serves as an abstract mentor in this narrative, which could instead be another more senior physician. She is initiated into the unknown world when she begins examinations and tests on her patient whom she suspects may have developed CSVD, but she is unsure until she amasses enough diagnostic evidence to meet the main story antagonist, CSVD, and make her diagnosis. She researches different treatment options that may work and discusses these with her patient, and re-enters the known world by proposing lifestyle changes to help her patient lower their blood pressure to slow or stop progression of the disease. She schedules follow-up visits with her patient and assesses possible long-term health outcomes for her patient. Her narrative ends with a call for prevention, where she outlines preventative measures that all people can take to mitigate risks of CSVD later in life.

This case study introduces several important design questions to consider when developing a

character-centered narrative. Centering a story's narrative around a human character whom the audience can more easily identify with, rather than a more impersonal recitation of statistics, can help an audience empathize and engage with the story (Mittentzwei et al. 2023). Story creators may consider spending more time developing the character at the outset of the story to help the audience form a bond with this character before their journey begins.

Chen et al. (2016) suggest guidelines for audience identification and self-referencing with the story and its protagonist. Allowing the audience to identify with and see themselves in the story is key, as people tend to underestimate their personal risk. In health, this underestimation leads to less personal motivation to make big lifestyle changes (Wachinger et al. 2013). The story creator can also consider how credibility can be differently perceived if a disease story is presented through the eyes of an experienced physician, or through a patient who the audience may more closely identify with and relate to. Physicians are often upheld as authority figures, but pressing too hard on this point could sacrifice the narrative's relatability to the audience.

To assess credibility, the Gaziano-McGrath scales of accuracy, fairness, trustworthiness, bias, and completeness are useful guides (Gaziano and McGrath 1986). Lastly, the story creator can consider audience engagement by measuring the users' perceived versus actual length of time spent with a story. Tying back into other questions connected to protagonist relatability and empathy, an optimal design choice would see a story that the audience wants to spend time in, where the story feels shorter than it is.

4.6 Outlook and Challenges for Narrative Medical Visualization

By blending traditional storytelling structures and devices with best practices for data visualization, narrative medical visualization can help to tell better data-driven medical stories. In this chapter,

we outlined the core ideas behind narrative visualization, and discussed how these ideas transfer and must be adjusted to address specific challenges for telling stories in medicine. By adopting narrative medical visualization practices, we can tell medical stories that can transform patient education and public health outreach. Narrative medical visualization is a growing area of study, with several challenges as well as opportunities to be aware of in this developing research space.

4.6.1 Community-Driven Stories

Stories are told by people, about people, for people. Without involving those for whom the stories are to be told by, or to, in the development and evaluation process, data-driven medical stories can fail to reach their target audience with their intended message. As story creators, our approaches must involve members from diverse communities if our goal is to communicate medicine to the general public. This involves thinking beyond Western structures of storytelling that have been investigated in narrative medical visualization to date. Furthermore, mounting evidence shows that the traditional “knowledge deficit model” of science communication is not particularly effective in inciting behavioral changes (Bucchi and Trench 2021; Simis et al. 2016). We need to adopt different, situated approaches to communicating data-driven medical stories. People need to feel personally motivated to make such changes, and understanding how to motivate requires a dialogue with the target audience communities.

4.6.2 Data Challenges

Data is a core component in narrative medical visualization, with an array of associated challenges ranging from data access and ethics to handling the myriad data types and quality. Most medical data is simply inaccessible for use in narrative medical visualization due to patient privacy. While some open-source data sources

exist, these are limited. Initiatives for producing data compliant with government regulations, e.g., data derived from data donors, could help increase medical data access.

Data quality is another challenge, especially for stories built on data from longitudinal clinical studies. The story creator must consider if the dataset is mature enough to draw and present valid conclusions, which involves assessing the completeness and comprehensiveness of the data. A dataset may be intrinsically biased in some way, leading to different conclusions than related datasets. If this happens, the story creator must carefully evaluate how to reconcile these differences, and if there is a more trustworthy source.

Clinical data can vary over broad scales of space and time. For instance, organs measure in centimeters but consist of tissues and cells measuring several orders of magnitude smaller. The molecular events triggering cellular mechanisms that drive organ functionality can occur in the space of nanoseconds, while treatment of a disease that results from a repeating series of misconfigured molecular events can take years. Given such variation, it is not surprising that the data describing these broad scale ranges are also numerous (Garrison et al. 2022). Medical data can include radiological and histological image data, numerical values from lab studies, and statistical information. These data can be acquired across myriad different devices, often with different calibration settings that tie into our earlier questions on data quality. Simulation data for biomedical processes may also be useful in a narrative, which further expands the data space.

4.6.3 Story Experience Challenges

With so many possible data sources, types, and story scenarios, authoring systems in narrative medical visualization should be flexible enough to support a range of interactions and rendering styles that the story creator can select for the story that they wish to tell. The system should also be robust enough to be made available to and usable by a broad audience. However, while many such

options should be available for the story creator, it is often not a good idea to expose so many options to the audience. Curated and thoughtful interactions and stylistic choices can lead to a more positive and impactful user experience.

While we discussed earlier the issue of data accessibility, user accessibility is a separate issue. Around 15% of the global population lives with some form of disability, which can include visual, motor, or cognitive disabilities. Narrative medical visualization seeks to reach a broad audience that encompasses people with such disabilities, but understanding the mechanisms that we as story creators can use to tell more inclusive stories is by no means a solved problem. Revisiting the first challenge regarding community involvement, this problem can only be solved by including those with disabilities in the story development and evaluation process.

Credibility is important in any science communication but can come with life-or-death consequences in the medical domain, e.g., if a person chooses to follow bad medical advice from an untrustworthy or unreliable source. An active research question in narrative medical visualization is how to best establish the credibility of a story, and how credibility can be differently perceived with different story narrators. Data provenance is another aspect of credibility. Apart from including the data source and providing annotations in the story that reveal relevant data source information, what other methods can we incorporate to better link our stories to the underlying data that drive these stories?

Closely connected to credibility is the question of ethics in storytelling. Although narrative medical visualization espouses a data-driven approach to storytelling, it is undeniable that humans are heavily involved in the process, and may, wittingly or not, insert their personal subjectivity or biases into the story. Considering how to send the desired story message without unduly influencing or manipulating the audience is a nuanced and challenging question. Ensuring that a data-driven medical story addresses both sides of an argument, or discusses both positive and negative

aspects of, e.g., a particular treatment, can produce a more ethical data-driven medical story.

Finally, the often highly specific needs and requirements of different topics in medicine mean that it is difficult to develop meaningful evaluation guidelines in narrative medical visualization that are both comprehensive and general enough for use across a range of use cases. We can look to other disciplines, e.g., in the learning theory and education domains, to develop more robust and general evaluation guides for the stories that we create, and to help prioritize the most important story characteristics for evaluation.

4.7 Conclusion

Much work remains to bridge narrative medical visualization research into practice, and to understand drivers for engagement and driving positive lifestyle-changing behaviors for audiences of such visualizations. Building on broader research and practice in narrative visualization and science communication, this chapter has provided a foundation for current approaches in narrative medical visualization, offering readers a basis for effective communication and directions for future research.

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