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Do Disease Stories Need a Hero? Effects of Human Protagonists on a Narrative Visualization about Cerebral Small Vessel Disease

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Abstract

Authors use various media formats to convey disease information to a broad audience, from articles and videos to interviews or documentaries. These media often include human characters, such as patients or treating physicians, who are involved with the disease. While artistic media, such as hand-crafted illustrations and animations are used for health communication in many cases, our goal is to focus on data-driven visualizations. Over the last decade, narrative visualization has experienced increasing prominence, employing storytelling techniques to present data in an understandable way. Similar to classic storytelling formats, narrative medical visualizations may also take a human character-centered design approach. However, the impact of this form of data communication on the user is largely unexplored. This study investigates the protagonist's influence on user experience in terms of engagement, identification, self-referencing, emotional response, perceived credibility, and time spent in the story. Our experimental setup utilizes a character-driven story structure for disease stories derived from Joseph Campbell's Hero's Journey. Using this structure, we generated three conditions for a cerebral small vessel disease story that vary by their protagonist: (1) a patient, (2) a physician, and (3) a base condition with no human protagonist. These story variants formed the basis for our hypotheses on the effect of a human protagonist in disease stories, which we evaluated in an online study with 30 participants. Our findings indicate that a human protagonist exerts various influences on the story perception and that these also vary depending on the type of protagonist.

CCS Concepts
• ***Human-centered computing*** → ***Visualization design and evaluation methods; Scientific visualization;***

1. Introduction

Using storytelling techniques to create data visualizations targeted at a broad non-expert audience has become a mainstream research topic in the last decade. These *narrative visualizations* shift the focus from enabling users to *analyze* data to *presenting* data.

The general public has a strong interest in medical topics, such as diagnosis, treatment, and prevention of diseases. Framing medical information in the context of a story with a particular narrative is common to make this information understandable. Extended reports on research related to COVID-19 and a variety of YouTube videos for health-related topics aim at general audiences using a narrative format [BDBB18]. Moreover, government agencies, such as the World Health Organization, use narrative approaches to inform the public about health-related developments. In contrast to artistic media, such as hand-crafted illustrations, which are widely used in health communication, our goal is to mainly use data-driven visualizations. News outlets increasingly provide narrative visualizations with advanced interaction possibilities in their online articles, e.g., to convey the spatio-temporal development of COVID-19 in terms of incidence, hospitalization, and death as well as differences in terms of age, and gender [Com20, PN21].

Meuschke et al. [MGS*22] state that data-driven disease stories need at least one character. Characters can be humans or objects, e.g., organs or diseases. Furthermore, characters can be classified as either protagonists (main characters the user can sympathize with), antagonists (opponents of the protagonists), or supporting characters (side characters that support the protagonist) [Cam08, Gio09]. However, the influence of a character on various factors, such as how involved the user feels or how much they trust the information presented, is little-explored. To address this gap, we investigate the impact of the protagonist's identity on the user in a disease story. For these purposes, we chose to tell a story about cerebral small vessel disease (CSVD), which is a widespread but largely unknown disease to the general public. Many risk factors for CSVD are pre-

ventable, making this a likely more actionable story to share rather than diseases that are purely heritable or terminal in nature. We created three different story conditions, following the structure of Joseph Campbell's *The Hero's Journey* [Cam08]. The conditions feature: (1) a patient as the protagonist, (2) a physician as the protagonist, or (3) no human protagonist. We formulated hypotheses on the presence, identity, and role of a human protagonist in disease stories, which we evaluated in a user study against a list of evaluation criteria from narrative visualization and health narratives. In summary, we make the following contributions:

- A human character-driven story structure for narrative visualization of diseases inspired by Campbell's *Hero's Journey* [Cam08].
- An analysis of the impact of different protagonists of a narrative visualization of disease on users.
- A set of evaluation criteria and concrete approaches for their measurement, bridging the space between prior work in the fields of narrative visualization and health narratives.

2. Related Work

Narrative medical visualization can be studied from two directions. The first direction is to review work about general narrative visualization and data storytelling. We pay particular attention to scientific and medical visualization. The second direction is to analyze science communication by hospitals, health organizations, and data journalists to educate people. We have carefully reviewed evaluation techniques to select a subset appropriate for the scope of this work, namely, assessing the influence of the protagonist of a disease story.

2.1. Background on Narrative Visualization

Foundational works identify narrative genres [SH10], narrative structures [HD11], narrative patterns [BSB*18], and the role of rhetoric to engage viewers [HDR*13]. Further visualization techniques for the presentation of data to a general audience are discussed by Robert Kosara [Kos16].

Visual data stories generally consist of four components, namely, *characters*, *conflict*, *content*, and *structure* [Dyk19, MGS*22]. *Characters* are not necessarily people but can be objects, too. In the story, they are confronted with a *conflict* they have to solve. The *content* of the story is built by introducing facts around this *conflict*. The story is organized according to a narrative *structure*. *Structures* can be classified as either being character-driven or plot-driven [YFM21]. The former closely follows a character through the course of different events (e.g., depicting inner conflicts and character development) while the latter focuses on building tension by creating a thrilling plot (e.g., depicting external conflicts and plot twists). A popular plot-driven structure is Freytag's Pyramid, which is based on Aristotle's Three Act Structure [Mad08]. It was used in many narrative visualizations [Dyk19, BG20, ARL*15] as well as in narrative medical visualizations [MGS*22, KSM*22]. Freytag's Pyramid consists of five acts being exposition, rising action, climax, falling action, and denouement. These acts describe the tension of the story. During exposition, the setting is introduced and the overall tension is low. Then, the action rises similarly to the tension until it comes to its maximum at the climax. Afterwards, the action is falling and the story ends with the tension being low again during denouement. Brent Dykes' storytelling arc [Dyk19] adapts the Three Act Structure for data storytelling. Yang et. al. [YXL*22] discuss how Freytag's Pyramid can be applied to create data stories. Another plot-driven structure is the CFO (Claim, Facts, Conclusion) pattern [Kos17]. However, these structures leave many open questions about the role and appearances of the characters. Therefore, we build our story on Campbell's *Hero's Journey*, a well-known character-driven structure. The *Hero's Journey* is a famous monomyth that describes typical stages a hero reaches throughout a story in chronological order [Cam08].

Furthermore, a story can present a narrative synchronously or asynchronously, i.e., with or without a narrator [LRIC15], which influences the user's role and agency in sharing the story. Narrative visualizations cover a spectrum ranging from author-driven to user-driven stories [SH10]. Author-driven stories combine a linear ordering of scenes with no interactivity to convey a clear message. With user-driven stories, the author has limited control of the user experience and the message they want to communicate. This relationship between user interaction and a pre-defined story is described as a *narrative paradox* [MLF*12]. We focus on structures that follow a predefined main story branch but offer interaction possibilities within, like the interactive slideshow [SH10]. Kleinau et al. [KSM*22] compared the genres slideshow and scrollytelling. The slideshow implementation was slightly preferred by the users. Roth et al. [Rot20] argued that slideshows give the author more control over the pacing of the story, preventing users from skimming through its content. On the other hand, pointing and clicking might become cumbersome and frustrating if the story is too long. Since our story is shorter than the visualization presented by Kleinau et al., which received positive user feedback, we chose to implement our story versions as slideshows.

2.2. Narrative Scientific Visualization

The area of narrative visualization concerning scientific visualization is hardly researched [TRB*18]. While there is some work done by NASA and in Science Museums [MLF*12], as well as in biological visualization [KSM*21], limited research on narrative scientific visualization exists. Wohlfahrt and Hauser [WH07] present an approach for storytelling with volume visualizations, focusing on how to balance guidance and interactivity. Although they employ medical volume data, they do not focus on informing about specific diseases and do not include other data types, such as 3D surfaces and slice images. Recent work explores preferences for the visual representation of biomedical scenarios of users with minimal and expert knowledge, focusing on the role of abstraction [GMF*21]. So et al. [SBŠ*21] mine social media data to create a story about different aspects of medical conditions for a general audience. Mörth et al. [MBS22] present a system for authoring narrative visualizations based on scrollytelling which incorporates means for the easy integration of scientific data such as volume data. A template for generating narrative medical visualizations related to diseases is suggested by Meuschke et al. [MGS*21, MGS*22]. They focus on how to present the main aspects of a disease comprehensively within a story.

Prior narrative visualizations of diseases have included human

characters either as realistic persons using photos [MGS*22] or as abstract stylized characters [KSM*22]. In both works, the protagonist is a patient affected by a certain disease. However, the influence of a patient as a protagonist is not investigated. Within disease stories, a physician would be another useful protagonist.

2.3. Science Outreach in Healthcare

Communicating medical findings to patients is part of the daily routine of physicians. They inform about, e.g., illnesses, medications, and vaccinations. In a broader sense, public health deals with the health of the general population and includes: "the art and science of preventing disease, prolonging life and promoting health through the organized efforts of society" [WHO22]. However, a distinction must be made between patient education and the education of the general population. When informing about diseases, patients are primarily interested in treatment options and prognosis, while the general population focuses more on prevention.

Communication in healthcare is important to enable self-determined decisions, e.g., regarding treatment choices or avoiding risk factors. Thus, medical institutions are searching for ways to better communicate with their patients. Students from the University of Tübingen create visualizations for the scheduling and decision-making processes of medical procedures [tue22]. Comics gained popularity in the field of *Graphic Medicine* [Wil12, AAF20]. The Charité in Berlin uses comics to improve patient education and investigated their effectiveness [BGH*19]. The German newspaper *Focus* uses videos to educate users about symptoms and prevention of common diseases, e.g., stroke [foc22b, foc22a], and employs slices and 3D renderings of medical volume data. However, handcrafted visualizations are still the most popular medium to promote health literacy [MRBK12, MvWHS15, HGPOBE20].

There are other works from medical research that are not targeting a general audience but are related to our work. Devi et al. [DKN*20] modeled a patient journey comprising of the steps a patient has to go through when being affected by a chronic disease. Another related concept is a clinical vignette specialized in oncology presented by Warner et al. [WMH*15]. Clinical vignettes are common in medical training, where a fictional scenario is described to measure a trainee's knowledge about a clinical situation.

2.4. Evaluating Narrative Visualization and Health Narratives

We focus on evaluation criteria that might be influenced by the use of different protagonists. Those are derived from health narratives, which are often text-based stories aiming to improve public health communication [BHS17], and narrative visualization [ABB*18].

A common goal of narrative visualization is to improve user engagement. O'Brien et al. identified six attributes of engagement and provided concrete questions to assess them [OT09].

Other evaluation criteria include identification with the protagonist as well as self-referencing (users transferring the events happening in the story to their own lives). Stories can be told from the perspective of different characters as well as using different points of view (POV). A POV describes the role of the narrator in a story. Many stories are either written in first person (e.g., through the eyes of the protagonist) or third person (through the eyes of an uninvolved narrator). Charles et al. [CPC10] showed how narrative variations can be generated by telling the same story from different characters' perspectives. Prior studies investigated the effect of the POV in health narratives regarding the user's identification with the protagonist [CBT17]. A high degree of identification can lead to self-referencing, which occurs when users connect the story's content to their own lives [CBT17]. While some studies found that the level of identification with the protagonist is higher for stories told in first person [NDRR14, NFM16], other researchers were not able to reproduce these findings and no study could show a connection between POV and self-referencing behaviors [CMB15].

Independent of the POV, protagonists can act as negative or positive role models. Chen et al. [CBT17] showed that users are more willing to identify with positive role models that followed the advice and managed to avoid negative consequences.

When communicating health-related topics, emotions play a major role in the persuasion of a narrative. The shift in emotion is called emotional flow. As such, the emotional flow is a key aspect to better understand the user's experience. The emotional flow in narratives was investigated by Alam et al. by measuring the shift between behavioral status and behavioral intention [AS20].

The perceived credibility of the information should be high. The Meyer modification of the Gaziano-McGrath scales [Mey88] is an established measure for credibility in online media and narrative visualizations [TVE10, TYI*15]. Credibility can be measured using different attributes, i.e., *accuracy*, *fairness*, *trustworthiness*, *bias*, and *completeness*. Questions on credibility can not only be applied to information in general, but to individuals and institutions as well [CP06, LBS*18].

3. Adapting Narrative Visualization for Disease Storytelling

While many scientific areas, such as mathematics and philosophy, feel abstract to a general audience, healthcare affects people personally. Thus, it is important to think about communicating risks appropriately. However, several studies show that most people tend to underestimate personal risks [WBK*12, WRBK12]. We aim at presenting the risks in a way that motivates personal changes to avoid negative outcomes without scaring users. In the following, we discuss the author's intent behind narrative medical visualizations and introduce our example of cerebral small vessel disease.

3.1. Narrative Intent and Health Promotion Goals

Prior narrative medical visualizations about diseases focus on a specific narrative intent, similar to the intents promoted in public health interventions [MGS*22, KSM*22]. Possible narrative intents for disease stories are:

- promote prevention, e.g., make lifestyle changes,
- promote secondary prevention, e.g., choose a healthier lifestyle after a disease was diagnosed,
- promote early detection, such as screening,
- convey coping strategies for how to get along with a disease where no known risk factors exist.

While some designers think visualizations should be neutral, Lee-Robbins and Adar [LRA22] argue that visualizations are never truly neutral and that neutrality is not always desirable. Instead, they propose to view the designer as a teacher and the audience as students and to formulate specific learning objectives accordingly. In medicine, the WHO employs health promotion strategies with clear intent. As an example, the World Blood Donor Day was introduced with the intent to motivate more people to donate blood [KKA*17]. On a smaller scope, physicians inform their patients and recommend treatment options as well as behavioral changes as part of their daily routine.

3.2. High Blood Pressure and CSVD: A Disease Story

We now discuss the medical scenario we chose for our story. Our main goal is to communicate that high blood pressure can lead to cerebral small vessel disease (CSVD), which strongly increases the risk of dementia. This message is supported by concrete data.

CSVD involves various conditions associated with damaged small blood vessels in the brain [WSB*13]. These damaged blood vessels cause further damage to the brain tissue. In the long run, CSVD can lead to motor and cognitive impairment and is a high-risk factor for dementia. CSVD occurs 6-10 times more frequently than stroke and is the most common incidental finding on brain scans [CŁDZP21]. While affecting a large part of the population, it is unknown to many people, making it a potentially impactful topic for scientific outreach. Furthermore, the prevention of CSVD can be done easily by maintaining a healthy lifestyle and regularly checking blood pressure. A challenge with choosing CSVD is that the mechanism of the disease remains unclear. However, we worked closely together with our clinical partner to present up-to-date information that is in line with the scientific consensus.

Many artistic media, e.g., hand-crafted illustrations, animations, and comics, are used to communicate medical topics (recall Sect. 2.3). Our goal, however, is to mainly present data-driven visualizations which allow to present state-of-the-art research to an audience with different levels of health literacy. However, in using data we face the challenge of combining medical volume data with tabular data and domain knowledge into an appropriate visualization. By creating disease stories, our goal is to provide a full image of the course of the disease including, e.g., symptoms, diagnostics, and treatment. However, the clinical data does not cover all aspects necessary to be communicated. These gaps are then filled using design elements like icons, textual descriptions, or annotations. Based on this observation, we identified three different types of content that are essential components of our disease stories:

- **Data-driven:** Content that is directly derived from the data.
- **Context-driven:** Content that cannot be derived directly from the data but represents common (domain) knowledge or information aggregated from multiple studies, often provided by the domain expert.
- **Character-driven:** Content that is based on a real or fictional human character, e.g., a domain expert or a person that is affected by the subject of the story like a patient.

Our clinical partner, who is a co-author of this paper, helped to review the content and discuss optimal presentation approaches. We aim at a general audience interested in medical topics. Presenting the data accurately may overburden users. However, oversimplification hampers the story's credibility. We chose to present information of the high-level relationships between different risk factors and the development of the illness in different parts of the body.

4. The Role of Characters in Disease Stories

While several studies investigate the influence of POVs or role models on the viewer, the protagonists in these stories are persons affected by a disease or its risk factors. However, a domain expert, e.g., a physician, is also a suitable protagonist in a disease story. The general influence of having a human protagonist is not yet known. We designed three story versions, keeping the general design of the story (e.g. colors and visualizations) the same, see Figure 1. We introduced the human protagonists using photos. Throughout the story, we mentioned them in the text of each view, and in the case of the patient, also with the help of icons. The full story versions can be viewed at Medical data stories.

Our main goal is neither a comprehensive explanation of the disease nor a design study of this specific example. Instead, we compare different protagonists and investigate their influence on established evaluation parameters such as user *engagement*, *identification*, perceived *credibility* of the information presented and perceived *length* of the story. We focus on the different protagonists and do not address the influence of:

- different numbers of characters,
- abstract (e.g. stylized/comic characters) vs. realistic (e.g. photos of real persons) characters,
- the POV (e.g., first-person vs. third-person), and
- the design choices made when creating the story, such as colors and visualization types.

4.1. Structure of a Disease Journey

We adapted the *Hero's Journey* and created a *disease journey* template for character-driven storytelling of diseases. This template describes how to incorporate the four main components of a story (*characters*, *conflict*, *content*, and *structure*).

The *Hero's Journey* presents three important *characters*: the protagonist and two supporting characters namely the mentor, and the antagonist. We already mentioned that the protagonist can be either human or an object (e.g., an organ) as long as the users can sympathize with them. The mentor can also either be a human, e.g., a physician giving advice to a patient, or an object, like a book. In the scope of a disease story, the antagonist is always the disease itself. The *conflict* arises between the protagonist and the antagonist. In our case, the protagonist has to face the antagonist in terms of being attacked by and fighting back against the disease. The *content* is defined by the stages of the disease journey and their order defines the *structure* of the story.

In general, the *disease journey* consists of three layers, see Figure 2. The **stages** of the disease journey describe the individual situations the protagonist has to face. They are arranged in a circle as the ultimate goal of the protagonist is to find a way back to their

(1) patient-centered **(2)** physician-centered **(3)** base condition

Figure 1: *Excerpts from the three story versions. We kept the overall design similar throughout all versions. In the brain visualizations, the damage caused by CSVD is highlighted in orange. The protagonists are included through text and, in the case of the patient, icons. The first row shows the introduction of the protagonists being the* ***(1)*** *patient and the* ***(2)*** *physician. For our* ***(3)*** *base story without a protagonist, we introduced the disease itself. In the second row, we use the phrases* ***(1)*** *"Emma, like 10% of female CSVD patients, is between 50 and 60 years old. About 20% of male patients are between 50 and 60 years old.",* ***(2)*** *"Ms. Schreiber observed that 10% of her female patients and 20% of her male patients with CSVD are between 50 and 60 years old.", and* ***(3)*** *"10% of female CSVD patients and 20% of male CSVD patients at the University Hospital in Magdeburg are between 50 and 60 years old.". In the third row, we used the phrases* ***(1)*** *"The MRI made it clear, that Emma really does have CSVD.",* ***(2)*** *"The MRI made it clear that one of Ms. Schreiber's patients really does have CSVD.", and* ***(3)*** *"The MRI made it clear, that this patient really does have CSVD".*

original life. These stages are divided in three **acts**: *departure*, *initiation*, and *return*. *Departure* describes how the protagonist is forced to leave their original life and start the journey. Meeting the mentor builds the transition to the second act called *initiation*. During *initiation*, the protagonist has to face the antagonist and deal with the main conflict. In the last act called *return*, the protagonist finds the way back to the *known world*. The division between *known world* and *unknown world* depicts the **context** of the protagonist's familiarity with the events. The protagonist has prior experience with the stages located in the *known world*, while stages located in the *unknown world* present unfamiliar events.

4.1.1. Patient-Centered Story Structure

In the first version of our story, we introduce Emma, a 59-year-old patient, as a fictional but representative protagonist. We describe in chronological order the common events that a patient experiences when diagnosed with a disease, see Figure 2, left. In this version, we depict the patient as a hero of a disease story, fighting against the antagonist being the disease. The patient is supported by one or more physicians acting as mentors. We do not introduce physicians as support characters, e.g., by giving them names or showing pictures of them, to make sure that all effects measured in the evaluation are caused by the protagonist.

The story starts in the **known world** with events familiar to the patient. During **departure**, the patient has to leave her **normal life** because of **symptoms** and **meets the physician**. During the **initiation**, the patient faces several stages in the **unknown world**. The patient has to undergo different **diagnostic** examinations and tests to receive a **diagnosis** and appropriate **treatment**. Finally, during **return** the patient re-enters the **known world** and **adopts** necessary lifestyle changes. After some time has passed, the effects of the **adherence** of the lifestyle, e.g., the disease becoming chronic or seeing a remission, can be assessed. The goal, in the end, is to return to **normal life** as far as possible. We end with a call for prevention by describing how the patient advises their family members to take preventive measures before the first symptoms occur.

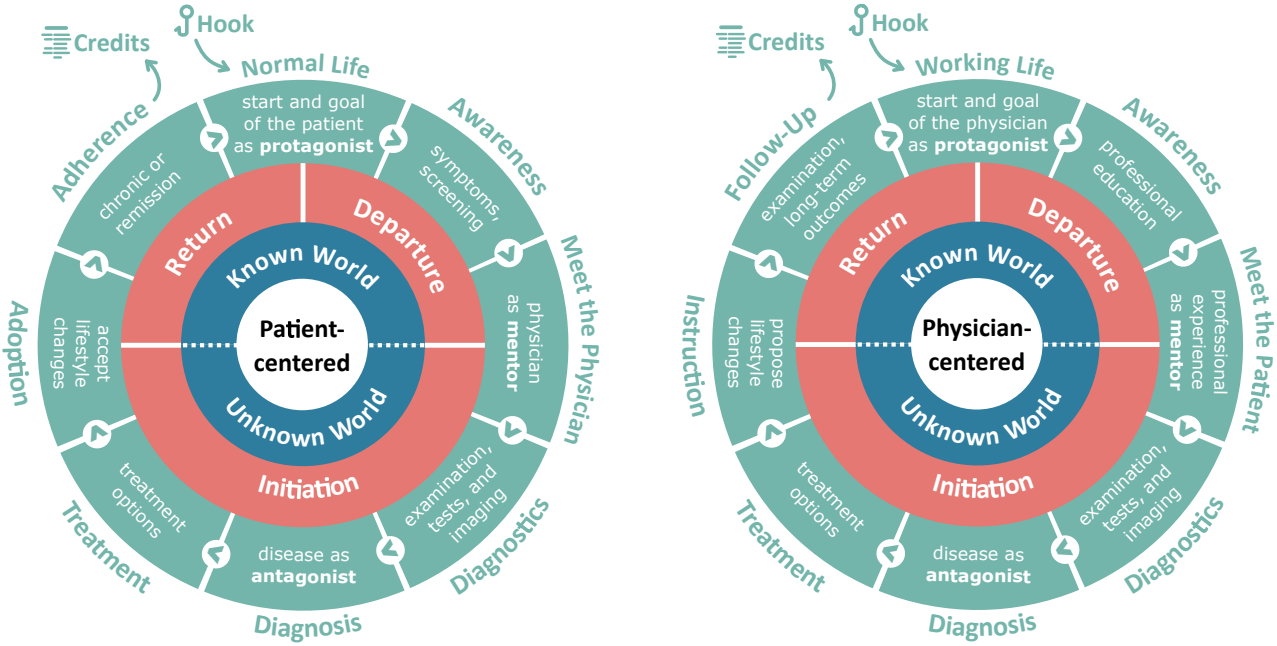

Figure 2: *The* disease journey *adapted from Campbell's* Hero's Journey *[Cam08] showing a structure for the patient-centered (left) and physician-centered (right) disease story. The structures depict the different stages the protagonist has to go through, dividing them in three acts, and putting them in the context of the protagonist's familiarity with the events. The story starts with a 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.*

While it would be possible to tell the patient's story from a first-person POV, we decided to use a third-person perspective. This way, all three versions are written from the same POV, making them more comparable. Furthermore, this structure has parallels to the narrative frameworks within the medical domain, see Section 2.3. The story is similar to patient vignettes, which are part of clinical vignettes describing a fictional patient. A patient vignette can easily be created by a domain expert to act as the basis for a patient-centered disease story following our proposed structure.

4.1.2. Physician-Centered Story Structure

We introduce our clinical partner, who is a neurologist with great expertise in CSVD, as the protagonist in the second version of our story. Similar to the first version we make the physician the only protagonist in the story. In many stages, the physician-centered story is similar to the patient-centered approach, see Figure 2, right.

Starting in the first act, **departure**, the story describes the **working life**, i.e., the clinical routine in the physician's **known world**. The physician became **aware** of the disease. When **meeting a patient**, the professional experience of the physician acts as a mentor. Since the disease can affect patients differently, the physician enters the **unknown world** at this point. During **initiation**, the physician triggers different **diagnostic** examinations and tests to be able to make a **diagnosis**. The physician proceeds by explaining **treatment** options. She **returns** to the **known world** by **instructing** a patient to adapt lifestyle changes. In **follow-up** examinations the physician can assess the long-term outcome of the disease by returning to her clinical routine. We end with a call for prevention from the physician explaining that preventive measures can protect against developing the disease.

4.1.3. Base Condition without a Human Protagonist

Our third story version is presented in the form of a report with no human protagonist. It serves as a base condition to compare the influence a human protagonist exerts on the perception of a disease story.

Meuschke et al. [MGS*22] propose a template for the storytelling of diseases derived from online health blogs. Similar to this story's version, these blogs inform about the course of a disease without any human characters. Many parallels can be found, the main difference being the order in which the information is presented. The template from Meuschke et al. starts with a broad definition of the disease, including statistical aspects and an anatomical overview. Afterwards, more detailed information about symptoms, diagnosis, treatment, prognoses, and prevention is presented.

We follow the chronological order in which patients have to face different stages of a disease. Therefore, we start with **introducing the disease**, followed by an introduction of the **institutions** that specialized in treating the disease. We then present an overview of common **symptoms** and **risk factors**. The **diagnostic** process is explained. After making the **diagnosis**, we **explain the disease** in more detail. We show a possible **development** over several years and how the condition can be improved by appropriate **treatment**. Furthermore, important **lifestyle changes** are highlighted. Similar to the other two versions, we end with a call for prevention.

Demographics					
Gender		Country		Age	
male	17 (57%)	Germany	21 (70%)	18-24	19 (63%)
female	11 (37%)	Norway	4 (13%)	25-34	6 (20%)
non-binary	2 (7%)	Other	5 (17%)	35-44	5 (17%)

Education and Literacy							
Education		Professional visual literacy		Professional health literacy		Experience with neurological diseases	
university degree	21 (70%)	SA	5 (17%)	SA	5 (17%)	SA	4 (13%)
high school graduates	6 (20%)	A	9 (30%)	A	3 (10%)	A	3 (10%)
middle school graduates	1 (3%)	N	5 (17%)	N	4 (13%)	N	8 (27%)
left school without a degree	1 (3%)	D	4 (13%)	D	8 (27%)	D	6 (20%)
completed training	2 (7%)	SD	7 (23%)	SD	10 (33%)	SD	9 (30%)

Table 1: *Demography and educational literacy of study participants. Other countries are Belgium, India, Iran, Spain, and Turkey, where one participant comes from each. Values to report the literacy of study participants follow a Likert scale: (SA) Strongly Agree, (A) Agree, (N) Neutral, (D) Disagree, and (SD) Strongly Disagree.*

5. Evaluation

In this study, we investigate the influence of the story's protagonist on the user based on common criteria from narrative visualization. Thus, we evaluate the user's engagement, identification and self-referencing, perceived credibility, emotional flow, and perceived time spent while interacting with the story.

Based on these criteria, we formulated five hypotheses. We assume that audience engagement can be increased by presenting a human protagonist inside a disease story (**H1**). This role can be played by an experienced physician as well as by introducing an affected patient. Furthermore, we investigate if the motivation to change the personal lifestyle is higher when viewing a story with a human protagonist compared to a base condition without any human protagonist (**H2**). We assume that members of a general audience likely identify most with a patient (**H3**). On the other hand, a physician as protagonist could make the information appear more credible (**H4**). Including a human protagonist makes a story longer, because personal character-related information needs to be added. However, we think that users are willing to spend additional time following the story of a human protagonist (**H5**). In summary, we formulated the following hypotheses:

- **H1:** Disease stories including a human protagonist are more engaging.
- **H2:** The motivation to change the personal lifestyle is higher when viewing a story with a human protagonist.
- **H3:** Users can identify the most with the patient as the protagonist leading to a higher degree of self-referencing.
- **H4:** Users rate the credibility of the information higher when it is presented by a physician.
- **H5:** Users are more willing to spend time viewing a story when they can follow a human protagonist.

5.1. Questionnaire Design

We used the software *SoSci* to design a digital questionnaire. Each participant was assigned to one of the three story versions and the questionnaire was presented to them right after viewing the story. Similar to most of the studies in narrative visualization, we also use five-point Likert scales to design the questionnaire. We included different sets of questions, each one measuring another criterion of the user's perception as described in the following. For further details, we provide the questionnaire as supplemental material.

Engagement. To measure engagement, we refer to O'Brien et al. who identified six attributes of engagement [OT09]. We excluded two attributes (*Aesthetics* and *Perceived Usability*), as they are not influenced by the protagonists. We evaluated the other attributes using statements based on the suggestions of O'Brien et al.: *Focussed Attention* (e.g., "I forgot about my immediate surroundings while viewing the story.", "I lost myself in the story."), *Novelty* (e.g., "The content of the story incited my curiosity.", "I felt interested in the story."), *Endurability* (e.g., "Viewing the story was rewarding.", "I would recommend viewing the story to my friends and family."), and *Involvement* (e.g., "I felt involved in the story.", "Viewing the story was fun.").

Identification and Self-referencing. We followed the guidelines of Chen et al. to measure the user's *identification* with the protagonist (e.g., "The main character and I are similar kinds of people.", "I like the main character in the story a lot.") [CBT17]. Identification is only applicable to our first two story versions containing human protagonists. Furthermore, we also referred to Chen et al. when measuring *self-reference* for all three story versions (e.g., "Do you think the story relates to you, personally?", "Did the story make you think about your blood pressure?").

Perceived Credibility. We used the Meyer modification of the Gaziano-McGrath scales to measure how high users rate the credibility of the information presented in the story. These scales ask the users to rate the credibility regarding *accuracy*, *fairness*, *trustworthiness*, *bias*, and *completeness*. Furthermore, we ask about the credibility of the human protagonists in the first two story versions.

Emotional Response and Emotional Flow. To measure the *emotional response*, we asked the users to rate their feeling after seeing the story using a 5-point scale ranging from extremely negative to extremely positive. The *emotional flow* was assessed by asking the users if they usually perform activities presented either as healthy

or harmful in the story (e.g., doing sports or smoking), called *behavioral intent*. In a second set of questions, we measured the behavioral intent by asking them to rate if they plan to do the same activities in the near future. This way, we followed the approach by Alam et al. to assess whether the presented information motivates people to change aspects of their lifestyle [AS20].

Perceived Time Spent in the Story. We ask the users if they would have *liked to know more* about the disease or the protagonists. This way, we assess if the users would be willing to spend more time in the story. We also asked if the story was *perceived as too long* and measured the *actual time* users spent viewing the story.

5.2. Participants

We recruited 34 participants using multiple channels. The survey was available online for two weeks. We posted the survey on the crowdsourcing platforms *Survey Circle* and *SurveySwap*, shared an invitation on dedicated groups on *LinkedIn* and *Reddit*, and contacted students of our university. Four participants who indicated they did not watch the story to the end were excluded. Two explained that the story did not catch their interest. Two others had technical problems because the story did not load properly in their browser. 30 data sets were left for evaluation. Seven (23%) of them viewed the patient-centered story, ten (33%) the physician-centered story, and 13 (43%) the base story.

The participants agreed that participating in the survey is voluntary and that we can use the resulting anonymous data for our study. The participants had the option not to answer personal questions.

Additionally, we collected the demographic background, general education and self-perceived literacy in visualization and medicine of the participants, see Table 1. The education was rather high with most of the participants having a university degree.

5.3. Results and Hypothesis Evaluation

We aggregated the results by calculating scores for the criteria, similar to [KLK19], see Figure 3. Thus, we took the averages of the questions for each criterion per story version. A score of 1 means that this criterion was rated low (disagreement). We chose another approach for emotional flow, since this criterion is supposed to show changes in the motivation to live a healthier life, see Figure 4. We calculated the difference between behavioral status and behavioral intent for each lifestyle aspect, and the average per story version was taken. To improve the readability of the plot, we inverted the scales for smoking and alcohol, since these are the only negative lifestyle aspects. This way, the plot shows positive differences (intention to choose a healthier lifestyle) and negative differences (intention to choose a more harmful lifestyle) for each aspect. Each criterion is used to evaluate one of our hypotheses.

(H1) Disease stories including a human protagonist are more engaging. The story versions performed differently in the individual attributes of engagement, see top part of Figure 3. While the stories with a human protagonist got noticeably higher scores concerning *focused attention*, *endurability*, and *involvement*, all three versions scored almost the same in terms of *novelty*. We assume that this result is due to the fact that participants were not familiar with CSVD and therefore the version without human protagonists aroused a similar level of curiosity. Therefore, we cannot make a general statement about engagement. However, we can see a tendency that stories with human main characters tend to have higher scores which are in line with our hypothesis.

(H2) The motivation to change the personal lifestyle is higher when viewing a story with a human protagonist. The average *emotional response* of the participants after viewing the stories was *neutral* for the physician-centered story and *positive* for the patient-centered and base stories.

The *emotional flow* differs between the lifestyle aspects, see Figure 4. We measured positive flow towards healthier behavior regarding a healthy diet, regular exercise, minimal alcohol consumption, and sufficient sleep for all story versions. We measured a negative flow towards harmful behavior for smoking.We cannot explain this result. The design of the questionnaire might leave some room for interpretation, e.g., users might interpret differently what terms like "on a regular basis" or "near future" mean. Therefore, future studies should allow participants to elaborate their decisions to support the interpretation of the results. Concerning blood pressure, the participants were asked whether they knew their blood pressure and if they planned to measure it in the near future. We assume that especially younger people (to which our participants belong) tend to assume that their blood pressure is okay and do not see the need to measure it. Rejecting our hypothesis, we cannot identify a general influence of human protagonists on the emotional flow. We assume that this is connected to the results of other studies showing that users tend to underestimate their personal risk leading to a low motivation to make lifestyle changes [WRBK12, SRS17].

The recommended lifestyle changes are generally known. Thus participants with a healthy lifestyle have probably adapted them before viewing the story. Since most of our participants were considerably below the age range where CSVD typically starts, the story might not motivate them to change their lifestyle, but rather to talk with their parents about the risks of the disease.

Furthermore, users might identify the hospital as main character in the base story. This would make the base story and the physician-centered story rather similar regarding the data being presented by a credible source, the only difference being the introduction of a concrete human character in the latter. While the patient is represented by the data (which is visualized by the patient's icon in the visualizations), the physician and the hospital act as presenters of the data. Therefore, the physician was mainly introduced using text instead of icons, which might lead to the physician-centered story being perceived as less character-driven as the patient-centered story.

(H3) Users can identify the most with the patient as the protagonist leading to a higher degree of self-referencing. Identification with the protagonists is generally low, see Figure 3. This could be due to the fact that participants were given little information about the characters, resulting in them being perceived as "flat". Since character-driven stories thrive on inner conflict and character development, human protagonists may be more relatable if they are presented as more complex characters. In contrast to our hypothesis, the physician got a slightly higher identification score. We also cannot see a higher identification of participants with similar demographic backgrounds to the protagonists, e.g., age and gender.

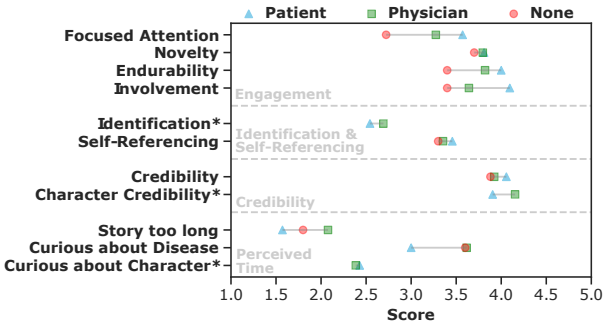

Figure 3: *The scores were determined by calculating the averages of all the answers for each criterion (separated by dashed lines) and story version. This way, we get scores for engagement, identification, self-referencing, credibility, and perceived time for each version. 1 means that participants strongly disagreed with the statement while 5 means they strongly agreed. Labels marked by an asterisk only apply to stories with human protagonists.*

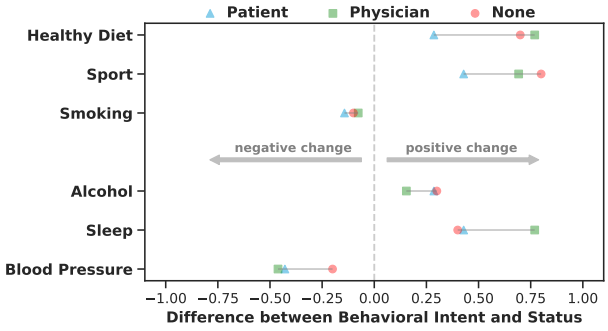

Figure 4: *The difference between behavioral status and behavioral intent averaged per story version. The results were inverted for smoking and alcohol to improve the readability of the plot. A positive difference means that participants intend to choose a healthier lifestyle option, and negative differences mean that participants plan to perform harmful lifestyle actions in the near future.*

We were able to measure a slightly higher degree of *self-referencing* in the patient-centered version, see Figure 3. It is possible that this result is due to participants having the feeling that *"this could be me"* with the patient as the protagonist, as the course of the disease presented seems more comprehensible when following a single character. This form of presentation is more in line with the participant's own experiences with diseases. On the other hand, the physician clearly speaks of several *"other"* patients, which could cause a feeling of *"that's them, it's not likely to happen to me"*. In summary, we cannot say that a high identification level results in a high degree of self-referencing. We can observe a slight tendency, that the self-referencing is highest for the patient-centered story although identification is highest for the physician.

(H4) Users rate the credibility of the information higher when it is presented by a physician. The credibility was rated similarly high for all story versions showing only a slightly higher score for the patient-centered story, see Figure 3 (cf. *Credibility*). This might be influenced by the institutions we showed during the story and in the credits. Since the participants knew that the story was created by a university, the university's clinic for neurology, as well as the German Center for Neurodegenerative Diseases, they likely rated the story content credible.

We asked the participants to separately rate the credibility of the human characters. There, the physician got a slightly higher score compared to the patient, see Figure 3 (cf. *Character Credibility*). While we cannot verify, that a physician as the main character increases the perceived credibility of the story, we can see that the physician was perceived as slightly more credible.

(H5) Users are more willing to spend time viewing a story when they can follow a human protagonist. The participants did not consider the stories too long, see Figure 3. The patient-centered story got the lowest score regarding the wish of participants to know more about the disease, see Figure 3 (cf. *Curious about Disease*). This could be because the patient's story is more likely to be considered complete after they have gone through the disease journey, whereas, e.g., the physician could tell more about her experiences with the disease (e.g., the course of various patients). Participants did not want to know more about the human characters, see Figure 3 (cf. *Curious about Character*). We cannot say for sure if that is caused by the protagonists being perceived as comprehensive enough or by not appearing to be interesting. However, since they are introduced only briefly, we assume the latter.

Additionally, we measured how long the participants stayed in the story. Participants spent less time in the base story (3:48min on average, range [1:29min, 6:42min]) compared to the patient-centered (4:47min on average, range [3:05min, 8:43min]) and physician-centered (4:48min on average, range [41s, 11:55min]) stories. Unrealistic short times can be caused by either participants not taking the survey seriously or because users accidentally closed the story and went through it again to get a participant ID at the end to continue the survey. We checked the validity of provided answers by making sure that users did not just select the same column in all questions. One participant entered a wrong ID, so we could not map the correct timing to this one case. The base story was slightly shorter due to the lack of character-specific information. However, this does not fully explain the differences in our measurements. Therefore, we assume that the lack of a human protagonist made users less willing to spend time with the story.

In summary, we cannot identify a difference in the perceived time spent in the story between stories with and without a human main character. However, we can see that participants were least likely to rate the patient-centered story as too long, which indicates that specific protagonists do have an influence on the user's perceived time spent in the story. Furthermore, we were able to measure that users spend more time in the character-driven stories, which supports our hypotheses.

6. Discussion

By including human protagonists in the narrative visualization of disease, our goal is to enhance health communication regarding the criteria engagement, identification and self-referencing, perceived credibility, emotional response, and emotional flow, as well as perceived time spent in the story. We evaluated three versions of a story about CSVD with different protagonists and discussed the results. In the following, we will discuss the limitations of this study as well as the lessons learned for the design of future disease stories.

6.1. Study Limitations

Our study has limitations, especially regarding representation. We evaluated different versions of a single disease story. Other disease stories, e.g., about cancer, might influence the user's perception in another way. Our story contains a lot of text, covering important aspects that cannot be conveyed through visualizations alone. Therefore, we are not able to say to what extent participants used the visual information. Furthermore, we focused on a subset of protagonists and one character per story. Other characters, such as family members and friends, might be similarly important. We acquired data from 30 participants. However, since every participant only viewed one story version, our results are based on a sample size per version, which is not statistically representative. Due to the study being held online, we were not able to assure similar numbers of valid participant responses for the story versions. Therefore, the number of participants per story varies greatly, being seven, ten, and 13 for the patient-centered story, the physician-centered story, and the base story, respectively. Furthermore, our participants have high literacy due to the platforms we used for acquisition.

We used the crowdsourcing platforms SurveySwap and Survey Circle where participants can answer surveys and, in turn, other users will answer their surveys. Twelve participants were acquired through these websites. However, we cannot say how many of them completed the survey. All other participants had an intrinsic underlying motivation (e.g., being asked personally) to take part in the study. Therefore, we cannot make statements about how users who come across the versions by chance, for example, while browsing the internet, would perceive them. Nevertheless, since the same bias applies to the participants of all story versions, the results are still comparable.

6.2. Lessons Learned and Study Implications

Overall, we were not able to derive definitive statements. However, we can clearly see different effects of the story versions on some criteria. Furthermore, we are able to derive new knowledge regarding the design of character-driven disease stories and their evaluations. In the following, we describe implications for future work.

(1) Increase engagement through human protagonists. We can see positive effects of human protagonists regarding most aspects of engagement on our users, which might be enhanced by more profound characters. Therefore, we recommend to include human protagonists in future disease stories.

(2) Create authentic characters. We are not able to see major differences in our story versions regarding identification. However, by that, we learned a lot about the creation of human protagonists for disease stories. Our focus was to include the protagonist in every view to let them drive the story. Thereby, we introduced them only briefly to not extend the story too much. At the same time, we expected the users to experience a more captivating story due to, e.g., identification. However, the characters were rather flat, likely making it difficult for users to sympathize with them. Since character-driven stories are brought to life by their protagonist, their character should be carefully presented in more depth. We are encouraged that users did not find the story too long.

(3) Build trust with your audience. The credibility of our story was perceived as high through all versions independent of the presence of a human protagonist. Therefore, we assume that showing that the story was created by reputable and trustworthy institutions has as much or even more influence on credibility as the presentation of a domain expert in our study.

(4) Telling the whole story. Even though the versions with human protagonists were the same length, we can see a noticeable difference in the users' assessment of whether the length was appropriate. Therefore, we assume that giving the user a feeling of telling a whole story (e.g., by following a patient through the course of a disease) is more important than the actual length of the story.

7. Conclusion and Future Work

We introduced two versions of a story structure for a character-driven design of disease stories. This structure allows to transform information about a certain disease, e.g., in the form of a patient vignette or blog post, into a story by presenting a template for the order of information and the inclusion of protagonists. This template could be used, i.e., in authoring tools that support creating disease stories. By comparing disease stories in terms of their protagonist, we sought to identify effects on the user's experience. Due to the limited sample size, we are not able to make definitive statements. However, differences between the story versions can be seen, implying that a disease story's protagonist has to be chosen carefully. Furthermore, we formulated lessons learned for the inclusion of characters in future disease stories based on our experiences.

Future studies are needed to investigate whether certain protagonists are particularly good at supporting specific intents of disease stories, e.g., which protagonists are best to convey information about prevention, screening, or coping. Additionally, a broader spectrum of disease stories can be used for such studies. Further studies could examine the effects of presenting multiple protagonists, e.g., patient and physician. Regarding identification, the influence of using realistic protagonists by including photos compared to stylized comic-like characters should be investigated. Disease stories might also target patient education, e.g., to prepare them for the consultation with a physician by giving an overview of treatment options. Therefore, additional studies are needed to investigate how the explanation of a disease needs to be adapted for patients.

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