LA CURA, AN OPEN SOURCE CURE FOR CANCER

Salvatore Iaconesi
Faculty of Architecture,
University of Rome "La Sapienza"

Abstract

When I was diagnosed with brain cancer, I opened up my medical records to the Web, asking for help. The response was incredible: a global source of crowd-generated information about how to cure my own cancer. This work explores the many issues involved in handling such a peculiar form of information (including privacy, preserving the complexity of the human being, the reliability of responses, and more) and the outcomes of the overall process.

"[Critique] does not aim to make possible metaphysics which becomes, in the end, science; its aim is to look as more as possible beyond and beside at the infinite work of freedom."

—M. Foucault, "What is Illuminism"

"Maybe today the most important objective is not to understand what we are, but to refuse it. We must imagine and build what we could be, to drop that political double bind which is constituted by the simultaneous individualization and totalitarianization of the structures of modern powers.

   The conclusion might be that the political, ethical, social and philosophical issue today is not to liberate individuals from the State and its institutions, but to free ourselves from the State and from the individualization which is bound to the State. We must promote new ways for subjectivity through the refusal of that kind of individuality which has been imposed to us for so many centuries."

—M. Foucault, "Why Study Power: The Question of the Subject"[1]

WHEN YOU ARE DIAGNOSED WITH CANCER, or with any other disease as serious as cancer, your life as a complex human being disappears, replaced by a series of protocols, data, images of your body, clinical exams and their results—vital parameters.

The human being disappears, replaced by information and images.

The people around you change, as well. Doctors speak a difficult language, which you don't understand and is not really meant for you to understand. Your disappearance also affects your friends and relatives: they greet you with "What do the doctors say?" before even saying "Hello."

In August 2012, I was diagnosed with brain cancer.

And I disappeared. If for a short while.

The first symptoms of this disappearance have been the progressive encoding of my life, starting with the hospital. Everything there immediately becomes encoded: the times

of your day, the places you can go, the food you eat, the medicines you have to take…Furthermore, this state of hyper-codification is not the subject of any dialogue. The hospital system and doctors do not contemplate it. It is "the protocol;" the doctor said it, someone else decided it (who?).

One day, during my short stay at the hospital, I discovered a thing.

Starting my journey as a "cancer patient," I began using the Internet to find out more about my condition, using scientific publications, web sites, social networks, e-patient portals, and information web sites about food, environment, traditional remedies, and even magic. And here it was: the most ecosystemic of human diseases—whose fundamentals deal with the environment we live in, the things we eat, the rhythms and stress of our daily lives, and with our lifestyles—unfolding at my curiosity's avail.

I had rapidly become a brain cancer research center even while being in the hospital: Nobody was really interested in telling me anything, in speaking with me, and I immediately opened up the process, using the Web.

One of the things that had the most evidence in all the major information sources at my disposal was nutrition. For example, many scientific publications show how cancer cells depend on sugar, needing much more than other cells in the body.

Sugar. Horror: immediately! The food they were giving me at the hospital was full of it! From breakfast, to snacks, to dinner, to a little cake on Sundays. Were they mad? They were trying to kill me.

No. It "simply" was about bureaucracy and administration. The catering companies hold very simple agreements with hospitals: Each day they provision a set number of calories, distributed along simple parameters (proteins, vitamins, fat…) and a series of profiles (omnivore, celiac, vegetarian, allergies…). None of these parameters allowed, *de facto*, to seriously approach the discourse on nutrition or to leverage the enormous amount of scientific and traditional resources that are available. Patients are forced to "do it yourself," hoping to understand the recommendations and organizing their meals in other ways (only available to the patients who actually have someone to bring macrobiotic food and vegetables for them).

And this is only the beginning.

> "THE HOSPITAL SYSTEM AND DOCTORS DO NOT CONTEMPLATE IT. IT IS "THE PROTOCOL;" THE DOCTOR SAID IT, SOMEONE ELSE DECIDED IT (WHO?)."

One day I asked to have a printed out image of my cancer.

I wanted to see it.

To speak with it.

To force it to leave the realm of taboo, and say to it: "Hi Cancer! How are you? What are you doing there? What is your purpose? Let's find an agreement!"

I wanted an image of MY OWN cancer to chat with it. And it was not possible.

Regulations on privacy (even though it was *my* cancer), on insurance issues (what if we tell him he has cancer and it's not true and he sues us), and on administrative/technician/technological issues (it is really hard to find a person in the hospital who is simultaneously authorized, able, and available to put an image of your own cancer on the USB stick you are handing them).

It was not possible to obtain an image of my cancer. I started to understand. This whole story was not about me. This industrial process that we call medicine was not really interested in me. But, rather, with a really simplified version of me, with all the complexity taken out, replaced with a truly and dangerously limited and encoded version of me. A version that had really little to share with me, so much as to be impermeable to any dialogue and reunification.

I was not expected.

The next day I left the hospital against doctor's orders. Before leaving the hospital, I asked for a digital version of my medical records: I really wanted that image of my cancer. Back home I had a surprise—and a confirmation. The digital archive was in DICOM (digital imaging and communications in medicine) format.

Technically speaking, it is an *open format*, with a peculiarity: It is really accessible and usable by professionals, not by *normal* people. The main purpose of this format is to simplify the transfer of data and images from one professional to the other. It is assumed to be taken and delivered to the next doctor, to the next professional.

Again: the human being is not expected. Not part of the equation. Disappears.

The effect of this comprehension was instant: I opened the files of my medical records, and I exported them in formats

that are accessible to anyone from their web browsers, smartphones, and e-mail (Fig. 1).

I published them (made public) onto a web site, *la Cura,** through which I asked everyone in the world to become diseased with me, to take part in my condition and, thus, in the cure.

The result has been amazing. Hundreds of thousands of artists, designers, researchers, doctors, surgeons, traditional healers, poets, and patients have shared stories, experiences, advice, therapeutic suggestions, works of art, ideas for web sites, services, online systems, and devices (Fig. 2).

An enormous space for discussion immediately opened up in which science, art, design, and personal stories each took the

> **"ONE DAY I ASKED TO HAVE A PRINTED OUT IMAGE OF MY CANCER. I WANTED TO SEE IT. TO SPEAK WITH IT."**

best from one another. A radical transformation instantly configured itself, in which human complexity was allowed to emerge: a continuous state of simultaneous translation from one language to the other in which it was not so strange for a neurosurgeon to speak with me and with a traditional Chinese doctor in a sincere attempt to learn from each other, to devise answers and solutions together, and to put them back into the ecosystem (Fig. 3).

People activated themselves. In between performance arts (Fig. 4), artworks (Fig. 5), and architectural projection mappings featuring the images of my cancer (Fig. 6), people formed discussion groups to verify hypotheses and share the results with everyone else, in an enormous, *collaborative and desiring* effort.
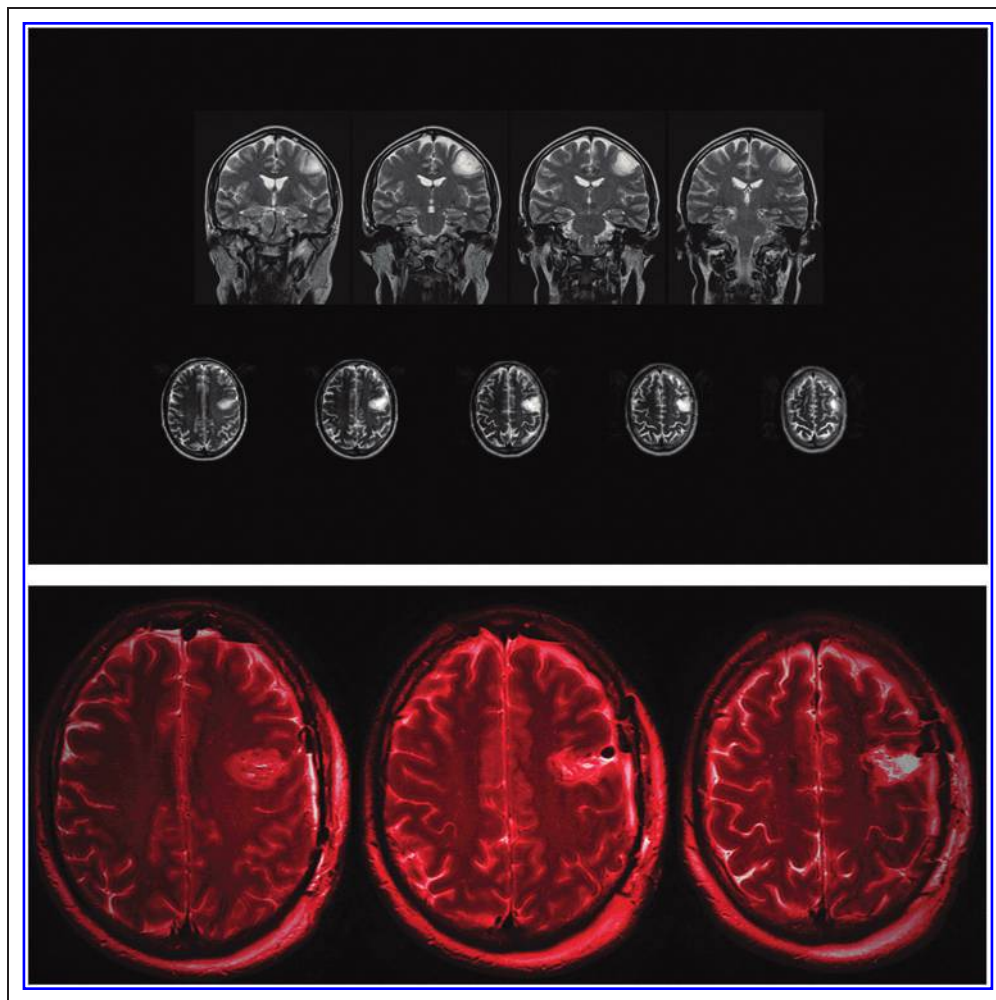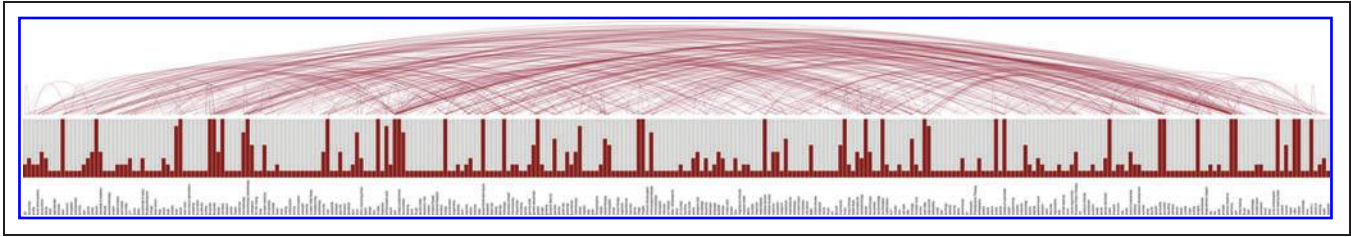

FIG. 1. The cancer and red cancer.

FIG. 2.   Information visualization of the online discussions.

"La Cura" has spread very quickly online and in traditional media,[2,3] and there have been more than 500,000 responses to it. These figures do not include the enormous number of comments posted on the Youtube and Facebook channels (e.g., only contributions via email and through the web site are taken into account in this figure).

With such a massive amount of information, we have been forced to use approaches that go well beyond those of traditional databases: This enormous amount of unstructured data was something that could not be approached lightheartedly (people were suggesting all kinds of cures), and information was simply too much to be handled manually.

We started developing tools to deal with all this information, including natural language analysis to subdivide information according to topics and factions as well as the use of a direct quantitative approach (e.g., relevant topics are the ones that people discuss the most and with coherent motivations/references).

But this approach, too, failed to highlight the most interesting elements that were being contributed, which were of two kinds:

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- technical
  ○ these were proposed solutions to technical problems (e.g., the technique used for surgery, a specific treatment);
  ○ in this domain a quantitative approach could be used to identify the most interesting things to watch out for in positive ways (e.g., the list of success cases for surgical techniques) and negative ones (e.g., the mythologies about alternative treatments, which could be aggregated—for example, under themes such as "Cannabis cures"—and easily observed, analyzed, and separated to verify the quality of the references provided);
- adaptive
  ○ these represented *in-between* advice/narratives, ranging from stories, personal experiences, advice about nutrition, artistic/poetic responses, among others;
  ○ while topics and keywords could be identified within them to simplify their navigation, it made little sense to aggregate them in any form: Each one constituted a different story/approach and really made much more sense if taken into account on a case-by-case basis;
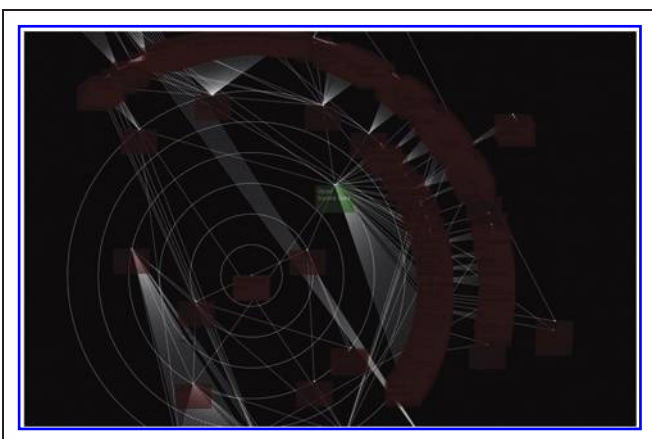
FIG. 3.   Information visualization of the online discussions.

FIG. 4.   "La Cura" at MAXXI Museum, Rome.

FIG. 5.   "The Healing" by artist Francesca Fini.

◦ these also represented an immense set of useful insights: through narratives and references that were not automatically verifiable, a wealth and richness of insights about nutrition, personal experiences, and stories emerged that have been fundamental to my well-being.

In the end:

- technical solutions were easily (and automatically) identifiable, and tools were quickly developed to be able to analyze them from a quantitative point of view (to analyze their success history across references and contexts) and then from a qualitative one (once the "more interesting" were identified, they were more thoroughly analyzed by me and my doctors/experts to judge and open discussions about them);
- adaptive contributions were organized according to topics/keywords/relations for easy navigation and access,

> **"WE CURRENTLY FIND OURSELVES IN A PARADOXICAL SITUATION IN WHICH ORGANIZATIONS AND INSTITUTIONS REALLY HAVE A HARD TIME DEALING WITH COMPLEXITY."**

and an additional, collaborative, crowd-based layer was built upon them;

◦ users could open discussions to extract information, create relationships, provide working hypotheses, and, in general, help me build a commons-based knowledge base that could be used in more general terms and with enhanced usability/accessibility by anyone wishing to dig into the scenario of the approaches available to confront cancer;

◦ artistic, poetic, activist, spiritual, and creative-oriented suggestions were also part of this domain, and they were successfully integrated into the overall information ecosystem.

This story implies many different things, from the more intimate to the more universal.

Here I will focus on three of them:

- complexity
- welfare
- open knowledge

We currently find ourselves in a paradoxical situation in which organizations and institutions really have a hard time dealing with complexity. Anthropological, social, economic, psychological, emotional, and spiritual complexity: these dimensions are all needed and fundamental to understand the dynamics of human societies. The large part of organizations—be it hospitals, global companies, or governments—live in a culture that does not include complexity, diversity, multiplicity, or the polyphony of the cities, regions, and nations of the planet.

In *la Cura*, we have been forced to do it. It was a matter of "life or death," so to say.

FIG. 6.   A three-dimensional replica of my cancer by Patrick Lichty.

And the results have been incredible.

We escaped the protocols, the procedures, the fill-in-the-blanks forms, and we embraced complexity. We created new tools in the process: technological ones, but, more important, cultural and relational ones.

This has opened up new spaces for discussion and relation. Domains in which to express ourselves with our science, art, and strategies with only one focus: the well-being of humans and their societies. These spaces—which are natively *peer-to-peer*—institutions, and organizations do not cease to exist but assume new roles that are really important: they become facilitators and enablers, to allow for the emergence of all these types of complexity, and of guarantors.

This is a new model. Truly new.

And now we have the technical tools to enact it.

What is missing is the awareness and profound desire to make it happen.

Welfare.

With the excuse of the crisis, everything is being taken away from us.

I have recently been in the United States for my Eisenhower Fellowship. I spoke about *la Cura* multiple times, even at TEDMED and TEDGlobal. When I told about how my surgery, in an excellent research center, cost me only 15 euros, they were amazed.

Access, basic rights, the respect of this wonderful constitution that we gave ourselves a few years ago: the right to health and to work.

Rights.

We must not be lazy: to maintain welfare, solidarity, and social sharing, we have to activate ourselves at all levels of society.

La Cura has shown this: the existence of a society that can really be aware that society is well if all of its members are.

The existence of a society that is able to share stories, experiences, knowledge, capabilities, arts, projects, resources, hospitality, and money with a single purpose: the well-being of human beings.

Open Knowledge.

I won't repeat the statistics that show how, if research, data, and knowledge would truly open up, if closets and drawers would open to reveal technologies, molecules, techniques, practices, and knowledge:

- many diseases would disappear;
- many of our energy issues would vanish;
- many elements would become clearer and comprehensible;
- many more researchers, representatives, scientists, experts, professionals, and ordinary people would have many more tools to open up planetary dialogues;

in a transformation that would be anthropological, not merely quantitative.

I will say this: open data, big data, are useless if they are not based on an anthropological, cultural, and attitude transformation; on the sense of desire for reappropriation of our reality and of our complexity as human beings.

This, for all of us, has been a global performance: for the reappropriation of our freedoms, complexities, and humanity.

It is an open source cure.

For all of us.

References

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Address correspondence to:

Salvatore Iaconesi
"La Sapienza" University of Rome
via G. Ghislieri 14
Art is Open Source (AOS)
00152 Rome
Italy

E-mail: salvatore.iaconesi@artisopensource.net