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Narrative Agency and Patient Perspectives in Chronic Illness Stories within the Medium of Graphic Medicine

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Abstract: The article explores the application of graphic medicine as a device to tell chronic disease stories, and how it could present a different platform of narrative agency, and provide more narratives to patients. As a visual, written format, graphic medicine offers patients a unique means of narrating their lived experience, which is difficult to accomplish within the conditions of traditional healthcare discourse that has a tendency to belittle the voice of the patient. Through the analysis of the chosen works in graphic medicine, this paper will show that the medium makes patients take ownership of the stories of their illness, thereby encouraging them to become self-advocates and enhance the healing of their emotions. Furthermore, it is proven that graphic medicine can positively impact relations between patients and doctors, creating empathy and understanding, and changing the attitude of the population to chronic disease. The article points out the potential of graphic medicine in improving communication in healthcare, and it can be a valuable tool in patient-centred care and medical education. Still, it should be researched in the future to learn the particular effects of graphic medicine on various chronic diseases, how it can be applied in health education, and how it can be deployed on online platforms to support interactions with patients. This paper highlights how the concept of graphic medicine is revolutionary in transforming how chronic illness is represented, construed, and narrated in the medical profession as well as in the wider society.

Key Words: graphic medicine, narrative agency, chronic illness, patient perspectives, healthcare communication, patient empowerment, medical education

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Introduction

Graphic medicine is a new art form that combines visual art and storytelling to present health experiences, especially chronic diseases (Williams, 2012). It represents a fresh way of presenting difficult medical issues through integrating the emotional power of personal stories and the explanatory capacity of graphic novels (Ravi Kasthuri & Venkatesan, 2015). What is significant about this medium is that it may give a new perspective on the healthcare scenario, particularly through the perspective of the patient, which most medical narratives usually disregard (Hunter et al., 2015; Shah & Robinson, 2011). Graphic medicine allows more people to understand the experience of illness on an emotional and cognitive level since both graphics and text are used to make it relevant to more individuals (Kovan & Soled, 2023).

The paper is geared towards understanding the role of graphic medicine in the narratives of chronic illnesses and how it functions as a voice of patients (Penney et al., 2016; Dow et al., 2012). By combining art and narrative, graphic medicine will enable patients to tell their stories, emphasizing their experiences, challenges, and successes (Devi et al., 2020). This study analyzes how graphic medicine can enhance patient agency in the storytelling experience and provide them with the ability to redefine their own

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narratives and make a contribution to the body of knowledge about chronic diseases (Gonzalez-Polledo & Tarr, 2016; Frank et al., 2016).

Although graphic medicine has been an accepted practice in healthcare, few studies have been done regarding the use of this approach in letting patients own their stories (Delbene, 2024; Elf et al., 2017). This paper fills the gap in comprehending the role narrative agency plays in the narratives of chronic illnesses as a part of graphic medicine. What does graphic medicine do to enable patients to have control over the telling of their stories? What does it make the reader think about chronic illness and what the complications of living with chronic illness are?

The main aim of the paper is to examine the place of graphic medicine in the telling of chronic illnesses with a particular emphasis on the narrative agency that it provides to the patient. Through the analysis of graphic medicine works, the paper will seek to examine how these stories create a realistic depiction of chronic illness through the lens of the patient in a manner that creates empathy, education, and a general awareness among the populace.

The paper is structured in six parts: Section I presents the importance of graphic medicine to storytelling on chronic illnesses and the focus and aim of the research. Section II examines how graphic medicine can be used in health narratives, how it is defined, how it has evolved, and how it is narrated. Section II explores the role of graphic medicine in enhancing the patient voice, which allows patients to take charge of their illness narratives. In section IV, the effect of the narrative agency on patient-doctor relationships, healthcare communication, and perceptions of chronic illness among the population is discussed. Section V provides the qualitative research design, data collection, and data analysis approaches to be employed in the research. Lastly, Section VI ends with significant results and recommendations on healthcare communication and proposes future research.

Graphic Medicine and its Role in Health Narratives

Definition and Evolution of Graphic Medicine

Graphic medicine is the use of comics, graphic novels and visual story to medical experiences and health-related stories (Mittenentzwei et al., 2023; Thórarinsdóttir & Kristjánsson, 2014). The medium has been refined over the years, beginning with the primitive drawings of medical books and gradually gaining popularity, with the publications of authors such as Dr. Ian Williams, with The Bad Doctor, and Sarah Leavitt, with Tangles: A Story about Alzheimer's, my mom, and me. These books have demonstrated how graphic medicine can cause the reader to be interested in a peculiar combination of facts, emotional, and personal narration. Graphic medicine is a mixture of text and images in contrast with the traditional medical texts to reflect the multidimensionality of living with a chronic illness, a more holistic approach to the patient (Jowsey, 2016).

Visual and Narrative Techniques in Graphic Medicine

The power of the graphic medicine is grounded on the reality that it employs graphic methods to support the story (Chou et al., 2011). With written text and sequential art, storytelling becomes a dynamic process, the illustrations not only explaining the symptoms, treatments and emotions, but also the psychological and social impacts of chronic illness (Garden, 2010). These pictures can be able to mirror the inner struggles and sufferings and they can hardly be described in words alone. Emotional undertones and color play, use of panelling and symbolism contribute to its emotional appeal and help the reader to get a better idea of the experience of the patient in a more visceral way (Gonzalez-Hernandez et al., 2017).

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In such ways, graphic medicine is informational, but it is also compassionate and familiarizes the medical experience and makes it more inviting and familiar.

Table 1: Key Visual and Narrative Techniques in Graphic Medicine

Technique	Description	Impact on Narrative
Sequential Art	Comics and graphic novels use a sequence of panels to represent time, action, and development.	Permits the dynamic representation of the illness development and the time flow.
Use of Color	Colors are commonly employed to represent feelings, phases of a disease or mental conditions.	Increases the emotional interest and makes the readers identify with the feelings of the patient.
Panel Layout	Changing the pattern of the panel (e.g. size, shape, spacing) to show the change in tone or pace.	Affects the speed of the story, whether it is tense, calm, or urgent.
Symbolism	Visual metaphors and symbols are used (e.g., medical tools, body imagery) to symbolize illness.	Gives the story added depth, using layers of meaning to make the story more complex.
Text and Speech Bubbles	The combination of speech bubbles and captions with imagery is used to give internal and external dialogues.	Establishes a one-on-one contact with the inner world of the patient and his or her external relations.
Perspective and Angle	Perspective changes, including close ups or long shots to add emotional nuance or solitude.	Modifies the emotional effect of scenes, emphasizing the moments of vulnerability or empowerment.

Table 1 provides an overview of the visual and narrative tools used in graphic medicine, such as sequential art, color, panel layout, symbolism, text, speech bubbles, and perspective. The two methods assist in telling about the course of illness, emotions, and the interior world of a patient, and help to make the narration more interesting and complex.

The Concept of Narrative Agency

The control over the narration and interpretation of the story is narrative agency. The concept is vital in the field of graphic medicine since it assists patients to become narrators of their experiences. Traditionally, medical narratives have been dominated by the medical practitioner and their clinical knowledge and they have been able to command little room to incorporate the patient voice. Graphic medicine turns this paradigm around, letting patients express their disease, treatment and emotional experience in their own words. This telling of stories becomes a claim of agency whereby the patients can destabilize the tendencies of reductiveness of chronic illness in mainstream media. Graphic medicine is hence a good approach towards enabling patients to own their own stories and reclaim their identity not only their illness.

Patient Perspectives in Chronic Illness Narratives

The Role of Patient Voices

Graphic medicine is important in giving voice to the patients through a platform where they can share their first-hand experiences with chronic illness. Historically, patient voices are a peripheral aspect of the medicine and the medical practitioner has been the one to narrate the story. The patients of graphic medicine receive a chance to control telling of their stories to accentuate the personal and emotional connotations to the health experience. This shift provides the alternative of an in-depth, more personalized representation of chronic illness not only the physical expression of it, but the psychological, emotional,

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and social impact of it that is often overlooked. Graphic medicine First-person narratives enable patients to be likable and familiar to more people because the narrative of the first person humanizes patients.

Empowerment through Storytelling

Narrative empowerment is the most important element of the patient-involved aspect of graphic medicine. Agency of illness and its representation is reclaimed by the patients when they become the narrators of their own stories. The sense of control is particularly important to people who have chronic conditions which may be long-term, stigmatized or poorly understood. Graphic medicine helps patients to break stereotypes and societal beliefs about chronic illness. To illustrate this, in graphic medicine patients are able to illustrate the invisible aspects of their illness such as fatigue, pain or mental health issues, which are typically difficult to communicate using traditional medical means. This type of story-telling assists in the dismantling of obstacles between the patient and the population, allowing empathy and understanding.

Case Studies of Patient Narratives in Graphic Medicine

Several strong case studies on the role of patient perspectives in the story of chronic illness are presented in a number of high-profile publications in the field of graphic medicine. One such book is cancer vixen by Marisa Acocella Marchetto which describes the personal experience of the author when it comes to breast cancer treatment. By use of humor and vivid illustration, Marchetto is able to not only describe her physical experience but also the emotional and psychological reactions to her diagnosis and treatment. The other book is the book of Tangles: A Story About Alzheimer's, My Mother and Me by Sarah Leavitt, which is a touching story about how Alzheimer disease impacts on its victim and his/her family. These works are illustrations of how graphic medicine can empower patients and their carers to publicly describe their highly personal, often painful experiences in such a therapeutic and educative way to others.

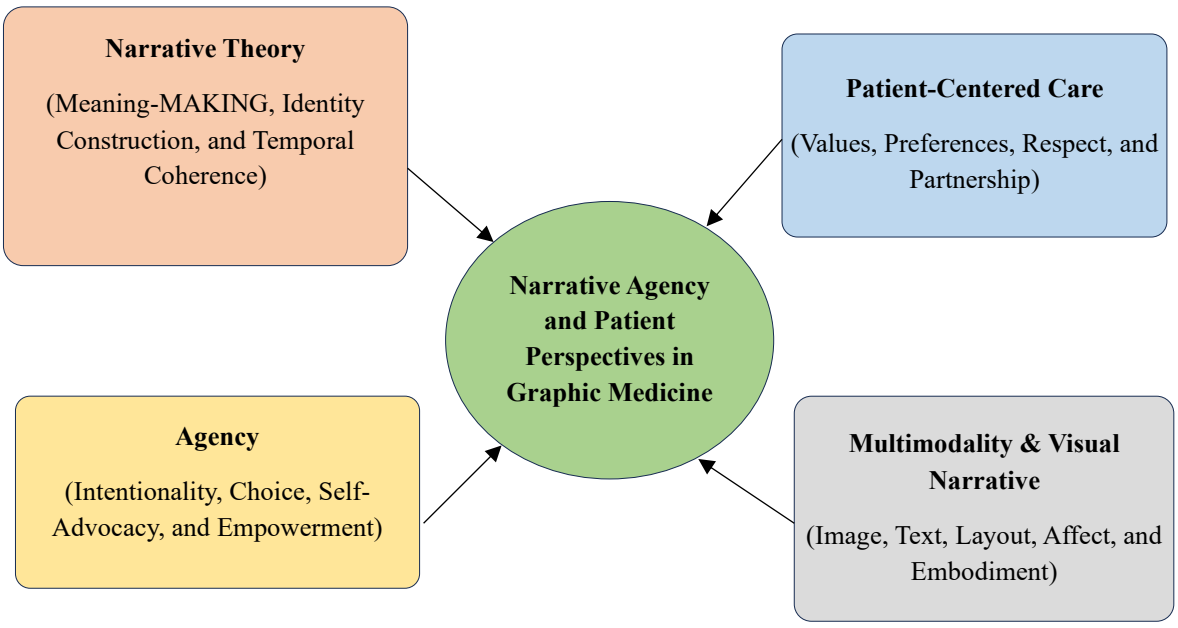

Figure 1: Theoretical Framework for Examining Narrative Agency and Patient Perspectives in Chronic Illness Stories within Graphic Medicine

The conceptual framework employed in this research to analyse the issue of narrative agency and patient views in graphic medicine is demonstrated in figure 1. It incorporates four major theoretical perspectives: Narrative Theory, which emphasizes meaning-making and identity building, and temporal

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coherence; Agency, which focuses on intentionality, choice, self-advocacy, and empowerment; Multimodality and Visual Narrative, which focuses on the interaction between image, text, layout, affect, and embodiment in graphic medicine. The framework will be used to connect these ideas with elements that can be seen in graphic medicine in order to better understand the ways that patient stories are made and conveyed within this medium.

Narrative Agency and its Impact on Healthcare Understanding

Agency in Healthcare Communication

Narrative agency in graphic medicine is important in transforming the structure of healthcare communication. Historically, the medical story has been controlled by the discourse of medical professionals and patients have traditionally been placed as passive consumers of healthcare services. Graphic medicine questions this top-down perspective by providing patients with a platform on which to take control of their stories, and to project themselves as active participants in the process of their own healthcare. By telling their stories as they perceive them, the patients are able to have agency over their stories, focusing on the physical expression of their conditions, emotional and psychological aspects of their conditions. This transformation can be used to humanise the patient and to place the voice of the patient at the centre of healthcare conversations, enabling the medical workers to be more empathetic and patient-focused in their communication with the patients.

Impact on Patient-Doctor Relationships

The use of narrative agency within graphic medicine can change the relationship between the patient and the doctor. Graphic medicine enables the patients to communicate their experiences graphically and textually to provide the healthcare provider with a more holistic picture of the life of the patient.

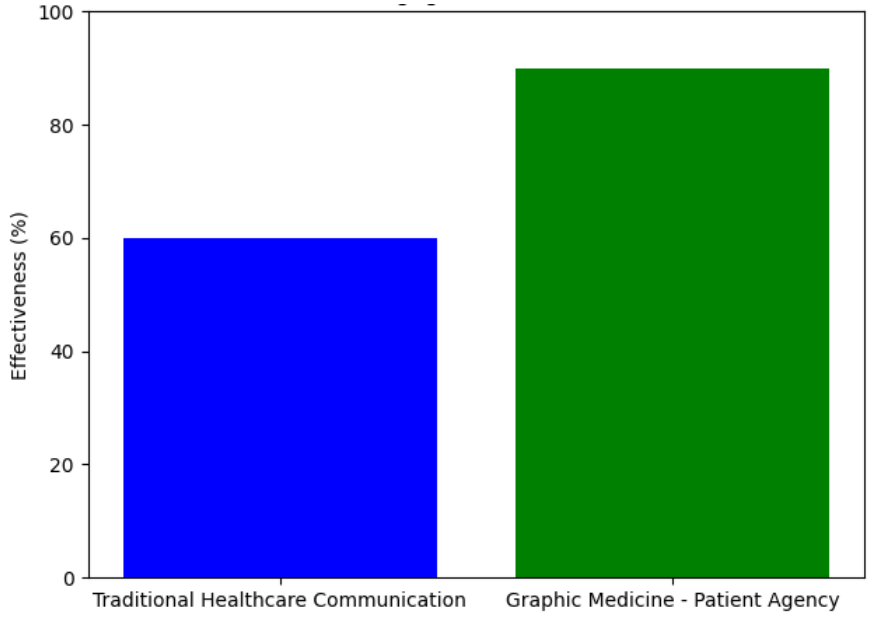

Figure 2: Effectiveness of Patient Engagement in Healthcare Communication

Such an in-depth knowledge can enhance communication between patients and physicians and lead to trust and empathy. Medical practitioners are able to understand the emotional and psychological aspects of an experience a patient goes through and these are not usually considered in the traditional medical

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evaluation. Patients become partners in the process of care and not subjects, which may result in more individualized and effective care as they assert their agency in storytelling.

Figure 2 makes a comparison of the effectiveness of traditional healthcare communication and graphic medicine in terms of patient engagement. The data sheds light on the greater efficacy of graphic medicine in facilitating patient agency and engagement in their healthcare stories.

Public Perception of Chronic Illness

Graphic medicine can help shape the perception of the masses about chronic illness. Humanizing chronic conditions, which are usually presented as abstract or purely medical issues, through the demonstration of individual stories of patients in a simple and engaging format, graphic medicine makes them more personal. The images and storytelling features of graphic medicine help readers to relate to the experiences of people with chronic illness and have an emotional reaction to it. By exposing this assumption, which most people hold about chronic illnesses, that it is only a disease that impacts only the physical aspect of an individual, these stories show the emotional, social and mental health issues that often come along with them. With such personal accounts being read, societal views of chronic diseases might change towards being more empathetic, understanding and supportive of the sufferers.

Methodology

Research Design

The research design of this study is qualitative research, in order to investigate the role of narrative agency in the story of chronic illness in graphic medicine. The qualitative method enables a detailed study of the role of graphic medicine as a stage of patient voices, both the textual and visual elements of the chosen graphic medicine works. The research focuses on the way the patients construct and disseminate their illness stories with a special interest in the agency, empowerment, and viewpoint themes discussed in terms of narrative analysis.

Participants

The participants of this paper will be a sample of graphic medicine products by patients or caregivers with chronic conditions. These writings consist of autobiographical stories and stories of caregivers, which give the reader an idea of what life is like with chronic conditions. The selection of the sample is based on the diversity of diseases the subjects cover, the different techniques of narration they employ, with the aim of exhausting the medium.

Data Collection Methods

The information is gathered by evaluating the graphic medicine texts. The texts will be selected based on their representation of chronic illness and use of narrative agency. It will be examined based on the close reading of both visual and textual elements of the stories and defining the ultimate structures of narratives, themes, and devices that offer the patient perspectives. Along with the analysis of the texts, the study involves interviews with the creators of the graphic medicine works, where possible, to learn more about the intentions, experiences, and the creative process of these narratives.

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Table 2: Sample Corpus of Graphic Medicine Texts

ID	Title	Author/Illustrator	Illness Focus	Year	Format
GM1	Hyperbole and a Half	Allie Brosh	Depression	2013	Webcomic
GM2	Marbles: Mania, Depression	Ellen Forney	Bipolar Disorder	2012	Graphic Memoir
GM3	The Secret to Superhuman Strength	Alison Bechdel	Autimmune	2014	Graphic Memoir
GM4	I Remember	Joe Brainard	Brain Tumor	2015	Graphic Memoir
GM5	Sick Girl	Amy Krouse Rosenthal	Cancer	2010	Memoir Comic
GM6	Chemo Girl	Emily Flake	Cancer	2012	Webcomic
GM7	Invisible	Megha Dukhar	Chronic Pain	2016	Graphic Memoir
GM8	Roller Girl	Victoria Jamieson	Anxiety	2015	Graphic Novel
GM9	Dear Katarina	Katarina Petit	Chronic Illness	2021	Webcomic
GM10	Gutless	Liesse Maveson	Crohn's Disease	2021	Graphic Memoir
GM11	Chronically Dolores	Dolores Cardenas	Chronic Illness	2022	Webcomic
GM12	Sarah Fawn Montgomery	Sarah Fawn Montgomery	Autoimmune	2023	Graphic Memoir

Table 2 includes 12 texts on graphic medicine, including the title, author/illustrator, focus of the illness, year published and format. The chosen works are between 2010 and 2023, and this is a range of chronic illnesses and forms of narratives.

UDL (Universal Design for Learning) Intervention

Besides the analysis of the works of graphic medicine as the main one, the concept of Universal Design of Learning (UDL) is also employed in the analysis of the way a graphic medicine can be used as a learning tool in the healthcare facility. UDL, as a concept focusing on accessibility and inclusivity, is used to analyze the means in which graphic medicine can be used to improve the learning process among various groups, such as patients, healthcare professionals, and the general population. This element of the research method examines the prospects of graphic medicine as a health literacy intervention, as well as an ethical instrument of healthcare education, empathy.

In Figure 3, the graphics of the sample medicine texts distribution can be seen according to the year of publication. It reflects the development of the genre throughout the years, but there is a significant rise in the number of publications between 2010 and 2013 and between 2015 and 2018.

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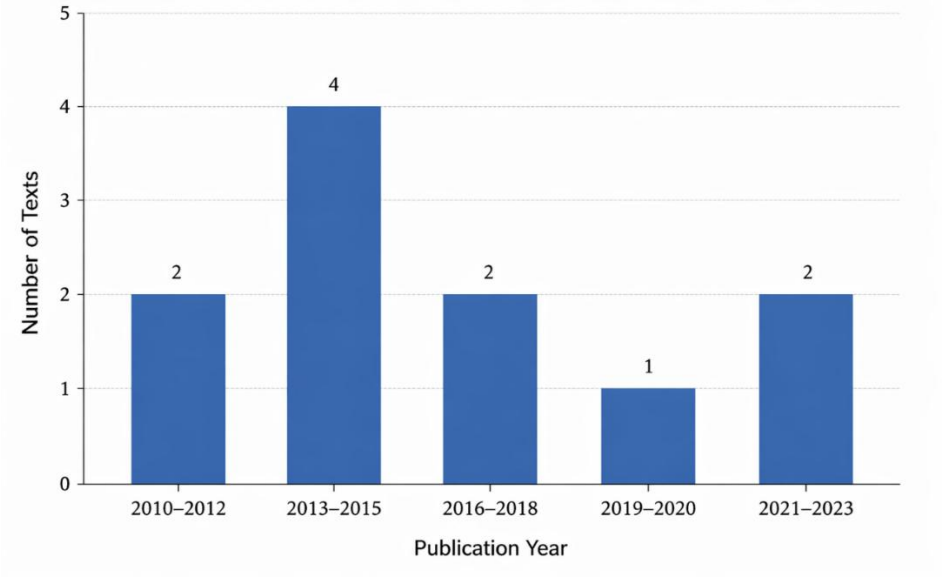

Figure 3: Publication Year Distribution of the Sample Corpus

Analysis

A multimodal discourse analysis framework will be employed to analyze the data, and it will take into account the visual and the textual aspects of graphic medicine. This method will allow for determining narrative strategies promoting patient agency and expression of patient views. A thematic coding process will also be performed in the analysis to reveal the repetitive themes like empowerment, identity, and the emotional impact of chronic illness. This analysis will be applied to the research questions and provide conclusions on the role of graphic medicine in the storytelling of chronic illness.

Conclusion

Graphic medicine provides a radical platform for the storytelling of chronic illness by enabling patients to tell their stories themselves, thereby increasing their agency and redefining the narrative of healthcare. The illustrations and the text would help to bring the graphic medicine closer to more people in a more advanced demonstration of the emotional, psychological, and physical sufferings of patients. The patient voices in the story process disrupt the top-down model of healthcare, whereby the patient has been a passive consumer of care. Graphic medicine, instead, makes patients active participants, which enables them to take charge of their stories and tell their own stories of sickness. This empowerment will not only help in the individual healing journey but will also improve communication between patient and healthcare provider, establishing empathy and understanding. Moreover, graphic medicine can alter the perception of people on chronic illness since it makes the patient more human and narrates their story to both inform and be part of an emotional appeal. The article has provided an understanding of the applicability of graphic medicine in enhancing healthcare services, patient-centered care, and shaping society's perception of illness. Future studies should focus on the impacts of graphic medicine on various chronic diseases and how it may be implemented in healthcare education, particularly to enhance empathy, health literacy, and the relationship with patient providers. Given the fact that this medium is still being developed, it has given patients greater opportunities to be involved in the healthcare process, as well as medical professionals to gain insight into the problem of living with chronic illness.

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