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# Affirmative Embodied Experience Matters: (Mis)Understanding and Representation in Digital Cancer Narratives

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### Abstract

Digital affordances reconfigure the perception of illness, revealing the cultural construction of embodied experiences. Though precarity and fragility deepen our understanding of cancer, the susceptibility to generate blame and misunderstanding reinforces panic in the afflicted. Self-blame subjugates individuals, perpetuating fear through falsified experiences and fabricated realities that homogenise personal experience of illness. Moreover, the manipulation of technomedicine to disseminate false hope and knowledge is significant. Conversely, digital narratives subsume shame, stigma, and silence and promote posthuman subjectivity, enabling fluidity in experience. The post-pandemic phase has opened up diverse platforms across media to articulate, interact, and convert one's feelings and emotions; social media platforms, WhatsApp groups, online blogs, and YouTube channels promote effective conversations. The tendency for an evidence-based understanding of disease remains dominant and illness marginalised; the concept of 'immunitas' emphasises biomedical discourses as indispensable and coercive control diplomatic. Drawing on select narrative accounts from TEDx and Advertisements, the article examines how digital cancer narratives affirm the lived experience, reclaim agency, and negotiate the interplay between power and knowledge. The reconfiguration of power dynamics provides inclusivity and relationality.

*Keywords:* affirmative, digital cancer narratives, embodied experience, power, representation

The ontological paradigm of digital humanities posits technology as a supplementary rather than intrusive entity that augments traditional notions of the study. The field of inquiry encompasses diverse perspectives from literature, philosophy, history, and cultural studies. It integrates critical digital studies (artificial intelligence, machine

learning), information and technology, data analysis, and computational tools in reconceptualising the world's perceptions. Digital health, a subset of digital humanities, involves using digital technology to make healthcare more efficient, accessible, and inclusive. Some primary vectors manifested in the field are Electronic Health Records (HER), healthcare commerce, telemedicine, mobile health apps, wearable and biosensing devices, digital medical devices, analytics/big data personalised medicine, gamification, and data visualisation. Besides, the discourse on bioinformatics is an emerging area of study where information about the human body is turned into data to improve health outcomes and control people. The veracity in accessing one's health becomes problematic when medical interventions involving technology detect hidden signs of disease, the screening strategy to find invisible diseases like 'HIV antibodies, tiny breast lumps, high lipid cholesterol levels, hypertension, precancerous cells, genetic markers for disease' (Lupton 99) make people appear vulnerable and fragile never than before.

At this juncture, critical inquiry like digital health humanities integrates 'digital technologies, health humanities, and medical humanities to address health-related issues, promoting patient-centered care and health equity.' It exposes the subjective experience of the patient undergoing any particular illness, providing a platform where the affected can share his/her notions of disease and experience of illness. It probes into how technologies can optimise health outcomes and create disparities among people. Technological advancement, especially in digital health through the medical humanities and literature framework, bridges the gap between knowledge and power in medical-assisted technologies, data-driven technologies, and people. The impact of information overload on our bodies, coupled with AI and therapeutic devices like Apple watches that monitor our pulse rate and glucose levels, raises concerns about the potential for manipulation and exploitation for commercial gain. Sousveillance and surveillance of bodies through technology empower and exclude the population gradually. Meanwhile, healthcare crowdfunding, unregulated telemedicine, digital health monopolies, and lack of transparency in health data sharing contain capabilities and possibilities of exacerbating disillusionment. While the negative implications are a growing concern, Paul Rainbow's

concept of biosociality examines the biosocial configurations of health developments through the 'intersection of class, gender or race, role of state and non-state actors or institutions including disease advocacy organisations, production of novel biomedical knowledge and technologies, generation of wealth and commercial interests in biology and 'life itself.' (Gibbon and Novas, 5) These widespread themes understand how biological and social factors affect individuals and collective identities. Power operates through individuals and communities where the need for protection, exclusion, connection, and inclusion becomes essential.

The wake of datafication and the production of narratives is addressed as a significant gap in digital health. Datafication involves converting into data aspects of the world previously not quantifiable, objective, and analysable compared to subjective and meaning-making narratives. Moreover, the visual rhetoric of illness has revolutionised social media platforms through paintings and advertisements. Advertisements portray the dangers of addiction, especially cigarettes and beedi, on people. Though the advertisements last a few minutes, their impact on catching the person's consciousness is remarkable. The present study attempts to unleash the politics of representation and how cancer care becomes a tool of coercive control rather than comfort. Though TEDx talks and advertisements on cancer highlight awareness regarding the illness/disease, the strategy of controlling the minds of the affected and instilling the notion of blame, shame, and guilt by promoting exclusion and hindering means of connection and making the individual feel marginalised and victimised have been in the forefront. '... 'Either Power negates life or enhances its development; or violates life and excludes it or protects and reproduces it; objectivises or subjectifies it-without any terms that mediate between them' (Esposito 46)

In the TEDx talk on 'How to change your perspective on Cancer,' popular oncologist Dr. V P Gangadharan exhibits the dominance of biomedical discourses and their role in reinforcing ideas about cancer. Cancer is perceived as solely biological and needs appropriate treatment and care, yet social phenomena like disgrace, self-blame, and stigma compound it. The conversation proceeds to how, in a reputed institution, he was described as a 'great doctor who helps

patients who are ready to leave this world and go to the other world (Gangadharan).’ He emphasises the social reconfiguration of cancer as death and reengineering cultural norms and beliefs that impede the mindset of a large population. He insists his agenda is to eliminate stigma and fear about the treatment and claims that cancer cure is promising over time. He specifies how obituary articles often address heart-related issues as a consequence but eliminate reason as cancer since the disease/illness is seen as obnoxious and secondary; he suggests redesigning the aesthetics of cancer from crab to rose as essential, thus reshaping existing knowledge and cultural acceptance of power. Meanwhile, Gangadharan compares his patient’s outlook to a picture that portrays dry or dead leaves as his/her impression of cancer; he establishes that the notion of cancer equals death gets materialised in the image. The doctor posits this view as negative and compares it to another image where he is glorified as St. Michael by refashioning the archangel to the doctor. The negative and positive sides of the painting are underscored. However, the phenomenological approach views each experience as subjective and an immersion of his/her feelings about the disease/illness that needs to be addressed. ‘The writer’s tale transcends the clinician’s history because his or her language is charged with meanings. The writer of literature can evoke a vicarious experience of illness and suffering...’ (Pellegrino xix)

The subjective experience of each individual is affected when he/she is facing a terminal illness like cancer. Gangadharan proceeds to distinguish the image as negative and follows a positive version portrayed by another person. The attempt to denote the stigma behind the disease is apparent, but the need to respect the views of the person affected is also essential, as there is a thin line between bright-siding cancer and living with cancer. Moreover, the appearance of living with cancer may sometimes subsume the hidden, invisible realities that the affected face. A closer examination of the intimate experience of cancer is revealed in the portraits that the doctor focuses on in his talk; digital storytelling thus opens a medium for representing these realities in subtle ways, and the framework of critical/medical humanities becomes the tool for underscoring the stark non-medical aspects. ‘Stay positive is the refrain, as if it were a sin to voice the intense pain and suffering of

cancer patients. Why are we so afraid to tell stories of the majority who die? Why keep promoting the positive anecdote (Azra Raza 7)? The presentation is an example of how medical discourses fail to realise subjectivity. However, it is aware of the social aspects that threaten the person and spreads awareness meaningfully through digital storytelling where the audience is larger. The impact it can spread on the consequences of stigma becomes the need of the hour. 'If you really want to understand someone's politics, understand their cognitive load, how prone they are to snap judgments, their approaches to reappraisal and resolving cognitive dissonance. Even more importantly, understand how they feel about novelty, ambiguity, empathy, hygiene, disease and dis-ease, and whether things used to be better and the future is a scary place.' (Sapolsky 477) The biopolitical dimension of medicalising the aspects of cancer needs to be expanded, and the role of stories is inculcated, making room to expand conversations.

The recent breast cancer awareness ad by Yuvraj Singh Foundation, which situated women's breasts to oranges, has provoked discussions about how Indian society deliberately condemns women's breasts, as their vaginas and breasts remain taboo for discussion. While the advertisement was the product of an AI-stimulated image, the aesthetic representation of breasts as oranges trivialises and insults women's bodies; women are still portrayed as objects of desire rather than individuals with agency and aspirations, and the agenda of making women silenced of their body parts in public has been of the essential components of patriarchy to tame and make them appear vulnerable. The invisibility of the breasts in the advertisements indicates Indian attitudes and behaviors toward wrapping women's bodies, rendering them always hidden and a source of objectification. On the other hand, society denounced Jilu Joseph's advertisement about breastfeeding awareness in public, making it sensational. Rather than considering women's health to be prioritised, the scheme of considering it as disposable and docile is featured and produced through transmedia. The subjectification of women's bodies perpetuates the marginalisation and exploitation of the affected.

The practice of removing clothes before the doctors was a hindrance, especially for women; in contrast, Marunnu by Punathil

Kunjabdulla mentions a scene where a person comes to a physician and says that he has an itch in his private area. The doctor asks him to remove the undergarments, looks through them, and suggests changing them. The students who witness the scene represent no form of giggle or an aspect of shame but participate in the doctor's conversation with the patient. As Simon de Beauvoir suggests, the body is not a thing. It is a situation, embodied experience, relationship with the environment, and socio-cultural factors that affect the body. Siddharth Mukherjee mentions the story of Atossa, daughter of Cyrus, recorded by the historian Herodotus: Atossa had a bleeding lump in her breast. .." If Atossa had desired it, an entire retinue of physicians from Babylonia to Greece would have flocked to her bedside to treat her. Instead, she descended into a fierce and impenetrable loneliness. She wrapped herself in sheets, in a self-imposed quarantine." (Mukherjee 41). The 'private shame' associated with breast cancer has been prevalent and still exists in upgraded versions. Audre Lorde in *The Cancer Journal* posits that after a mastectomy, she was forced to believe that something was wrong with her in not wearing prosthetic breasts and acknowledging herself.

The accountability in addressing issues related to breasts becomes a growing concern when breasts are objectified rather than viewed as flesh and blood. The unburdening of shame and stigma associated with breasts happens only when society is empowered to look beyond the breast, a sense of responsibility in making women aware to prioritise their health, and ensure that breasts are not material for consumption and oppression. On a different plane, when men are affected with penile cancer, they face difficulty in opening up as there is much silence regarding how masculinity is thwarted forever. As Arthur W. Frank in *The Wounded Storyteller* exposes, not all stories are equal. A deeper understanding of the nuance of the statement reveals that accessibility to better healthcare depends on socioeconomic factors like income, expenditure, gender, and race. A closer analysis of breast cancer and penile cancer remains predominant in addressing issues related to gender, thus alienating specific experiences as invisible and reduced only to bodies. Furthermore, it is also poignant to address that educated urban women/men may have better access to healthcare than their rural

counterparts, thus producing a constant gap in availing healthcare resources.

The Ministry of Health and Family Welfare exposes the adverse effects of smoking on the lungs through the advertisement 'Sponge.' The ads focus on how individuals who smoke are more prone to chronic diseases. The tendency to blame the individual is constantly reflected in the advertisement, 'The imputing of blame for illness based on the assumption that ill people have indulged in 'risky' activities means that the ill are forced to protest that they have done all they can to avoid its onset...Such a claim is demonstrating that in an age in which a lifestyle choice rather than an act of God is viewed as the cause of disease, the ill are placed in a position in which they must justify themselves' (Lupton 93). Advertisements signify cancer as the sole responsibility of the individual affected. Tobacco certainly causes a serious threat to our lives when consumed for a prolonged period, but the advertisements unleash to control and regulate the individual lives.' "Academic investigators could provide data about risks and argue incessantly about proof and causality, but the solution had to be political. 'The obstinacy of[policymakers]," he wrote," compels one to conclude that it is their own addiction...which blinds them." (Mukherjee 257) The regulation of the lives of cancer patients begins when cancer is represented only as personal rather than social; advertisements hardly address how the sick who have/had lung cancer are made to believe that the reason for their illness is only due to their intake of tobacco when the history of cigarettes provide a terrible story of how cigarettes were initially advertised understanding the psychological vulnerability that the person and means to manipulate them. When affected, ostracising the person regarding the disease is quite common. Hardly do advertisements reveal what it means to be affected by illness. When an individual is affected, the community becomes his/ her aid to recover the illness. Medical treatment plays an important role in tackling the disease. However, the healing begins when the individual is understood. Stigma related to cancer based on preconceived notions is one of the significant barriers. Though awareness regarding cancer is prevalent, the attitudes, assumptions, and behavior toward the illness are evident.

The systemic forces constantly drag awareness campaigns on cancer to spread panic amongst the masses. Even though they claim the potential of ads to raise responsible citizens, their primary aim is to instill fear in people's minds. The agenda of saving lives begins at the cost of losing one's liberty. Rather than exposing the bleak realities of regulating lives, expansion through notorious methods is done. Advertisements as a form of art convey the hidden dangers of tobacco but fail to address manipulation. Though packets of cigarettes instruct the person that it is harmful, the constant reinforcement of the ads in the theatres projecting a one-sided story of illness is political. Our understanding of the pathological is rooted in an awareness of the human organism's fragility-not simply its mortality. However, that has always and everywhere inspired fear of the ultimate loss of control, but its susceptibility to disease, pollution, corruption, and alteration are things that we experience in our own bodies and observe in others. (Gilman 23). The knowledge of human fragility and precariousness to the unprecedented crisis has made the logical construction of disease/illness fearful. The reification of sick bodies and visceral exploitation demands social justice and need for ethical concerns.

Diagnosis of cancer and treatment affect people in diverse ways; socioeconomic factors shape the perception of cancer. When the sophisticated have financial resources and get access to the best quality treatment, they maintain a positive outlook on cancer in life and share positive experiences through public platforms and social media. As they get better treatment, chances of survival increase, and becoming better can be attained. The issue addressed is the stigma of cancer that penetrates the lives of the affected invisibly and visibly. While the lower- or middle-class people struggle to cope with the available resources and fear of dying of cancer, the family and children become drastically disrupted by the diagnosis and cost of treatment. As the cost of cancer treatment cannot be managed, it puts their life at more risk, and even though they look forward to being positive, their situation fails. The philosophical framework of Agamben's concept of *zoe* and *bios* enables one to look beyond the realm of class differences and unleash the approach of viewing some lives as dispensable and disposable and others as qualified or distinguished.

To conclude, the article looks into the diverse representation of cancer in the media through popular media platforms, YouTube, and advertisements. The framework of digital health humanities features aspects of technologically assisted devices to enhance and empower society; the focus of the study assimilates health-related technologies employed for better access to healthcare and improving lives. Even though technological advancement has grown rapidly, the societal constructions of shame, blame, and stigma are still evident. Through TEDx talk and advertisements on cancer, the study focuses on subjectivity that asserts the patient's agency, autonomy, and accountability and the need for interconnectedness, inclusivity, and relationality with species that make this world a better place to live. The negative and positive sides of the painting are underscored, and the phenomenological approach views each experience as an immersion of his/her feelings about the disease/illness that needs to be addressed. The embodied experiences of the person affected matter, and each person's cancer journey is unique and intimate. Affirming their experiences allows them to express themselves without judgment and makes them feel worthwhile.

The advent of advertisements in spreading awareness of issues related to tobacco and cancer is acknowledged, but the harsh realities of cultivating victim blaming and promoting them as the true version of the illness are accountable for interrogation. Similarly, metaphors can be a way of transgressing knowledge on cancer but also have the potential to marginalise the person affected if not conveyed effectively and efficiently. Women's bodies are commodified as objects of desire and alluded to weird metaphors that require redesigning cultural interpretations of cancer. The deeply infantilising and 'cutesy euphemism' are representative of how stereotypes continue to minimize and trivialise women when affected by life-threatening conditions. The association of women's breasts in voyeuristic language needs to be rewired, and cultural constructions like shame, stigma, and silence need to be amplified, thus enabling affected individuals and people, in general, to be vociferous and culturally sensitive in creating metaphors. Therefore, in this era of misinformation and medical misogyny, evidence needs to be evaluated, and emotional contagion should be cautioned as huge chunks of information are available to us.

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