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## The Ethics of Drawing Illness: Interdisciplinary Negotiations in a Participatory Graphic Narrative Project

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### Abstract

This paper illustrates how the design of health-related comics contributes to reflecting on the methodological and ethical challenges of qualitative research. In line with Comics-Based Research (CBR), we demonstrate how creating a comic on medical topics emerges from continuous and iterative dialogue among multiple voices: patients, sociologists, artists, and physicians. On an ethical and methodological level, our study explores the creation of a comic book about pancreatic diseases with varying stages of severity and possibilities for cure and recovery. Constructing a comic in such contexts provides a new way of visualizing and understanding the illness experience. Representing traumatic memory in comics can profoundly affect readers and those whose memories are depicted, while also helping researchers to amplify the voices of individuals whose experiences have been marginalized or misunderstood. Our goal was to create a product that was both a graphic memoir based on true stories and a scientific and informative resource. However, the graphic novel was not merely a tool for disseminating research; it was the central focus of our project, with all aspects designed around this medium. This included the development of interview protocols and the selection of participants, ensuring that the process remained aligned with the principles of participatory and co-constructed storytelling.

### Keywords

comics-based research, graphic medicine, ethics, reflexivity, interdisciplinary

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# The Ethics of Drawing Illness: Interdisciplinary Negotiations in a Participatory Graphic Narrative Project

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This paper illustrates how the design of health-related comics contributes to reflecting on the methodological and ethical challenges of qualitative research. In line with Comics-Based Research (CBR), we demonstrate how creating a comic on medical topics emerges from continuous and iterative dialogue among multiple voices: patients, sociologists, artists, and physicians. On an ethical and methodological level, our study explores the creation of a comic book about pancreatic diseases with varying stages of severity and possibilities for cure and recovery. Constructing a comic in such contexts provides a new way of visualizing and understanding the illness experience. Representing traumatic memory in comics can profoundly affect readers and those whose memories are depicted, while also helping researchers to amplify the voices of individuals whose experiences have been marginalized or misunderstood. Our goal was to create a product that was both a graphic memoir based on true stories and a scientific and informative resource. However, the graphic novel was not merely a tool for disseminating research; it was the central focus of our project, with all aspects designed around this medium. This included the development of interview protocols and the selection of participants, ensuring that the process remained aligned with the principles of participatory and co-constructed storytelling.

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## Introduction

In the sociology of health and medicine, illness is not merely a biomedical condition but a multifaceted experience embedded in both social and cultural dimensions (Conrad & Barker, 2010). This perspective challenges reductionist and mechanistic views, framing illness as a dynamic phenomenon that evolves alongside historical, social, and scientific developments. The ways in which illness is understood and represented are shaped by implicit societal agreements, making it not only a personal experience but also a socially negotiated construct central to sociological inquiry (Barker, 2010; Conrad & Barker, 2010).

From a sociological standpoint, illness is profoundly influenced by everyday interactions, cultural narratives, and broader societal frameworks that shape patients' lives and relationships (Pope, 2020; Williams, 2021). Beyond the practical challenges of symptom management, the social construction of illness determines how it is perceived and often stigmatized. Goffman's seminal work on stigma (1969) highlights how illnesses that are not immediately visible or remain poorly understood subject patients to social labeling, marking

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their bodies as “deviant” within dominant norms. This stigmatization adds layers of psychological and social burden to an already complex experience.

In this context, alternative narrative forms such as graphic novels and comics offer valuable ways to represent marginalized voices and complex illness experiences. These mediums provide a communicative space that traditional academic and clinical discourses often fail to capture (Moretti, 2023a). By merging visual and textual storytelling, graphic narratives allow for nuanced explorations of illness, presenting it as both a medical condition and a lived experience shaped by cultural and social forces.

The intersection of graphic novels and social research has gained increasing attention, particularly in health-related fields. Scholars such as De Stefano et al. (2023), Barberis and Grüning (2021a), Alamalhodaie et al. (2020), and Short et al. (2013) emphasize the role of graphic social science in incorporating comics into research beyond academia, fostering engagement with diverse audiences through communication, education, and advocacy. Situated within Comics-Based Research (CBR; Cancellieri & Peterle, 2021; Kuttner et al., 2021), graphic narratives have been recognized as effective tools for both data collection and dissemination. Their ability to bridge the gap between scientific discourse and public understanding makes them particularly valuable in addressing complex health-related issues.

With this article, we aim to contribute to the growing body of literature on Comics-Based Research by focusing on its ethical, methodological, and epistemological dimensions. Specifically, we explore how co-creating comics with patients diagnosed with pancreatic diseases challenges conventional research paradigms, fostering a more participatory and inclusive approach to illness representation.

First, we present the methodological foundations of our study, outlining how Comics-Based Research operates as a participatory framework that integrates patient narratives into visual storytelling. By drawing on the principles of Graphic Medicine and multimodal qualitative research, we demonstrate how co-constructed comics facilitate nuanced, emotionally resonant portrayals of illness experiences.

Second, we discuss the ethical implications of participatory research, emphasizing the tensions between representation, agency, and vulnerability. Ethical challenges arise at multiple levels, from the negotiation of narrative authority to the emotional and temporal complexities of depicting progressive illnesses. By conceptualizing ethics as an iterative and dialogic process, we argue for a more reflexive and responsive approach to research ethics in graphic social science.

Third, we analyze the broader implications of visual storytelling for healthcare communication and social science research. Comics not only offer an alternative means of engaging patients, caregivers, and medical professionals but also function as a space for counter-narratives that challenge dominant biomedical discourses. By merging the principles of narrative-based medicine and participatory social science, this study illustrates how comics serve as both a research tool and a transformative medium for knowledge production.

Through this exploration, we aim to highlight the methodological potential of comics while critically reflecting on the ethical and epistemological considerations that emerge in participatory graphic medicine. In doing so, we contribute to ongoing discussions on the role of visual methodologies in health research, advocating for a more inclusive and co-creative approach to studying and representing illness narratives.

### **Co-Creating Illness Narratives**

The integration of comics into health-related research has emerged as a powerful methodological approach that transcends traditional qualitative techniques (Williams, 2012). By merging artistic expression with narrative inquiry, Comics-Based Research (CBR) fosters

a participatory and multimodal form of knowledge production. This approach not only enhances the communicative potential of health narratives but also reconfigures the researcher-participant dynamic, enabling more inclusive and co-creative engagements. From a methodological perspective, Graphic Medicine (GM; Williams, 2012) provides a framework for investigating the intersection of medicine and visual storytelling. GM emphasizes the therapeutic and reflective potential of comics, highlighting their capacity to convey illness experiences in accessible, empathetic, and emotionally resonant ways. This multimodal approach enhances research by fostering deeper engagement with patients, caregivers, and healthcare professionals (De Stefano et al., 2023; Kara & Brooks, 2020; McNicol, 2019).

Within this framework, researchers can employ graphic pathographies—narratives that document illness experiences—or graphic memoirs of trauma in several ways: (a) by inviting participants to illustrate or annotate their experiences; (b) by integrating sketches, drawings, or graphic notes into the research process; (c) by collaborating with professional artists to visually represent research findings; and (d) by co-constructing graphic narratives as part of an iterative, participatory research process (Sassatelli, 2024). Among these approaches, co-creating graphic novels stands out as an innovative method that blends traditional qualitative research with creative, participatory techniques. It reimagines research as a collaborative endeavor involving patients, healthcare professionals, social care workers, artists, and sociologists.

The co-creation process reflects what Barberis et al. (2021b) define as the EthnoGraphic Novel, a graphic memoir or pathography grounded in qualitative data, designed to amplify real-life stories while addressing ethically complex issues. This approach is inherently dialogic, requiring researchers and participants to co-decide how to “write through images” (Barberis et al., 2021b; Mutard et al., 2022; Ware, 2004). By doing so, it transcends traditional barriers of reticence and bias, enabling participants to articulate deeply personal and often stigmatized experiences in ways that are both socially and emotionally accessible.

Previous studies have demonstrated the effectiveness of participatory action research in engaging diverse groups in the co-creation of comics as a research tool (Cederved et al., 2022; Kuttner et al., 2021; McNicol, 2019; Villar & Johnson, 2021). This method fosters empathetic, self-reflective dialogue between patients, caregivers, healthcare professionals, and artists. By facilitating collaboration with “hard-to-reach” communities, it enhances emotional and social understanding while offering therapeutic benefits at both individual and collective levels (Chen & Jhala, 2023; Moretti et al., 2025). Furthermore, the act of co-creating graphic narratives provides a meaningful space for participants to reflect upon and process their lived experiences.

While graphic narratives often depict fragmented life stories, they serve as a powerful entry point for examining the social and cultural dimensions of illness. Unlike conventional research methods that seek to document objective truths, comics embrace imagination and abstraction to capture complex emotional realities. Through visual storytelling, participants can structure and express experiences that might otherwise remain disconnected or unspoken (El Refaie, 2010; McNicol, 2014).

This method provides an alternative framework for representation that transcends biomedical and cultural categorizations (De Souza, 2004; Silva et al., 2017; Ulanowicz, 2011). Ultimately, the use of graphic novels and comics in social research fosters a space for inclusive, empathetic, and participatory storytelling, allowing researchers and participants to co-create knowledge that is both meaningful and impactful.

## **Methodology**

This study adopts a qualitative approach to explore the experiences of patients affected by pancreatic diseases, integrating their voices into an innovative research framework that

emphasizes the co-construction of knowledge through comics. By embedding patients as co-creators in the development of illustrated narratives, we challenge the traditional power dynamics between researcher and participant, fostering a more egalitarian space for meaning-making (Kuttner, 2015).

Between June and August 2023, we conducted in-depth, semi-structured interviews with six patients experiencing diverse pancreatic conditions. While a sample size of six may appear limited by conventional research standards, it aligns with qualitative research approaches that emphasize depth over breadth, particularly within participatory and co-creative methodologies (Creswell & Poth, 2018; Pope, 2020; Tracy, 2010; Villar & Johnson, 2021). In this study, participants were not merely interviewees but actively engaged in the co-construction of the final research output, a process that required intensive collaboration, iterative dialogue, and sustained engagement (Patton, 2015; Riessman, 2008). This methodological choice reflects the principles of information-rich case selection, where fewer participants allow for deeper exploration of individual experiences and the development of nuanced, contextually rich insights (Denzin & Lincoln, 2018; Smith et al., 2014). The interviews were arranged in collaboration with the healthcare professionals involved in the study, ensuring that participants were adequately informed and comfortable with the research aims. While most interviews took place in person, one was conducted online due to hospitalization, and another was conducted at the participant's home to accommodate his health condition. The sociologist and a medical professional were present in nearly all cases, ensuring both methodological rigor and ethical sensitivity (Chan et al., 2015).

The participants<sup>2</sup> and their respective conditions are summarized in the table below:

**Table 1**

<i>Participant</i>	<i>Condition</i>	<i>Interview Mode</i>	<i>Additional Details</i>
<i>Karl</i>	Acute Pancreatitis	In-person	-
<i>Francesco</i>	Chronic Pancreatitis	In-person	-
<i>Monica</i>	Cystic Tumor	In-person	-
<i>Elisabetta</i>	Cystic Tumor	In-person	-
<i>Stefano</i>	Pancreatic Adenocarcinoma	In-person	Interview at home due to condition
<i>Paolo</i>	Neuroendocrine Tumor	Online	Hospitalized at the time of interview

The interviews followed an open-ended structure, allowing participants to shape their narratives, emphasizing the aspects of their illness that they deemed most significant (Hyvärinen, 2019). Beyond medical symptoms, they were invited to discuss their emotional, social, and existential experiences. They also had the opportunity to include details about their relationships with family members, caregivers, and friends, highlighting the broader social ecology of illness (Mattingly, 2019).

A fundamental aspect of this research is that the comic was not merely a medium for collecting or disseminating data but the core around which the entire study was designed. This approach required a significant methodological shift: instead of treating comics as an auxiliary tool, it became the central object of inquiry, shaping research questions, participant engagement, and the analytical framework itself (Sousanis, 2015).

This methodological stance demanded that every phase of the research—from interview structuring data analysis and final representation—be tailored to suit the construction of the

<sup>2</sup> Four out of six participants chose to use their own name in the stories.

comic. Participants were not only involved in telling their stories but also in actively shaping the illustrated narratives. They contributed to key decisions regarding the depiction of their experiences, such as color choices, levels of abstraction, and symbolic representation of medical conditions. Moreover, they were consulted on how their stories should conclude, ensuring that each narrative carried a message that resonated with their personal journey and perspective.

These discussions allowed for continuous reflection on the representation of patients' experiences, balancing artistic interpretation with narrative fidelity. In addition to structured meetings, ongoing communication with the patients was maintained at various stages of the creative process. This iterative engagement ensured that participants had opportunities to review, modify, and provide feedback on the evolving visual narratives.

The sustained interaction between researchers, artists, and patients extended beyond data collection, persisting through the production phase until the final publication of the comic, which was released approximately one year later, in the summer of 2024. The comic strip was co-designed using patient-based qualitative research. In all stages of research and comics construction, the multimodal design (McNicol, 2019) approach echoes the specific characteristics of comic jam (Herd et al., 2020), i.e., the involvement of a range of expertise in addition to patients, created an interaction between expertise in a participatory and iterative process.

## **Reflexivity**

Reflexivity is a critical practice in qualitative research, allowing scholars to examine their positionality and its influence on the research process (Markham, 2020). In this study, reflexivity was particularly relevant due to the highly interdisciplinary nature of the team, which included sociologists, medical professionals, artists, and patients. This diversity enriched the research but also introduced epistemological and practical tensions that shaped both ethical considerations and data interpretation.

One of the key challenges involved balancing subjective illness narratives with biomedical accuracy. Sociologists aimed to preserve the richness of patients' personal experiences, while medical professionals prioritized providing correct health information to the audience. Similarly, the artistic team brought an aesthetic and symbolic dimension to the project, which at times conflicted with the research team's goal of faithful representation. These negotiations required continuous mediation to ensure that the final product was both visually compelling and true to the lived experiences of participants.

A distinctive feature of this study was the unprecedented level of involvement of patients in the interpretation of findings. Unlike traditional research, where data analysis is typically researcher-driven, patients actively shaped how their stories were represented, requesting modifications or adjustments to ensure alignment with their personal experiences. While this participatory approach empowered participants, it also introduced reflexive challenges, as researchers had to relinquish some interpretative authority and engage in ongoing negotiations of meaning (Finlay, 2002).

The co-construction of the graphic novel exemplifies "collaborative reflexivity" (Arvey, 2003; Lyle, 2009; Pope, 2020), where multiple actors with different expertise engaged in iterative discussions and adjustments. This process challenged conventional researcher roles, requiring sociologists to act as mediators between medical professionals, artists, and patients, adapting their methodological stance to accommodate diverse perspectives. Ultimately, reflexivity in this study was not merely a theoretical concern but an active, evolving process that shaped every stage of the research.

## **Ethical Consideration**

The research proposal was approved by the Bioethical Committee at Bologna University, meeting institutional and federal ethical guidelines. Participants were fully informed about the study's objectives, methodology, and potential risks, with interview completion considered as implied consent, a standard practice in qualitative health research (Hammersley & Traianou, 2012; Wiles et al., 2007). Given the participatory nature of this study, ethical considerations extended beyond interviews. Informed consent was also obtained from all individuals visually represented in the final graphic novel. To protect confidentiality, names and identifying details were anonymized unless explicit permission was granted. Participants could withdraw at any time or request changes to their representation before final publication. Special attention was given to the emotional impact of revisiting illness experiences, emphasizing an "ethics of care" approach that prioritized participant well-being and agency throughout the research process (Branicki, 2020; Clark et al., 2010).

## **Data Analysis**

The collected data consisted of multiple sources, ensuring a comprehensive and multi-perspective analysis. These included transcribed interviews with patients, field notes recorded by researchers during the creative process, meeting discussions with medical professionals and artists, and final reflections and exchanges with patients. This diverse dataset allowed for a richer understanding of both the experiential and interpretative dimensions of illness narratives.

Following the principles of Grounded Theory (Glaser & Strauss, 1967), the data were systematically analyzed through an iterative coding process. Key themes and patterns emerged inductively, allowing theoretical insights to be grounded in the lived experiences of participants rather than imposed a priori. The integration of different types of qualitative data strengthened the depth of the analysis, capturing not only the individual illness trajectories shared in interviews but also the collaborative dynamics that shaped the co-construction of the graphic novel.

## **Results: Navigating Ethical Boundaries**

Through our analysis of the results, three key ethical aspects emerged as central challenges in participatory comics-based research: (1) the researcher's role in participatory storytelling; (2) the emotional and psychological impact of reliving illness experiences through visual storytelling; and (3) the ethical considerations related to audience reception.

### **The Researcher's Role in Participatory Storytelling**

One of the first ethical challenges involves the emotional intensity of interviews. Participants were not merely recounting experiences; they were reliving moments of vulnerability, knowing that their words will be visually interpreted and made permanent in a drawn form. This weight of permanence makes the act of sharing more emotionally charged, as reflected in a field note from an early interview: "At the beginning, he was hesitant. 'I'm not sure how to tell this story,' he said. It wasn't just about talking—it was about knowing that what he shared would be drawn, turned into something permanent" (Research's field note, Interview 2).

Creating a space of trust and emotional safety was therefore essential. Interviews were structured to allow participants to express themselves freely without pressure to conform to

predefined narratives. However, this process occasionally blurred the boundaries between research and emotional support. One researcher reflected on the ongoing nature of participants' engagement beyond the interview setting:

She thanked me after the interview, saying it felt good to talk. But later, she sent a message with more details, things she had forgotten to say. I realized that for her, the conversation wasn't over—even though, from a research perspective, it should have been. (Research's field note, Interview 3)

A particularly challenging aspect of this research was the transition from spoken words to drawn images. Unlike text, where meaning can remain fluid and open to interpretation, the act of visually representing a participant's experience requires making definitive choices about what will be depicted and how. This process sometimes caused discomfort among participants, as they were confronted with a version of their story that felt more "fixed" than anticipated.

During storyboard review sessions, participants provided feedback that led to significant revisions in their visual representations: "This moment was hard for me, but I don't want it to seem overly dramatic. It was painful, yes, but not like this" (Meeting notes, patient feedback 6).

Another critical issue was temporal framing. While traditional illness narratives often include reflections on past, present, and future experiences, some participants preferred to remain in the present, avoiding speculative depictions of what lay ahead. This preference was especially pronounced among those with chronic or terminal illnesses: "I can tell you what happened, but I don't know what comes next. I don't want to imagine a future I might not have" (Interview 5).

This concern led to ethical discussions within the research team about how to handle the depiction of future trajectories in the graphic novel:

R1: Should we leave the last page open-ended?

R2: Open-ended for the reader, or for the participant?

R3: If they don't want to see their future imagined, we shouldn't impose it.  
(Meeting notes, researcher discussion)

The necessity for continuous ethical reflexivity became apparent as researchers worked to ensure that the act of representation did not override participants' agency. This process extended beyond methodological concerns, highlighting the emotional labor required of researchers in participatory storytelling. Unlike traditional qualitative research, which often maintains a clear boundary between researcher and participant, this study required ongoing interactions, follow-ups, and revisions that deepened researchers' emotional involvement.

For some, this meant navigating complex relationships with participants who saw them not just as facilitators but as trusted confidants. This emotional burden occasionally extended beyond the research setting:

After we finished the interview, he kept messaging me about the project and about his health. It felt like he needed to stay connected. At some point, I wasn't sure if I was responding as a researcher or just as another person he could talk to. (Field note, Interview 2)

To manage these dynamics, the research team implemented structured debriefing sessions, providing researchers with opportunities to reflect on their own emotional engagement and develop strategies for maintaining professional boundaries while upholding the trust established with participants.

### **Centering Participants: Ethical Considerations in Comics-Based Research**

While much of the ethical discussion in participatory research focuses on the responsibilities of the researcher, it is equally important to consider the ethical dimensions that impact participants. The transition from verbal storytelling to visual representation introduces distinct challenges, particularly in relation to emotional well-being, autonomy, and the evolving nature of illness experiences. Through interviews, field notes, and research meetings, two primary concerns emerged: the emotional toll of revisiting traumatic experiences and the logistical complexities posed by participants' clinical conditions.

Participants, particularly those sharing deeply personal or medical narratives, often oscillated between a desire to tell their stories and the emotional burden of re-engaging with difficult memories.

Some participants initially approached the project with enthusiasm but later found the process more taxing than expected. As one participant reflected: "I didn't expect to feel so much while seeing my story take shape. It made me reflect in ways I hadn't anticipated" (Interview 4).

Another described how the act of seeing their experiences illustrated added a layer of emotional immediacy: "Looking at my story in images made me realize how much has changed since then, both in my experience and in how I see myself" (Interview 6).

Given the emotional weight of this process, the research team noted several instances where participants required additional time before continuing. A field note recorded: "The participant took some time before continuing, mentioning that the drawings brought back strong emotions" (Field note, Interview 6).

This highlighted the need for a trauma-sensitive research approach, ensuring that participants had control over when and how they engaged with their narratives. In a research meeting, one team member raised the question: "Should we build in mandatory reflection periods, where participants can pause before deciding whether to proceed?" (Meeting notes, researcher discussion).

To address these concerns, the team implemented flexible pacing strategies, allowing participants to pause, revisit, and modify their narratives at their own comfort level.

The ethical dimensions of informed consent in comics-based research extend beyond standard qualitative practices. Unlike written narratives, where textual anonymity can be preserved, participants in this study were not only narrators but also visual subjects. The act of being drawn and depicted in a fixed form raised concerns regarding self-representation and identity.

Several participants expressed uncertainty about how they would be visually portrayed. One interviewee remarked: "I wasn't sure how I would be represented visually, and that made me feel a little uncertain at first" (Interview 2).

This concern prompted the research team to introduce an additional review stage, where participants could provide feedback on their illustrated representations. This ensured that their likeness aligned with their self-perception and personal comfort levels.

While some participants found the process cathartic, others felt more vulnerable, prompting discussions on how to create an "exit strategy" for those who wished to disengage at any point. A research team member noted: "We need to make sure participants have an exit

strategy—ways to disengage or pause when needed, without feeling pressured to complete their narratives” (Meeting notes, researcher discussion).

To mitigate concerns, the team developed an adaptive consent framework, which allowed participants to modify, update, or withdraw elements of their stories at different research stages.

Beyond emotional concerns, another key ethical challenge involved the practical limitations faced by participants with progressive illnesses. While many were eager to contribute, worsening health conditions sometimes made sustained engagement difficult. One field note captured such a case: “The participant was eager to share their story, but as their condition worsened, follow-up conversations became increasingly difficult” (Field note, Interview 5).

In response, a team member suggested adapting the research workflow: “We might need to create a phased validation system, so that if a participant is unable to continue, we still have a version of their narrative that they approved” (Meeting notes, research discussion).

For participants with chronic conditions, the challenge was ensuring that narratives remained representative of their evolving experiences. One participant noted: “I feel comfortable sharing this now, but I wonder how I’ll see it in the future” (Interview 3).

This raised broader discussions about transparency in participant-driven storytelling and how best to reflect the fluidity of lived experiences. The research team debated whether to include an acknowledgment of narrative shifts in the final publication: “If a participant’s situation changes dramatically, should we include a note in the final publication acknowledging this shift?” (Meeting notes, researcher discussion).

To address these concerns, the team adopted a flexible storytelling approach, treating narratives as evolving representations rather than fixed accounts.

### **Ethical Dimension of Reaching General Audience**

Beyond the ethical considerations surrounding researcher-participant dynamics, another crucial challenge was how to communicate illness narratives to a broad audience while preserving both the uniqueness of individual experiences and the scientific accuracy of the information provided. This balance proved complex, as each illness journey is distinct, making it difficult to craft messages that resonate universally.

One primary concern, reflected in field notes, was the risk of overgeneralization. Some participants worried that their experiences might not be representative and feared that readers would assume their journey applied to all individuals with the same condition. As one participant expressed: “I know my story is just one example, and I hope people don’t assume it applies to everyone” (Interview 1).

This raised the challenge of balancing specificity with broader accessibility, ensuring that personal stories retained their authenticity while remaining relevant to a wider audience.

The multiplicity of audiences added another layer of complexity. Readers included patients, caregivers, healthcare professionals, and the public, each with different expectations and ways of engaging with the material. Some found comfort in relatable experiences, while others sought more medical guidance. A research team member reflected on this discrepancy: “Some patients found comfort in seeing an experience similar to theirs, while others wished for more factual guidance about their condition” (Meeting notes, researcher discussion).

This highlighted the tension between storytelling as a means of empathy-building and its role in medical education. The challenge was ensuring that the comic provided both an emotional connection and accurate medical information, without compromising either aspect.

Internally, the research team debated how much medical detail to include. The collaboration between medical sociologists, physicians, and artists revealed different

perspectives on how to strike this balance. As one researcher noted: “We had discussions about how to present medical facts without making the story feel like a textbook.” (Meeting notes, researcher discussion).

Meanwhile, an artist involved in the project emphasized: “Our goal was to maintain the authenticity of the patient’s voice, but we also had to ensure the information was clear and responsible” (Meeting notes, artist discussion).

Thus, narrative integrity and factual reliability had to be continuously negotiated, ensuring that neither over-medicalization nor emotional oversimplification distorted the participants’ lived experiences.

Beyond textual concerns, ethical questions extended to visual representation. Decisions about color schemes, panel arrangement, and artistic style influenced not only emotional perception, but also readability and accessibility for diverse audiences. A field note captured an internal debate: “Would using darker tones for hospital scenes make them appear too distressing? Should we depict medical equipment in detail, or would that alienate readers unfamiliar with these devices?” (Field note, research discussion).

These considerations had profound ethical implications: How much should be shown? How should emotions be conveyed visually? The team recognized that visual choices could shape audience perceptions of illness experiences, influencing how narratives were understood and empathized with.

To navigate these challenges, the team adopted an iterative review process, incorporating multiple rounds of feedback from medical experts and artists. This helped maintain scientific accuracy without compromising the deeply personal nature of each story.

Rather than attempting to craft a single, universally relevant message, the research team ultimately embraced a multi-layered narrative structure. This approach allowed for different forms of engagement—some readers would connect primarily on an emotional level, while others would focus on the medical aspects. By designing the graphic novel to function on multiple levels, it became a tool for both education and reflection.

## Discussion

In this section, we delve into the ethical dimension of participatory action research, reflecting on its role as a cornerstone of social research involving graphic illness narratives. Building upon the theoretical and methodological premises outlined earlier, this discussion examines how ethical considerations intersect with the co-creation of knowledge in health-related research. Specifically, we explore the challenges and opportunities of employing a participatory and collaborative approach in projects that engage patients as active contributors, highlighting the implications for both the research process and its outcomes.

In the context of participatory research, ethics moves beyond compliance with formal regulations and becomes an active, iterative negotiation between researchers and participants (Czerwiec et al., 2015; Lategan, 2014; Parsons et al., 2021). This perspective aligns with the ethical considerations discussed earlier, emphasizing that co-creation in graphic medicine requires an ongoing dialogue that accounts for power dynamics, vulnerability, and the representation of illness experiences (Dicé & Zoena, 2017; Lupton, 2021). Researchers must navigate tensions between respecting participant agency and ensuring the integrity of the knowledge produced, particularly when dealing with sensitive health-related narratives.

In the field of health sociology, attention to ethical considerations is particularly critical (McAleese & Kilty, 2019; Surmiak, 2020). Research involving participants in health-related projects often requires revisiting traumatic or painful experiences, imposing an emotional burden that must be carefully managed (Martineau et al., 2020; Schofield et al., 2021). Selvakumar and Kenny (2021) underscore the importance of an “ethics of care” in such

contexts, which prioritizes: (1) respect for participants and their lived experiences; (2) recognition of their dignity, rights, and autonomy; (3) transparency in communicating research objectives, ensuring participants are fully aware of the implications of their involvement and can withdraw at any time without negative consequences; (4) confidentiality and anonymity; and (5) the use of appropriate methods and tools to safeguard participant well-being while minimizing risks, harm, or discrimination (Hammersley, 2015; Martineau et al., 2020; Schofield et al., 2021).

Reflecting on ethics in health sociology research also involves addressing what Cribb (2022) refers to as the “implicit normativity” underlying empirical work. This approach aims to mitigate uncertainties and potential impacts that empirical activities may have on participants. Fieldwork conducted by sociologists in medical contexts often raises ethical concerns stemming from, for example, tensions between findings that emerge during research and a critical perspective on medical practices or existing regulations, which may influence decisions perceived as “fair” (Anspach & Mizrachi, 2006; Dalla Nora et al., 2016).

Building on these studies, this contribution focuses on the role of ethics in participatory action research involving graphic illness narratives. Specifically, ethical considerations must permeate every phase of such research - from design to implementation and dissemination. As noted by scholars (Lategan, 2014; Parsons et al., 2021), even the most complex research relationships can stimulate co-creation of value and individual and collective well-being. This reflection must address strategies to break down traditional barriers between researchers and participants while ensuring participants play a central role in the decision-making process behind the creation of the graphic narrative.

Here, we propose to conceptualize ethics as a participatory approach, emphasizing the mutual responsibility of researchers and participants to engage actively with one another and with the broader research context. Within this framework, both researchers and participants collaborate in the co-creation of knowledge, as opposed to its extraction. Traditional narratives in social research have often been dominated by clinical or scientific perspectives, sidelining the emotions, daily struggles, and authentic voices of patients. By involving patients directly in the creation of a comic, a collaborative space is established where their voices, experiences, and perspectives are valued equally alongside those of the researchers. Through storytelling, patients can articulate not only the physical symptoms and emotional, social, and psychological dimensions that affect their well-being but also the complex challenges they face. This process of co-construction contributes to a more authentic and comprehensive representation of the ethical challenges tied to illness narratives, integrating scientific, personal, emotional, and visual dimensions.

Expanding on this notion, we argue that participatory ethics in creating graphic illness narratives reconfigures the epistemic hierarchies that traditionally characterize qualitative research. By repositioning patients as co-creators rather than passive subjects of study, the research process transcends the conventional observer-observed dichotomy (Kapofu, 2021; Marvasti, 2014; Rosvik, 2024). This epistemological shift aligns with the principles of contemporary participatory and decolonial methodologies, which critique the extractive nature of knowledge production and advocate for more equitable research paradigms (Banks & Brydon-Miller, 2018). In this context, participatory ethics operates not merely as a set of procedural guidelines but as an ongoing relational practice that demands continual negotiation, reflection, and adaptation.

However, adopting a participatory approach to ethics presents several challenges. First, in the context of research, fostering engagement does not eliminate the vulnerability associated with illness. This vulnerability must be addressed and adapted throughout the research process (McNicol, 2023). Czerwiec et al. (2015) introduce the concept of “graphic pathographies” which illustrate how shared experiences often require less formal spaces to encourage open

dialogue, flatten hierarchies, and promote greater openness to research. The presence of vulnerability does not necessarily negate agency; rather, it necessitates an ethics of care that prioritizes emotional safety, autonomy, and consent as evolving rather than static elements of participation (Banks & Brydon-Miller, 2018).

Second, the co-creation process involves empathetic and responsible negotiation between parties. For example, when working with participants facing critical clinical conditions, such as pancreatic cancer, the uncertain and often limited future may pose challenges in determining which temporal dimensions to prioritize within the comic. The ethics of temporal representation in graphic medicine is complex: should narratives emphasize retrospective reflections, immediate lived experiences, or imagined futures? Each choice carries ethical weight, affecting how participants relate to their own stories and how readers interpret illness as a temporally bounded or fluid experience. These concerns echo broader debates in narrative ethics regarding whose voices are privileged in constructing illness discourses (Charon, 2017; Loy & Kowalsky, 2024; McAleese & Kilty, 2019).

Finally, the medium itself presents limitations: as these stories are inherently individual, it becomes difficult to generalize a unified message to other patients, given that every illness experience is unique and deeply personal. While some critics may view this as a limitation, we argue that the strength of participatory graphic medicine lies precisely in its resistance to homogenization. Instead of producing a singular, standardized narrative, co-created comics offer polyvocal accounts that acknowledge and preserve the plurality of illness experiences. This aligns with qualitative research traditions that value depth over breadth, prioritizing the richness of individual narratives over statistical generalizability (McNicol, 2023).

At the same time, this participatory ethical approach also offers significant advantages. By co-creating a shared pathway of visual storytelling through the dual channels of words and images, the graphic medium highlights the potential to embed communication about pathological conditions within a broader social context. Comics serve as a tool for mediating and "repairing" understanding, enabling reflection on personal illness experiences in a voice closer to the patient's and their families' everyday reality. Moreover, the visual component of comics fosters accessibility, bridging gaps between medical discourse and public understanding in ways that textual narratives alone often struggle to achieve (McNicol, 2023).

By merging the approaches of narrative-based medicine and graphic illness narratives, participatory ethics aims not only to amplify the voices of patients and families within the care process but also to empower them to reflect on the implications of their participation in research. This approach transcends traditional top-down ethical frameworks based solely on consent and confidentiality, instead encompassing the entire construction of meaning and promoting inclusivity in the study of illness (Kaźmierska, 2020; Žydzūnaitė, 2018).

## Conclusions

This study highlights the potential of graphic illness stories as an innovative and participatory approach to exploring illness narratives. By integrating sociological, artistic, and medical perspectives, we have demonstrated how graphic storytelling can foster a more inclusive and co-constructed representation of illness experiences.

A key contribution of this research is its emphasis on participatory ethics, which goes beyond procedural compliance to actively engage with the complexities of representation, narrative agency, and audience reception. By adopting a multimodal methodology that merges textual and visual storytelling, this study underscores the value of comics as a medium that facilitates knowledge production, emotional engagement, and public communication in health-related research.

Moreover, the findings suggest that co-creating illness narratives through comics has implications beyond individual storytelling. It serves as a tool for fostering dialogue between patients, healthcare professionals, and researchers, contributing to a more empathetic and socially attuned understanding of illness. The ethical considerations discussed in this study reinforce the importance of ongoing reflexivity, iterative collaboration, and shared decision-making in participatory research.

### **Limitations of the Study**

While this study offers valuable insights, it also raises important questions about the broader applicability of Comics-Based Research in the field of health sociology. The participant selection process may have introduced bias, as those involved were primarily individuals enthusiastic about the project, potentially excluding perspectives from patients less willing or able to participate. Additionally, assessing the actual impact of Comics-Based Research on knowledge production remains challenging, requiring further studies to measure its influence in academic and clinical settings. Lastly, the co-creation process demands sustained engagement, which may not always be feasible for patients with severe or progressive conditions. Future research should further investigate the long-term impact of graphic narratives on knowledge production and patient engagement, as well as explore how this methodology can be adapted to different medical and social contexts.

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