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Variante*

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nouvelle variante*

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Illness Narratives in AI-Generated Images: Toward a Theory of a New Variant

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Susana de Noronha

Introduction

- 1 Why should artificial intelligence (AI) image generators and their application in the depiction of illness narratives matter to social scientists and societies? AI is now undeniably a reality pervading our daily lives, from science and technology to the arts (Lanzeni, 2022). AI develops within a discourse of improvement, built on the promise of low-cost accessibility, efficiency, and productivity, with a focus on decision-making through data-informed insights and the automation of repetitive tasks, promising faster and more accurate results. However, the advantages and problems emerging from the “datafication of society” (Pink, 2018) – that is, the collection, accumulation, and use of vast amounts of data by AI systems – are being extensively analysed across various scientific fields, attesting to AI’s multifaceted ontology and agency.
- 2 AI image generators are promoted within a similar boundary-pushing discourse, offering users a personalised exploration of an unconventional and constantly evolving aesthetics, allegedly redefining the limits of creativity and expression. Through human-AI collaboration, they enable experimentation with diverse artistic concepts, styles, and techniques, by selecting preferences and generating “unpredictable and novel outcomes”. Yet, issues such as copyright infringement, the spread of misinformation and fake content, the misrepresentation of specific groups (Hakopian,

2023), and cultural appropriation are just a few of the challenges affecting their accuracy and fairness, undermining transparency and accountability. Moreover, since datasets are neither neutral nor free from bias, and are shaped by a “coded gaze” (Buolamwini, 2023), AI may amplify inequality, reinforcing discrimination, exclusion, and erasure, and perpetuating stereotypes related to race, gender, age, and ability (Benjamin, 2019; Broussard, 2023; Crawford, 2021; Elam, 2022; Noble, 2018; Stypinska, 2023).

- 3 While the providers of AI image generators use the notion of the unexpected and the improvised – significant traits of conventional artistic approaches – the workings of algorithms and machine learning models are nevertheless different. The number of text-to-image AI generators now reaches several hundred, with Bing Image Creator, DALL-E, Leonardo Ai, Midjourney, Nightcafe, Stable Diffusion, and starryai frequently appearing on lists of recommended applications. Sustained by and learning from large sets of pre-existing images, the artificial agency of text-to-image generators is partly achieved through visual patchwork. Critics – reopening, within new contours, former discussions about “ready-mades”, “*objets trouvés*”, or even collage – argue that these images are simply transformed replicas, amounting to plagiarism, where notions of creativity, craftsmanship, technical skill, originality, authorship, copyrights, and ownership cannot be applied.
- 4 However, “words do things” (Austin, 1962), and although agency is partly mediated through a machine, these images come into existence through the heterogeneous input of humans: “prompts” – instructions in written format that guide the algorithm towards the image envisioned by the user. Writing this sequence of instructions – describing the subject or content, setting or context, art form, style, lighting, colours, and framing – is a detailed process, requiring one to learn how to write effective prompts to avoid failed or unsatisfactory images. This skill takes time and practice, or can be acquired through learning from others, or even with the aid of an AI prompt builder or generator. Users must also adapt to the filters and restrictions of AI generators concerning sexually explicit content, depictions of violence and gore, the use of hate speech or offensive material, and (in)sensitivity to cultural and religious beliefs, among other guidelines. There are also downloadable tools, such as NMKD Stable Diffusion GUI, Automatic1111, and FreedomGPT Medusa, that, unlike the most commonly used platforms, allow uncensored and unfiltered outputs, bypassing ethical content limitations. While several apps are available for free, others require paid subscriptions, with monthly plans ranging from € 10 to € 120, depending on the generator and the options for basic, standard, or advanced/professional use – a choice that obviously impacts image quality.
- 5 AI image generators can also function as enhancement tools (image-to-image generators), transforming and/or blending images created and uploaded by the user, such as photographs, paintings, and drawings, allowing an intersection of media and methods (Santaella, 2022). Additionally, specific AI image generators offer applications for live or real-time drawing, enabling users to roughly sketch and then refine and upgrade their images online. Fostering a more ethical form of co-creation, users can also curate a dataset of their own creations and use it to train the AI generator model, enabling it to learn their visual language, and generate new images that reflect one’s individual aesthetics and creative approach. Additionally, users can download images from these AI-based generators and further work with them through digital

manipulation or collage, or by printing them onto paper as surfaces for material intervention – drawing, painting, cutting, and reassembling – thereby adding new layers of human agency to this collaboration. Taking these specifications into account, “there are no simple, uninteresting, or insignificant objects, only simplistic and uninterested readings” (Noronha, 2015, p. 19). The ongoing controversy will not change the fact that part of our experiences, ideas, and imagination is now taking form – not on canvas or paper – but through AI-generated images, powered by algorithms.

- 6 The expression “unpredictable outputs”, commonly used to define AI-generated images, has a deeper parallel meaning. While the potential applications of AI image generators as expressive and interventive tools for people with illnesses and related disabilities (mental, neurological, autoimmune, chronic, non-communicable, degenerative, among others) are beginning to surface in news articles, online journals, magazines, and art and technology blogs, emerging scientific research and literature remain largely inattentive to the impact of generative AI on the transformation of illness narratives.

1. Illness narratives have a story of their own

- 7 Illness narratives – defining illness as the personal, cultural, and social experience of living with a disease or physical disorder – are embedded in sociocultural patterns that shape what can be said and shown (Gwyn, 2002; Mattingly, 2001). “Regarding the pain of others” (Sontag, 2003), social sciences are not exempt from these patterns, but by reflexively confronting their own biases, roots, and rules, anthropology and sociology have continually sought to explore different realities as change has emerged in society and science. As a research topic, illness narratives have a story of their own. Words – their substance, potential, and agency – were at the core of our earliest inquiries and analyses. In the effort to understand illness and expression, or the patient’s “explanatory model” (Kleinman, 1988), these insights were often gained through structured conversations, where researchers controlled the dialogue with a predefined set of questions, following their own concerns. The proliferation of illness narratives in literary non-fiction, written by patients or survivors, urged social scientists to acknowledge and make sense of stories whose authors had their own agendas. Diaries and essays authored by scholars, poets, feminists, and activists became central to discussions, sparking increased interest in scientific analysis (Armstrong-Coster, 2005; Diedrich, 2007). Additionally, a growing body of literature began to explore the potential of autoethnography, as researchers chose to tell the stories of their own illnesses (Frank, 1995; Jain, 2013; Paget, 1994; Sedgwick, 1999; Stacey, 1997; Stoller, 2005). Situated between science and autobiography, the focus of these reflections and analyses remained on words, whether spoken or written.
- 8 However, a story can also be told without words, using a different language – such as a sequence of images or a single image that can encapsulate an entire illness experience (Noronha, 2009, p. 45). Although research on illness narratives in the visual arts is still intermittent and limited, it is gradually expanding, leading to publications where HIV-AIDS, cancer, mental illness, and, more recently, COVID-19 take prominence (Bell, 2006; Bolaki, 2016; Engelmann, 2016; Morcate and Pardo, 2022; Noronha, 2009, 2015, 2019; Sagan, 2014). The naked body and its parts, from its external openings to internal organs, enduring extreme conditions of pain and suffering– but also subtle and blatant

visual metaphors and their multiple meanings – materialising the intimate and the private, are recurring elements in images that have found their place in galleries, books, art magazines, and websites, reaching and impacting the community.

2. Entering the field: Two decades of illness narrative research

- 9 In the last two decades, art-based illness narratives achieved a new level of sociocultural impact with the use of digital and online media, where they are shared and proliferated. The internet has thus become one of the most prolific contexts for the public display of these stories. Cancer is, undoubtedly, one of the most frequently depicted health conditions in these artworks and projects, motivating my own contribution to the discourse on illness narratives in the visual arts. Following a digital ethnography approach (Kozinets, 2009) – assembling and analysing a wide-ranging international list of artistic narratives displayed on the internet, and examining not only the images but also the accompanying texts or discourses when provided – my previous work aimed to respond to a series of unanswered questions at that time (Noronha, 2009, 2015). My research revealed that there is no separation between humans and objects, and especially, no separation between the experiences we undergo and the stories we tell – in this case, the art we create. My work unfolded in three distinct parts, each sequentially dismantling separations or rigid classifications between these realities.
- 10 The first part of my research (Noronha, 2009), which breaks down divisions between experience and “representation”, highlights the epistemological dimensions of art-based illness narratives. It deconstructs the notion of art as a mere reproduction of reality, redefining it as a constitutive part of experience and a form of knowledge, deeply embedded in the way patients live, understand, and cope with illness, bridging individual expression and collective activism. Analysing visual representations of biomedical technologies and materialities within the same art-based format, the second part of my research (Noronha, 2015) presents an understanding of illness as a modular process, an experiential assemblage that also encompasses objects, thereby breaking down divisions between experience and material culture. It outlines an alternative ontology, a “third half of things”, according to which people, experiences, objects, and knowledge are part of an undivided reality, being or becoming mutually complete (Noronha, 2015). From theory to practice, the third part of my research (Noronha, 2019) focused on the development of a novel methodology – “creative ethnographic drawing” – which breaks down divisions between social science and art, merging illustration with writing. Resulting from informal conversations with patients, without a predefined questionnaire, it brought forward what was regarded as relevant from their perspective. By adding metaphor and imagination to the creative process, the drawings and paintings materialise ideas and facts that would otherwise be untranslatable into conventional realistic illustration, transforming my interlocutors’ words and stories into a meaningful sequence of images. However, there is work to be done, considering the new connections between humans and artificial intelligence devices, as well as the changes they bring to the interplay among words, images, and the stories we tell.

(In)conclusion: The unfinished shape of a new variant and the work ahead

- 11 A variant, by definition, is a “form or version of something that differs in some respect from other forms of the same thing or from a standard”. AI image generators are giving rise to a new variant of illness narratives that calls into question many of the assertions made regarding their connections to preceding forms of art and image-making. A variant is, as the term implies, unprecedented, while nonetheless retaining details from previous forms. But what exactly is new about the way patients create their images and tell their stories? In terms of the use of text-to-image AI generators in the depiction of illness narratives, an exploratory survey of the internet reveals the diversity of actors participating in this process, ranging from professional and amateur artists to beginners with no skills or previous experience in the arts, as well as individuals with disabilities for whom other media were inaccessible. These individuals do not use lines or shapes to create their images; they write them down. Words and images are inextricably linked in this new creative process or mechanism, while the result – the output or image – is always unanticipated, corresponding, or not, to the intention of the “writer of images”. While previous media allowed for a direct connection between the inner and outer worlds, such as the imprint of blood, pus, urine, scars, and even residues of organs and body parts on paper, canvas, plaster casts, and preservative containers, patients using AI image generators can, if they wish, rely solely on the intertwining of words and technology to express and extend their embodied experiences into images.
- 12 We are not only involved in the creation of a variant; we also have the opportunity to develop a new theory. The social sciences must interrogate and analyse the changes brought about by this technology, developing a comprehensive theory on the embeddedness of AI-generated images in illness experiences and narratives and vice versa. What kind of relationships, possibilities, and challenges might emerge from this new articulation of humans, AI image generators, words, and images? In what ways do AI-generated images matter for a renewed relationship not only with our bodies but also with our surrounding world, particularly in how we experience and represent illness and resistance? In what ways do AI image generators change, expand, or limit the metaphors we use and the subjects we choose to give shape to our narratives, such as events, memories, thoughts, emotions, desires, sensations, people, relationships, spaces, objects, and other non-humans? This new technology not only changes the way we create images but also brings into the creative process individuals and experiences that have, until now, been absent from illness imagery. Recognising that the conditions that engender the reproduction of inequality in generative AI are as significant as its opportunities for inclusive agency and representation, we must also address the invisibilities and absences generated by this new technology and visual format. Hopefully, the entanglements of machines and artificial intelligence with what makes us human may open new paths for dismantling ontological separations and classifications that are no longer effective in understanding reality.

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RESUMOS

An evolving technology – artificial intelligence (AI) image generators – is engendering a new variant of illness narratives that calls into question the assertions made about their connections with preceding forms of art and image-making. The social sciences must interrogate and analyse the changes brought about by this technology, developing a comprehensive theory on the embeddedness of AI-generated images in illness experiences and narratives, and vice versa. We must ask in what ways these images matter for a renewed relationship not only with our bodies, but also with our surrounding world, in how we experience and represent illness and resistance.

Uma tecnologia em evolução – os geradores de imagem com inteligência artificial (IA) – está a dar forma a uma nova variante de narrativas de doença que desmonta parte das afirmações feitas sobre a ligação das mesmas com anteriores formas de arte e de criação de imagens. As ciências sociais devem interrogar e analisar as mudanças engendradas por esta tecnologia, desenvolvendo

uma teoria abrangente sobre os encaixes das imagens geradas por IA nas experiências e narrativas de doença e vice-versa. Temos de perguntar de que forma estas imagens são importantes para uma relação renovada não só com os nossos corpos, mas também com o mundo que nos rodeia, na forma como vivemos e representamos a doença e a resistência.

Une technologie en pleine évolution – les générateurs d'images par intelligence artificielle (IA) – donne naissance à une nouvelle variante des récits de maladie qui remet en question les affirmations concernant leurs liens avec les formes antérieures d'art et de création d'images. Les sciences sociales doivent interroger et analyser les changements apportés par cette technologie, en développant une théorie globale sur l'intégration des images générées par l'IA dans les expériences et récits de maladie, et inversement. Nous devons nous demander en quoi ces images sont importantes pour une relation renouvelée non seulement avec nos corps, mais également avec le monde qui nous entoure, dans notre façon de vivre et de représenter la maladie et la résistance.

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Palavras-chave: geradores de Imagem com IA, narrativas de doença, palavras, imagens

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