

Hacking the Disease: Salvatore Iaconesi's Sense-Making Quest for an Open-Source Cure for Cancer

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Abstract

The experience of illness, as narrated by those who suffer from it, can provide significant insight for medical and health professionals, helping them to understand what their patient is going through, from a psychological and existential point of view. These narratives can also help to bridge the distance between science and experience, and to heal the gap that divides the sick person from the rest of society. The work that Salvatore Iaconesi and Oriana Persico have done with their performance *La cura (The cure)* – started when he was diagnosed with brain cancer in 2012 – takes this kind of narrative and self-reflexive experience even further, in order to explore the relationship between culture, technology and biology, with the aim of redefining the meaning of cure (and, consequently, of illness and health) in a collective and inclusive way. *La cura* can thus be seen as a piece of work that, by belonging to the Medical Humanities, can also take a step forward in building a theoretical and practical dialogue between different disciplines in order to respond to the challenges of our digital (and biotechnological) society.

Keywords

Brain cancer, digital technologies, collective performance, technoculture, human narrative

Introduction

There is an ongoing debate about how to define the Medical Humanities (hereafter MH). This debate focuses, for example, on whether MH is a field or a discipline or whether it is multidisciplinary or interdisciplinary and it may seem that these issues are never really settled¹. This ongoing epistemological questioning, far from being sterile and limiting, can instead be enriching because it takes into account many different perspectives and it also entails a rich flexibility between the plurality of approaches that characterizes the MH.

The aim of this article is not to delve deep into this debate, but a few observations are necessary in order to situate the case study proposed here and to clarify the reasons why, in the author's opinion, it not only rightly falls within the MH but it could also be a relevant example to follow because of its deep implications, which regard many different interconnected medical, societal and biopolitical elements.

In the MH debate, the approach taken by Chiapperino and Boniolo is particularly interesting, because they consider MH as a “*humanistic problem-based approach to medicine aiming at influencing its nature and practice*”². In their intent to abandon the dispute between multidisciplinary and interdisciplinary, they explain that

What appears to be relevant is neither the language deployed by disciplines to answer some questions nor the search for an agreement on core issues between experts. Rather, as argued by Popper (1963) while discussing the status of scientific disciplines, what counts as necessary is the capacity to deal with problems under analysis.³

This ‘problem solving’ approach is relevant to the performance *La cura* by Salvatore Iaconesi and Oriana Persico, which is the main focus of this article. The performance – which is made up of a website and a book, a GitHub repository and a continuous dialogue through social media, email and live workshops – started when Iaconesi was diagnosed with a brain cancer in 2012. *La cura* is a quest for meaning that the artists have decided to undertake in order to respond with their full humanity and in a collective dimension

1 See Victoria Bates et al. (eds.): *Medicine, Health and the Arts: Approaches to the Medical Humanities*. London, New York 2014, 4.

2 Luca Chiapperino, Giovanni Boniolo: Rethinking Medical Humanities. In: *Journal of Medical Humanities* 35.4 (2014), 377-387, 383 (emphasis in the original). <https://doi.org/10.1007/s10912-014-9269-5>.

3 *Ibid.*, 379.

to the illness: it is the search for answers and solutions to a problem. Furthermore, it is a process aiming at building a framework of meaning, which is at the core of what MH attempts to examine, in pair with narratives of medicine.⁴

There is also another aspect that needs to be highlighted:

The medical humanities has been very good at incorporating the insights of cultural relativism and subjective difference, recognising that it is very difficult—in fact, close to impossible—to truly understand someone else's experience of illness from the outside, or at least without undergoing a similar physical experience yourself. Just think about how different it is to cognitively understand how to fix a broken leg, versus actually having a broken leg. Each patient's reaction to illness is unique. Various existential matters, such as the meanings attached to illness and the way a person's identity changes as a result of illness, are often as important to patients as their physical experience of pathology and recovery.⁵

La cura goes at the heart of these existential matters that are “essential to medicine”⁶ and it does so in ways that are proper to MH. What we find in Iaconesi and Persico's work is precisely the attempt to share the individual experience of illness and to bring it back to its social dimension, with the intention of reaching out to a potential community willing to participate in the collective search for a cure which is, at the same time, a search for a meaning.

The research interest in Iaconesi and Persico's work lies in its capacity to open up new ways of thinking about the interconnectedness of different aspects (cultural, social, economic, medical, technological...) and the role of digital technologies in shaping contemporary society, including the health sector. This could contribute to the development of new theoretical tools for managing the radical changes brought about by digital technologies. The work of Iaconesi and Persico can therefore be viewed as one of the “methods from other humanities fields with rich histories of analyzing technology and media” that “are urgently needed to grasp the technological transformation of medicine occurring today”, because “the digitalization of medicine—and of patient life—happening now requires a different kind of health humanities, one attuned to technology and media not

4 See Thomas R. Cole et al.: *Medical Humanities: An Introduction*. Cambridge 2015, 31.

5 Claire Hooker, Estelle Noonan: “Medical Humanities as Expressive of Western Culture”. In: *Medical Humanities* 37.2 (2011), 79-84, <https://doi.org/10.1136/medhum-2011-010120>, 82.

6 Cole et al., *Medical Humanities*, 208.

only as tools (how health-care professionals typically view technology) or as methods of representation (how media are typically viewed), but rather as technoculture”⁷.

This technocultural approach could also help to respond to the challenges that are posed by the interrelationship between different forms of digital writing (ranging from human language to computer code to genetic editing tools⁸), which Iaconesi and Persico explore in parallel in their work. Today, these forms of writing, these flows of information are crucial because they integrate technological and biological aspects and redefine not only writing, which, with the diffusion of texts produced by Large Language Models, is becoming more and more estranged from us⁹; they also redefine life as we know it.¹⁰ *La cura* touches on some of the core questions of being human in the digital age, including the experience of illness, and it fits fully in the artistic journey of the couple.

Salvatore Iaconesi has been a hacker, engineer, designer and artist, and together with his partner Oriana Persico, an artist and communication specialist, they have set out to explore digital technologies and their relationship to human life, to cultural expression, and to the exploration of possible new directions for the evolution of our digital societies. It is impossible to summarize here their artistic journey,¹¹ but it is important to highlight the biopolitical implications of their work, which constitute a relevant part of the theoretical underpinnings on which *La cura* is also based.

Among their projects, it is worth mentioning *Angel_F*, a performance involving a community-based Large Language Model (the acronym Angel F stands for Autonomous Non Generative E-volutive Life Form¹²). The performance raised questions about digital rights, copyright, human identity and how the mutations brought about by digital technologies

7 Olivia Banner: Digital Life and Health Humanities. In: Paul Crawford, Brian Brown, Andrea Charise (eds.), *The Routledge Companion to Health Humanities*. New York London 2020, 39-42, 40.

8 It is not possible in this paper to explore the details of genetic writing/editing tools such as CRISPR-Cas9 from a humanistic perspective but suffice it to point out that the reference to writing is not just metaphorical but relates to the way genetic information is handled in biotech labs. See Kevin Davies: *Editing Humanity: The CRISPR Revolution and the New Era of Genome Editing*. New York 2020.

9 See Matthew Kirschenbaum: Prepare for the Textpocalypse. In: *The Atlantic* (March 8, 2023). <https://www.theatlantic.com/technology/archive/2023/03/ai-chatgpt-writing-language-models/673318/> (7.12.2024).

10 In the midst of the transformations brought about but digital technologies, genome editing (a tool that is a direct consequence of the ever-increasing computing power) “has revitalised and reconfigured debates about the relation between nature and culture, ontology and technology, society and the self” (Erica Borg and Amedeo Policante: *Mutant Ecologies. Manufacturing Life in the Age of Genomic Capital*. London 2022, 91).

11 For a complete overview on their projects and a detailed press review, see: [AOS] *Art Is Open Source* (no date). <https://www.artisopensource.net> (30.11.2023).

12 Salvatore Iaconesi, Oriana Persico: *Angel_F: diario di una intelligenza artificiale*. Roma 2009, 52.

have an impact “on the ways we perceive identity, sexuality, public and private spaces”.¹³ The couple also worked on “the first publication of a new literary genre: algorithmic autobiography”¹⁴ with the performance *Ghost Writer* which they used to explore the way autobiography is never a solitary endeavour especially in our time of digital data, as they explain: “We are constantly leaving digital traces in our lives, whether we realize it or not, whether we want to or not. A number of subjects constantly keep track of these fragments of ourselves, constructing multiple versions of narratives of our lives, each with different focuses, parameters, viewpoints, perspectives”.¹⁵

These performances, as well as *La cura*, explore human narratives and their interactions with technology and biology. They question the boundaries that digital and scientific advances are increasingly challenging, particularly with progress in fields such as neuroscience and biotechnology. The exploration of identity in the digital age, the self and the ways in which we narrate ourselves is a deep biopolitical inquiry that includes issues such as illness and health, thus situating itself within the MH.

La cura: hacking the disease

The performance *La cura* came about the moment Salvatore Iaconesi was diagnosed with a brain tumour. The gesture that initiated this biopolitical performance is the hacking of his medical record to share it online. Hacking was necessary because the data on the two CDs that formed Iaconesi's medical record were not directly accessible and understandable:

quello che ho trovato è stato un insieme di file in formato ‘dicom’ (digital imaging and communications in medicine), il quale è, tecnicamente e formalmente, un formato aperto. Ciò non vuol dire che sia un formato inteso per essere comprensibile e usabile dalla gente comune. [...] Il dicom è un formato per professionisti, per specialisti, per esperti tecnici. per aprirlo servono software specifici e spesso l'installazione di componenti aggiuntive sul proprio sistema operativo, oltre alla necessità di eseguire configurazioni. [...] Ma in tutto questo le persone sono assenti. Il formato dicom non è per le persone.¹⁶

¹³ Angel F. In *[AOS]: Art Is Open Source* (no date). <https://www.artisopensource.net/projects/angel-f/> (30.11.2023).

¹⁴ GhostWriter. In *[AOS]: Art Is Open Source* (no date). <https://www.artisopensource.net/projects/ghost-writer/> (30.11.2023).

¹⁵ Ibid.

¹⁶ “What I found was a set of files in ‘dicom’ (digital imaging and communications in medicine) format, which is, technically and formally, an open format. That is not to say that it is a format intended to

The next step was to upload the data online, create the website dedicated to finding “an open source cure for cancer”, and upload a video to YouTube explaining the project.¹⁷ The decision to open up and share medical data was a form of reaction to the bureaucratization of disease and the healthcare institution, which is increasingly understood as a set of rigid protocols to be applied and interpreted according to economic rather than health-related parameters. In this way, hacking a medical record is an action that goes far beyond the domain of IT. Iaconesi

ha hackerato la malattia, o meglio ancora la codifica di paziente e il destino previsto per lui dall'intero processo di ospedalizzazione e così perfettamente racchiuso in quei cd. [...] La conoscenza del codice gli ha consentito di 'aprire' i dati, di riprendersi con essi ciò che rappresentavano: la gestione del suo corpo. Trasformando il formato dicom in formati usabili da tutti, Salvatore ha tradotto il linguaggio degli scribi nella lingua del popolo, quella parlata e accessibile a tutti.¹⁸

The concept of cure used by the artists is to be understood in the broadest sense. In the video message posted on YouTube cited above, Iaconesi explains that the data of his tumour have been made available to everyone so that everyone could participate, according to their knowledge and sensibility, in this therapeutic project, in which the therapy certainly goes through medical aspects, but also and perhaps above all touches on human and community aspects. Hence the call for contributions in all forms: texts and works of art, dietary advice, sharing similar experiences of those who have lived through the disease or those who have accompanied a loved one in facing cancer. Iaconesi continues: “[volevo] organizzare i dati in modo che avessero senso per me, in modo da poterli rappresentare e visualizzare, far entrare i dati clinici nella mia vita, nella mia arte, nella mia professione, nel modo in cui creo relazioni con chi mi sta intorno”.¹⁹

be understandable and usable by ordinary people. [...] dicom is a format for professionals, for specialists, for technical experts. To open it requires specific software and often the installation of additional components on one's operating system, as well as the need to perform configurations. [...] But in all this people are absent. The dicom format is not for people.” Salvatore Iaconesi, Oriana Persico: *La cura*. Torino 2016, 116-117.

17 Salvatore Iaconesi: “My Open Source Cure”. In: *YouTube* (Sept 10, 2012). <https://www.youtube.com/watch?v=5ESWiBYdiN0> (30.11.2023).

18 “[He] hacked the disease, or better yet the coding of the patient and the fate envisioned for him by the entire hospitalization process and so perfectly encapsulated in those CDs [...] Knowledge of the code allowed him to 'open' the data, to take back with it what it represented: the management of his body. By transforming the dicom format into formats usable by all, Salvatore translated the language of the scribes into the language of the people, the language spoken and accessible to all.” Ibid., 125-126.

19 “I [wanted] to organize the data in a way that made sense to me, so that I could represent and visualize

This intention is clearly about building the frameworks of meaning mentioned in the introduction, and it goes in the same direction of what Susan Sontag thinks, when she writes: “As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have. The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythicize it”²⁰

Moreover, this hacking operation is carried out on the entire society, on its codes and its organization and so it represents an interdisciplinary rupture with interesting consequences for the medical world as well: “His disease has thus become globally shared, has hybridized all boundaries, connected science and humanities, and made science a little more human and familiar. His disease has pervaded any aspect of real life, it now has a face, and it is not only a mere nosological classification on medical textbooks”²¹

The book *La cura*, which is both part of the performance and a narrative of what was experienced, is a rather peculiar text because it is at the same time a biography and an autobiography, a theoretical essay and a collection of practical tools. The book is divided into eight parts; in each of them we find a chapter that is a first-person narrative by Iaconesi, starting from the first symptoms and the first hospitalizations (marked with the letter S); a second chapter that is narrated in the first person by Oriana Persico, thus building a narrative at the same time biographical (she talks about her husband's illness) and autobiographical (she talks about her living this situation, letter O); a third part, in the form of essays, in which the themes touched by the two personal narratives are explored as humanistic and scientific investigations (letter R, for research); and a final chapter in which the authors present tools and techniques useful for dealing with the themes encountered in the previous chapters, like software, tutorials, short manuals and links and references to material available online (letter W, for workshops). The workshop archive, published on GitHub and still partially available online²², was “una base di conoscenza

it, so that clinical data could fit into my life, into my art, into my profession, into the way I create relationships with those around me”. Ibid., 116.

20 Susan Sontag: *Illness as Metaphor and AIDS and Its Metaphors*. New York et al. 1990, 7.

21 Nicola Bragazzi: From P0 to P6 Medicine, a Model of Highly Participatory, Narrative, Interactive, and ‘Augmented’ Medicine: Some Considerations on Salvatore Iaconesi's Clinical Story. In: *Patient Preference and Adherence* 7.7 (2013), 353-359, 354, <https://doi.org/10.2147/PPA.S38578>.

22 See xDxD vs xDxD: LaCuraBook. In *GitHub* (3 Dec 2017). <https://github.com/xdxdVSxdxd/LaCura-Book> (30.11.2023).

aperta e dinamica”²³ that anyone who wanted to participate in the performance could access, contribute to improving the documentation and engage in discussion.

The performance constantly crosses the boundaries between public and private, boundaries that the digital environment has already made fluid and porous²⁴. The artist's work analyses these boundaries in depth, in the light of their experience of illness, with its burden of suffering and the difficulty of deciding which elements of their intimacy to make public and which to keep private.

This collective performance generates many different reflections, starting from the ones about the illness, in an interesting parallelism between the replication of cancer cells and the replication of the process of writing and promoting what one has written (which, moreover, could be extended to the hypertrophy of online presence in the age of social media and the quantified self²⁵):

il cancro è replicazione: selvaggia, incontrollabile replicazione di cellule all'interno del nostro organismo. Riguarda l'espansione e le energie legate all'espansione. Adesso provate a immaginare di pubblicare un libro. Il libro, ovviamente, deve prima essere scritto. Poi, una volta pubblicato, va presentato [...]. Per farlo, ogni volta bisognerà replicare la propria esperienza: decine, centinaia di volte. Replicazione. Ancora. Per far funzionare il libro là fuori nel mondo, sarà necessario mettere in atto molteplici e potenti forme di replicazione. Temevamo questo meccanismo. [...] La domanda a cui dovevamo e volevamo rispondere non riguardava la pubblicazione del libro, ma come sottrarlo al processo di replicazione. Guardando il problema da questa prospettiva è emerso un elemento determinante. Scrivere un libro sulla Cura significava anche scrivere la storia di una performance [...]. La performance implica partecipazione e non replicazione; tecnicamente è non-replicabile. Abbiamo deciso che questo libro avrebbe fatto parte della performance, che ne avrebbe mutuato i modi e gli strumenti.²⁶

23 “An open and dynamic knowledge base”. Iaconesi, Persico, *La cura*, 23-24.

24 About the transformation and the loosening of these boundaries, see Marcello Vitali-Rosati: *On Editorialization: Structuring Space and Authority in the Digital Age*. Amsterdam 2018.

25 Quantified self refers to the practice of tracking oneself through technology, like devices and apps that measure the heart rate, blood pressure, physical activities, hydration, sleep... For an in-depth analysis of the phenomenon, see Deborah Lupton: *The Quantified Self: A Sociology of Self-Tracking*. Cambridge 2016.

26 “Cancer is replication: wild, uncontrollable replication of cells within our bodies. It is about expansion and the energies related to expansion. Now try to imagine publishing a book. The book, of course, must first be written. Then, once it is published, it has to be presented [...]. To do that, each time you will have to replicate your experience: dozens, hundreds of times. Replication. Again. in order for the book to work out there in the world, it will be necessary to put in place multiple and powerful forms of replication. We feared this mechanism. [...] The question we needed and wanted to answer was not about publishing the book, but how to take it away from the replication process. Looking at the problem from this perspective, a crucial element emerged. Writing a book about *La Cura* also meant writing the story of a performance [...].

If a performance can avoid the process of replication that the publication of a book would have represented, we can add that the collective performance they publicly called for becomes even more meaningful in a deeper sense, when we consider that cell replication in cancer happens when cells stop cooperating, as Aktipis argues: “Cancer is what happens when cells stop cooperating for the benefit of the multicellular body and start overusing resources, trashing the shared environment of the body and replicating out of control”.²⁷ The request for cooperation in finding a cure for cancer represents a remarkable paradigm shift from the normal codification of the patient, even as a concrete metaphor to counteract the loss of cooperation of the cancer cells in Iaconesi's body.

The choice of performance addresses another concern of the artistic duo, namely the need to show the process without the story taking over.²⁸ This attitude clearly reflects the hacker ethos: open the tools, make them accessible, show everyone how it is done. But it is also a choice that stands in direct contrast to the style of contemporary communication (not only in journalism), which instead aims to produce strong emotions, to create and show the ‘human case’ in order to gain a larger audience, to get clicks. *La Cura* then becomes a hacking applied to society as a whole, to its communicative vices, to its economic imperatives.²⁹

In the first pages of the book, Iaconesi explains that when he first found himself in the hospital, after a fainting spell, the fears about his state of health were combined with another discomfort: the health institution was not talking with him but *to* him, in a closed language that made it impossible to understand what was going on, a language that was dehumanizing. As the artists believe that health is not only a medical issue but also a linguistic and cultural one,³⁰ the first questions they pose arise from observing the bureaucratization and standardization of processes related to health and illness. They argue that medicine codifies people according to what is considered deviant from a norm and

Performance implies participation and not replication; it is technically non-replicable. We decided that this book would be part of performance, that it would borrow its ways and tools”. Iaconesi, Persico, *La cura*, 27–29.

27 Athena Aktipis: *The Cheating Cell: How Evolution Helps Us Understand and Treat Cancer*. Princeton 2020, 175.

28 Iaconesi, Persico, *La cura*, 26.

29 On hacking as an interdisciplinary practice, see Tad Suiter: Why ‘Hacking’?. In: Daniel J. Cohen, Tom Scheinfeldt (eds.): *Hacking the Academy*, Ann Arbor 2013, 6–10. For practices of hacking applied to language and society, see Roberto Laghi: Sandra Lucbert, *Personne ne sort les fusils* (Paris: Seuil, 2020). In: *Sphères* 5 (2020) [Special Issue: *Objectivité dans la recherche scientifique*].

30 Iaconesi, Persico, *La cura*, 52.

this is not only a matter of procedural and cultural aspects because economics also comes into play, and “la malattia per come veniva certificata dal dottore viene soppiantata dalla malattia presunta della burocrazia dei manager dell’industria della salute mediante la riorganizzazione dei pazienti”.³¹ Health and illness are, *de facto*, on the market, as if they were just another commodity³². All the more so in a digital society where everything can be measured, where the patient becomes algorithmic, the center of the “ascesa dell’essere umano come oggetto di osservazione continua, automatizzata, algoritmica e ubiqua, attraverso i dati digitali, le immagini e la possibilità di codificare la propria vita in tempo reale”.³³

This codification of human life occurs through the transformation of our biological life into data, some of which is voluntary (the aforementioned quantified self),³⁴ hence the questions the artists pose: “come cambia la vita, il benessere e la salute degli esseri umani nell’era dei dati, dell’informazione e della conoscenza? Come possono essere utilizzati i dati per le pratiche della salute e della medicina? Quali sono le implicazioni per i diritti, le libertà, il benessere e la salute delle persone?”³⁵

According to some doctors and researchers, it is necessary to continue to adapt the therapeutic approach to the new demands of society and to the new challenges posed by digital technologies, which touch both the work of doctors (think of the ever new and more sophisticated tools at their disposal) and the lives of patients (for example, in the creation of communities of dialogue and exchange of experiences on the internet). This is what we refer to, for example, when we talk about “P6 medicine”, where the six P stand

31 “Illness as it was certified by the doctor is supplanted by the assumed illness of the bureaucracy of health industry managers through the reorganization of patients”. *Ibid.*, 57.

32 In this regard, it is interesting to note what Audre Lorde was writing in 1980, while observing the lack of information and prevention about breast cancer in the USA: “We live in a profit economy and there is no profit in the prevention of cancer; there is only profit in the treatment of cancer.” Audre Lorde: *The Cancer Journals*. New York 2020, 1024.

33 “Rise of the human being as an object of continuous, automated, algorithmic and ubiquitous observation, through digital data, images and the ability to encode one’s life in real time”. Iaconesi, Persico, *La cura*, 58.

34 These technologies, which combine access to big data with the application of machine learning systems, point to the personalization of services, from displayed advertisements to medical treatments, as Joque illustrates: “our interactions are becoming personalized, from shopping to cancer treatments, where treatments now can depend on the genetic makeup of a patient’s cancer cells.” Justin Joque: *Revolutionary Mathematics: Artificial Intelligence, Statistics and the Logic of Capitalism*. London, New York 2022, 1-2.

35 “How does the life, well-being and health of human beings change in the age of data, information and knowledge? How can data be used for the practices of health and medicine? What are the implications for people’s rights, freedoms, well-being, and health?” Iaconesi, Persico, *La cura*, 62.

for “personalized, predictive, preventive, participatory, psychocognitive and public”³⁶. This understanding of medical practices underscores the fundamental interconnections between biological, cultural, psychological and social aspects as well as digital technologies, which is at the core of Iaconesi and Persico's performance. In this sense, Iaconesi embodies

the patient-activist of the ‘Health 2.0’ movement in at least two ways: first, on a personal level, by trying to figure out how he should act vis-à-vis the treatment of his own brain cancer, by reaching out to actors other than the traditional medical authorities and, second, on a more general level, by trying to raise awareness of cancer by not letting himself be defined by the medical gaze alone, widening the notion of what a cure could be.³⁷

The patient-activist Iaconesi, moreover, follows the hacker ethos and part of that is the openness of the process and the data. At a time when digital services, data and our own interactions are increasingly privatized for profit (even in the healthcare field and even with biological data), the openness of the performance is a radical gesture that means, as the authors write, that data and, in a broader sense, knowledge itself should be considered as commons, in both scientific and medical fields.³⁸ For this reason, the intention that gave rise to the performance includes the effort to build a society in which technology becomes an enabler of greater humanity.³⁹ Iaconesi wants to reprocess the data in a way that makes sense to him and, by bringing together different kinds of information and knowledge from different people, he aims to produce “una comprensione più complessa”⁴⁰ of his illness.

36 Bragazzi, *From P0 to P6 Medicine*, 353.

37 Christian Lenemark: *Doing Illness: Cancer Narratives in Digital Media*, In: *Tidsskrift for Forskning i Sygdom Og Samfund* 16.31 (2019), 251-267, 258. <https://doi.org/10.7146/ufss.v16i31.116968>.

38 Iaconesi, Persico, *La cura*, 89.

39 *Ibid.*, 115.

40 “A more complex understanding.” *Ibid.*, 116.

Breaking codifications, sharing information

La cura is a biopolitical collective act of recoding and reprogramming, and information is one of the threads that connect the many aspects this act touches. For example, if we consider communication between cells an exchange of information, cancer cells replicate and reproduce erratically because “il sistema informazionale del corpo non ha o non fornisce informazioni sulla direzione o sull’arresto del processo di replicazione. In questo senso diciamo che *il cancro è la perdita di significato*”.⁴¹ *La cura* is based on the assumption that cancer is an ecosystemic disease and that in order to cure it we must also act outside of hospitals, “mettendo in discussione i nostri modi di vivere, mangiare, consumare, passare il nostro tempo, desiderare, e in cui il soggetto della cura non sia solo il malato ma l’intera società.”⁴² The reflection of the authors goes further:

In questo senso il cancro rappresenta uno specchio interessante dell’intera società contemporanea, dove gli andamenti tecnici e tecnologici provocano la codifica progressiva delle nostre vite, intrappolandoci nei dati e nelle classificazioni che ci vengono inflitte: gli algoritmi ci classificano e trasformano le nostre vite, incluse le informazioni e i saperi cui possiamo avere accesso e, quindi, la nostra comprensione dei significati e delle nostre stesse sensibilità. In più di un modo siamo simili alle cellule staminali: reifichiamo i nostri sé perché non ci sono (o non siamo in grado di percepire) messaggi ecosistemici aperti, coerenti, rilevanti, capaci di generare significato e senso. L’unico modo di risolvere questo problema è allora quello di iniettare nel sistema dosi di informazione positiva, coerente, essenziale e significativa, prodotta in maniera aperta dall’intero ecosistema, da tutti i punti di vista, sul significato (e il senso) dell’ecosistema stesso.⁴³

41 “The body’s informational system does not have or does not provide information about the direction or about stopping of the replication process. In this sense we say that *cancer is the loss of meaning*.” (Emphasis in the original) Ibid., 173.

42 “Questioning our ways of living, eating, consuming, spending our time, desiring, and in which the subject of the cure is not only the sick person but the whole society.” Ibid., 172.

43 “In this sense, cancer represents an interesting mirror of contemporary society as a whole, where technical and technological trends are causing the progressive encoding of our lives, trapping us in the data and classifications imposed on us: algorithms classify and transform our lives, including the information and knowledge we can access and thus our understanding of meanings and our own sensibilities. In more ways than one, we are similar to stem cells: we reify ourselves because there are no (or we are unable to perceive) open, coherent, relevant ecosystem messages capable of generating meaning and sense. The only way to solve this problem, then, is to inject doses of positive, coherent, essential and meaningful information into the system, produced in an open manner by the entire ecosystem, from all points of view, about the meaning (and sense) of the ecosystem itself.” Ibid., 175.

This digital ecosystem has an impact on the lives of users who, very often, do not even realize it to a full extent. If we think about it, this is similar to what happened to Iaconesi with his medical records and with the language of medicine, as he himself acknowledges:

lo scenario è per certi versi simile a quello della Cura: la perdita dell'umanità, rimpiazzata da una serie di sintomi (le ricerche effettuate, i comportamenti online, i click) utilizzati per generare una diagnosi che trasforma la vita determinando ciò che è permesso, ciò che è suggerito e anche le cose che rimangono fuori dalla percezione, perché 'non sono quello che vuoi veramente.' [...] Se l'algoritmo sa 'cosa voglio', rimane poco spazio per 'quello che non so di volere'.⁴⁴

The role of digital technologies is indeed very important in *La cura*, which is “simultaneously a struggle against the impersonal approach of institutional medicine, eventually leading to the alienation of the patient, and a critique of its biopolitical epistemology, driven by a blind faith in statistical data and a trust in mechanical devices to control the body of an individual-turned-population”⁴⁵. This critique of the biopolitical epistemology does not limit itself to institutional medicine, but it is aimed at our digital society as a whole, since the digital is more and more enmeshed with the bio(techno)logical and this issue is at the core of the work of Iaconesi and Persico and the dialogue they created.

The performance has in fact become a global conversation of gigantic proportions, since the authors received nearly a million messages (including emails, comments on the videos and discussions on social media). This was perhaps an unexpected amount of work for the duo, who had to identify, organize and catalogue them. Most shocking, however, was the tone of the messages they received, which showed “un desiderio tangibile di affrontare l'operazione da un punto di vista nuovo, inusuale, inaspettato” and, above all, “il desiderio di cambiamento”.⁴⁶ The people

44 “The scenario is in some ways similar to that of *La cura*: the loss of humanity, replaced by a series of symptoms (the searches made, the online behaviours, the clicks) that are used to generate a diagnosis that transforms life by determining what is allowed, what is suggested, and even the things that remain out of perception because ‘they are not what you really want.’ [...] If the algorithm knows ‘what I want’, there remains little room for ‘what I don’t know I want’”. Ibid., 137-139.

45 Roberta Buiani: Re-Mapping Life: From Info-Scientism to Affective Ecologies in Medical Visualization and Beyond. In: *Approaching Religion* 7.2 (2017), 50-61, 58. <https://doi.org/10.30664/ar.67736>.

46 “A tangible desire to approach the operation from a new, unusual, unexpected point of view”; “the desire for change”. Iaconesi, Persico, *La cura*, 180.

volevano essere parte attiva del processo di trasformazione del significato della parola *cura* e degli impatti di questo cambiamento sulla medicina, sulla malattia e sul benessere della società, delle scienze, della politica. Volevano essere gli attori di una performance biopolitica che parlasse di vita e di umanità, della loro complessità, dell'informazione, della comunicazione, dei saperi; e attraverso tutte queste cose, combinate insieme, volevano contribuire a definire una realtà più positiva, possibile, costruttiva, solidale e libera.⁴⁷

In these reactions, the questions that Audre Lorde asked about her experience with breast cancer certainly resonate and the quest of meaning for the individual is never apart from the quest of meaning for the collectivity:

How do I provide myself with the best physical and psychic nourishment to repair past, and minimize future damage to my body? How do I give voice to my quests so that other women can take what they need from my experiences? How do my experiences with cancer fit into the larger tapestry of my work as a Black woman, into the history of all women? And most of all, how do I fight the despair born of fear and anger and powerlessness which is my greatest internal enemy?⁴⁸

This “Transformation of Silence into Language and Action”⁴⁹ breaks the taboo of the disease (which seems to be particularly strong for cancer) and brings it back into society, into public debate. It is important to note that both Audre Lorde and Iaconesi and Persico, in creating language and action, build a discourse that is very different from the dominant media discourse. This collective narrative discourse is an example of a form of life-writing that “can facilitate a holistic approach to care as by considering the individual not just as a body that requires treating, but as a human interacting and being influenced by the world around them” and through which “awareness can be raised about different social and cultural factors that can impact health and well-being”⁵⁰.

47 “[They] wanted to be active participants in the process of transforming the meaning of the word cure and the impacts of this change on medicine, illness, and well-being in society, science, and politics. They wanted to be the actors in a biopolitical performance that spoke about life and humanity, their complexity, information, communication, and knowledge; and through all these things combined, they wanted to help define a more positive, possible, constructive, supportive, and free reality.” Ibid., 180.

48 Lorde, *The Cancer Journals*, 218-226.

49 Ibid., 234.

50 Frances Cadd: *Life-Writing*. In: Paul Crawford, Brian Brown, Andrea Charise (eds.): *The Routledge Companion to Health Humanities*. New York, London 2020, 276-281, 279.

The artists' attitude was indeed very distant from what the media expect from a patient. The artistic duo realized that their way of narrating through the performance was the opposite of what the media was looking for: through the performance, Iaconesi and Persico seek to slow down the flow and build collective meaning beyond codifications, labels, and bureaucratic or commercial logics; instead, the media must attract maximum attention, audience, to guarantee themselves views, ratings, advertising revenue. Despite all the efforts of the authors, the media kept getting back into categorization of illness and patient (and his struggle against cancer⁵¹), oversimplifying the ideas behind the performance and the performance itself and falling back, again, into reductive forms of codification.

The authors decided to divide all the information they received into three macro-areas: “la *knowledge base* (la base di conoscenza), la discussione e la vita”.⁵² The first area contained all the information shared with the aim of finding a cure for cancer: from nutrition to experimental therapies but also works of art, games or travel suggestions to deal with the psychological and human complexity of the disease. The second area was a kind of large journal in which to collect messages received, notes on live conversations, photographs, newspaper clippings – essentially the relationships with people, dialogues and emotions related to them. The third area, ‘life’, contained everything that could not be catalogued and classified, a space without software “perché si configurava dentro di noi come uno stato di stupore informato dal continuo flusso degli eventi”. The three macro-areas thus formed “un ambiente [...] mentale, tecnologico, informazionale, di servizio, di comunicazione, esperienziale”, a form of “*etnografia peer-to-peer*”.⁵³

One of the elements that helped them make sense of all the data and information they were receiving was the overwhelming desire to participate, to contribute to this collective journey to not only find a cure for cancer but also to fundamentally redefine the concept of cure itself. In fact, they write that “la sensazione era di assistere alla creazione emergente

51 The codification of illness and patient in the media when they refer to cancer is almost always connected to a military terminology, as Sontag already pointed a few decades ago: “The controlling metaphors in descriptions of cancer are, in fact, drawn not from economics but from the language of warfare: every physician and every attentive patient is familiar with, if perhaps inured to, this military terminology”. Sontag, *Illness as Metaphor*, 64.

52 “The knowledge base, discussion, and life.” Iaconesi, Persico, *La cura*, 190.

53 “Because it was configured within us as a state of awe informed by the continuous flow of events”; “mental, technological, informational, service, communicative, experiential environment”; “*peer-to-peer ethnography*”. *Ibid.*, 191.

di un intelletto esteso e partecipativo, in cui tutti contribuivano con il proprio sapere e le proprie competenze, in maniera dialogica e conversazionale”⁵⁴.

In this extended intellect, the concept of information was addressed not only in technological terms but also in genetic terms. According to Pier Mario Biava, physician and author of the book's preface, on the one hand “la vita si organizza sulla base di programmi informativi che forniscono, alla stregua di applicazioni, pacchetti di istruzioni precise” and, on the other hand, “l'informazione trasportata contiene anche l'indirizzo di destinazione”.⁵⁵ Biava's approach to cancer aims at reprogramming cancer cells through “un codice, definito *epigenetico*, in grado di regolare l'accensione o, al contrario, lo spegnimento dei geni che sono responsabili della sintesi delle diverse proteine”.⁵⁶ Underlying this approach is the research based on the reasoning that what cancer cells express is an inability to correctly decode information:

questo avviene perché il codice che le cellule tumorali utilizzano per interpretare i messaggi che arrivano dalle cellule sane del corpo è un codice che appartiene a una delle possibili configurazioni presenti negli stadi indifferenziati dell'embrione (di fatto le cellule tumorali sono cellule staminali embrionali), in cui il messaggio di fondo significativo è: organizza la vita. E così le cellule tumorali organizzano la propria vita, anche se questo avviene a spese dell'intero organismo, di cui esse non fanno più parte.⁵⁷

If cancer is also an information and code problem, *La cura* becomes “un viaggio nella rottura dei codici”.⁵⁸ In this collective journey to break the codes which organize our lives in their various aspects, the authors thus move from hacking to epigenetic reprogramming, presenting a narrative and performative action that can shed light on the challenges posed by the development of powerful computational technologies and advances in sci-

54 “It felt like witnessing the emergence of an extended and participatory intellect, with everyone contributing their knowledge and expertise, in a dialogic and conversational manner”. Ibid., 219.

55 “Life is organized on the basis of information programs that provide, like applications, packets of precise instructions”; “the carried information also contains the destination address”. Pier Mario Biava: *Prefazione*. In: Iaconesi, Persico, *La Cura*, 11-22, 20.

56 “A code, termed *epigenetic*, that can regulate the switching on or, conversely, the switching off of genes that are responsible for the synthesis of different proteins”. Ibid., 15.

57 “This happens because the code that cancer cells use to interpret the messages coming from the healthy cells of the body is a code that belongs to one of the possible configurations present in the undifferentiated stages of the embryo (in fact, cancer cells are embryonic stem cells), in which the underlying signifying message is: organize life. And so cancer cells organize their own life, even if it is done at the expense of the whole organism, of which they are no longer a part”. Ibid., 17-18.

58 “A journey into code breaking”. Iaconesi, Persico, *La cura*, 244.

entific disciplines such as medicine, of course, but also neuroscience and biotechnology. Or, as Borg and Policante put it, “It is no longer possible to think of the molecular realm of the genome as being isolated from socio-economic tendencies, technological interventions and political struggles”.⁵⁹ The work of Iaconesi and Persico engages in this critical approach, bringing the focus on the consequences of translating biological life (DNA and medical data) into digital information “that may be copied, stored, transmitted, edited and hacked”.⁶⁰

As they search for meaning in this constant flow of information and codification, the authors turn their attention to cybernetics and ecology and the relational aspects of this sense-making process. They come to view consciousness as an ecosystem, something that is made and constantly shaped by interactions with other subjects and objects, human and non-human. Thus, they write that this approach requires “una profonda riconsiderazione dei confini tra gli individui: se la nostra coscienza origina tanto da noi quanto dalle nostre interazioni con gli altri, deve cambiare la nostra concezione di cosa siano un individuo, una relazione, l'ambiente, la città e la società”.⁶¹

The need to rethink the way we conceptualize the individual, consciousness and life itself is a key part of their work, it is the result of the experience of going through the illness in the collective and inclusive quest for meaning they have begun. This self-narrative journey through MH touches on biology and technology and on the interactions of different information flows and different agents, human and non-human. In doing so, the authors anticipated the debate on issues that would become mainstream only a few years later: the role and possibilities of artificial intelligence, of biotechnological tools such as CRISPR-Cas9 and of the work on consciousness and intelligence that is being developed in neuroscience and other disciplines with theories such as ‘active inference’, which tries to explain how the brain and consciousness work.⁶²

59 Borg, Policante: *Mutant Ecologies. Manufacturing Life in the Age of Genomic Capital*. London 2022, 15.

60 Ibid., 65.

61 “A profound reconsideration of the boundaries between individuals: if our consciousness originates as much from us as from our interactions with others, our conception of what an individual, a relationship, the environment, the city, and society are must change”. Iaconesi, Persico, *La cura*, 251.

62 To have an (over)simplified idea, Karl J. Friston's hypothesis is that consciousness is reducible to the law of physics and active inference theory views the brain as a prediction machine (that treats information probabilistically). The topic is too wide and complex to be detailed here, so I refer to some fundamental texts: Thomas Parr, Giovanni Pezzulo, K. J. Friston: *Active Inference: The Free Energy Principle in Mind, Brain, and Behavior*. Cambridge, Massachusetts, 2022; Mark Solms: *The Hidden Spring: A Journey to the Source of Consciousness*. New York 2021; Anil K. Seth: *Being You: A New Science of Consciousness*. London 2021. As for the debate about intelligence, its possible definitions and the forms it can take, I refer to

Perhaps, the most important aspect of their performance is that they started this collective dialogue and reflection from the direct experience of an illness that disrupted the flow of meaning of their lives. From this starting point, they have rooted the debate in the everyday experience of a large community, contributing to the necessary endeavour to define new theoretical frameworks for our digital era, beyond the academic milieu to which this debate often seems to be relegated.

Conclusions

Moving from the individual to the collective dimension and from the question of the illness to the functioning of society itself, Iaconesi and Persico show a possible path for a deeper understanding and a redefinition of illness, health and cure. Because illness is never isolated from other than medical aspects and the sick person is not separated from the rest of society. Thus, to question these definitions, which belong to the health and medical domain, is to question the structure of our society and its underlying ideology. Moreover, we can argue that, as *La cura* shows, MH can be a privileged field of knowledge where it is possible to create a fruitful debate between medical professionals, humanities researchers and people who have suffered or are suffering from illnesses in order to underline the complexity of the experience of being sick and its interconnection with all the other aspects of human life. The work of Iaconesi and Persico appears to be unique, on the one hand, for the original idea of searching for an open source cure for cancer that is collective and that tries to cover medical, nutritional, psychological, cultural, existential and relational aspects; on the other hand, because this questioning goes so deep in the search for meaning that almost nothing is left unquestioned and the implications of this work can reach far beyond the medical field.

They reflected on the different information flows in our society, from the personal data that is extracted from us or that we share online to the communication dysfunction that occurs in cancer cells, from how our consciousness manages complex processes to the story we tell ourselves, whether we are healthy or sick, to the way in which we can break

Catherine Malabou: *Morphing Intelligence: From IQ Measurement to Artificial Brains*. New York 2019; Max Tegmark: *Life 3.0: Being Human in the Age of Artificial Intelligence*. New York 2017; Nello Cristiani: *La Scorciatoia. Come le macchine sono diventate intelligenti senza pensare in modo umano*. Bologna 2023; Luciano Floridi: *The Ethics of Artificial Intelligence: Principles, Challenges, and Opportunities*. New York 2023.

the codification and regain a deeper, fuller humanity for individuals and for society as a whole.

The complexity that emerges from their work concerns the medical issue in a sense that touches the whole depth and fullness of being human, a condition that exceeds the reductive codification of patient. Medical professional, people who have cancer and those who accompany a loved one through the disease could benefit from this approach. Even more, since the book is an instruction manual more than a simple narrative, they could use it as a toolbox, as a trace to follow for everyone in their own way, also because “If ‘Medicine’ (capital M) stands for the power of the clinical encounter and assessment, and the authority of diagnosis and treatment, then the articulation of the experience of such processes maps out a path by which the patient might reclaim the meaning of being unwell”⁶³.

The meaning-making journey that Iaconesi and Persico built with their performance is, on the one hand, a radical and fully successful attempt to redesign the relational paths between medical professionals and the people who seek their help. On the other hand, and on an even deeper level, they participated in the contemporary debate about the radical transformations that digital technologies and advances in science have brought about, and they did so in a collective and grassroots way. If “The humanities are a means to think critically and ethically about emerging biotechnologies, especially in the fields of genetics [...] and disease control [...] and their societal impact at a time of rapid acceleration [...]”⁶⁴ the work of Iaconesi and Persico still stands, after a decade, as a significant example to follow.

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63 Stuart Murray: Afterword: Health, Care, Citizens. In: Anne Whitehead et al. (eds.): *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh 2016, 627-632, 628.

64 Claire Nettleton and Louise Mackenzie (eds.): *Art and Biotechnology: Viral Culture from CRISPR to COVID*. London 2024, 3.