

Re-mapping life

From info-scientism to affective ecologies in medical visualization and beyond

In this paper, I discuss the significance of medical visualization in relation to recent creative practices that could dismantle, or at least redress, some of its most long-lasting tenets. In fact, driven by an almost cult-like and disproportional trust in mechanization, quantities (of data), quantification and medical visualization tend to either isolate and fragment life and its constituents, reducing it to a series of discrete fragments, or to re-compose, modulate and filter these constituents through sophisticated aesthetic systems and clever design schemes, creating dogmatic and standardized views of phenomena and general trends in the study of diseases. In reflecting upon this special form of 'info-scientism', I would like to draw attention to the potential benefits of visualization beyond the immediate ones deriving from the display of large amounts of scientific data and from its alleged and much worshipped mechanical accuracy. Specifically, the question I pose is: what happens when the relational and affective aspects of medical phenomena – elements considered marginal because subjective and un-measurable – are re-introduced? I will focus on two particular examples that prioritize an ecological approach over the current strictly numerically and technologically run practice of information validation and visualization.

I will use Ron Wild and Joseph Geraci's *Oncomap* as a case study that seeks to reveal, and at the same time transcends, the conceptual paradigms informing the faith in quantification and data collection of visualization. An artist/scientist collaboration, *Oncomap* attempts to visualize the complexity of cancer research, diagnosis and treatment in one single place in order to underline its complicated technical, scientific and emotional intricacy. I will briefly compare the above visual example to another interdisciplinary endeavour, *La Cura*, whose effort towards data sharing and data trans-

parency aims to fight the isolation of the patient, and blind reliance in the authority of one medical entity.

Zoom in - zoom out

Technicians, clinicians and researchers have recently been enjoying a variety of technological devices and visualization techniques designed to help interpret, diagnose and communicate specific medical conditions. New data-mining techniques and the digitization of scientific and medical procedures have made it possible to capture and synthesize specific details about phenomena that might otherwise lie undetected. New visualization software has enabled scientists to examine, package and communicate these data in more immediate visual forms (Friendly 2008). This seems to be another example of the benefits of new technology enhancing scientific discovery and innovation. The specific qualities of digital tools (mainly their scalability, variability and partial numerical automation, as described by Manovich 2001) have enabled visualization to process increasingly large quantities of data, rendering this practice a very versatile activity, which can zoom in and dissect particular objects of research, capturing their recondite details in all their molecular and/or fractional minutiae. At the same time, it can zoom out and capture an entire phenomenon in its entirety, as an agglomerate of colourful and interdependent parts.

The rise of the trend known as Big Data, which as a consequence of its popularity and growing technological accessibility has brought about a new confidence in the mechanisms and technologies of visualization, claiming to measure, rank and classify all aspects of the world in precise and allegedly

objective, yet aesthetically stunning, ways (Dalton *et al.* 2016, Thatcher 2014). It is not surprising then that many scientists and clinicians have welcomed its emergence with much enthusiasm, seeing as they do, in the ability to access, collect and represent increasingly large sets of data using semi-automatic digitization processes, a remarkable opportunity. (Murdoch and Detsky 2013, for instance, spoke of the application of Big Data in healthcare as an ‘inevitable’ step.) By capturing and synthesizing data extracted from examinations and medical procedures, a particular organ, or systems of organs are treated as maps and are reproduced in forms easy to read, not only to better examine a condition, or to establish the existence of anomalies, but also to create more communicable illustrations. Visualization studies specific morphological configurations by displaying the parts of which a micro-organism is composed, based on digitized data from an electron microscope, or by simulating the strings of proteins existing in a virus (Chandler and Roberson 2009). With their clarity and accuracy achieved thanks to a combination of aesthetics and technology, these illustrations are very effective in communicating particular information about diseases, dysfunctions and anomalies. At the same time, they seem to immediately inspire confidence in the information displayed.

Take for instance the simulations produced by the Biomedical Simulation Lab at the University of Toronto (Steinman and Steinman 2011). One of their goals is to create visual models and animations that render the blood flow inside aneurysms starting from data collected from delicate medical procedures such as angiograms (fig. 1). The resulting simulations are often created with a number of professional and communicative purposes in mind, involving intense and multi-phased exchanges of information and communication between clinicians, technicians and engineers. To facilitate communication, these simulations need to offer an overall, clear and visual rendition of the phenomenon: this means that graphics and aesthetics have to be mediated in order to allow all professionals involved to read the simulations leading to the data consistently (Steinman and Steinman 2007). The resulting visualization is not a realistic portrayal of the aneurysm, but an ideal rendition containing only those data which are necessary to achieve its effective comprehension. The objective is to visualize different dynamic behaviours within the occluded blood vessel that will be useful in identifying the

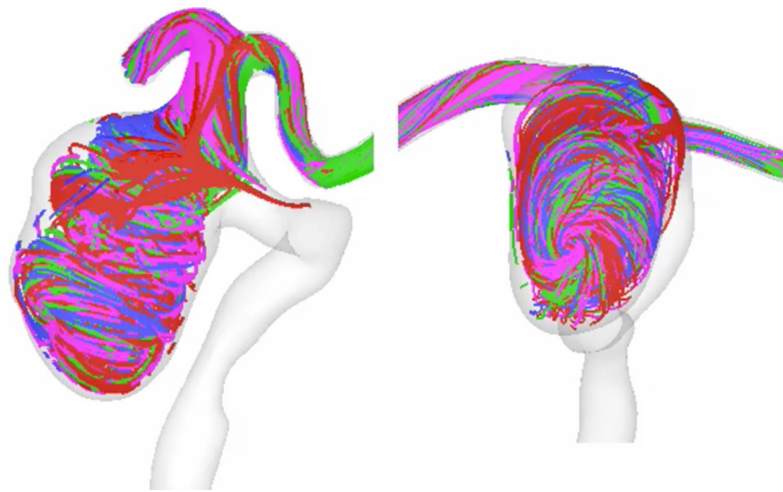


Fig. 1. Virtual slipstream animation of pulsatile flow in a giant aneurysm CFD model reconstructed from 3D rotational angiography. Courtesy of David Steinman, Biomedical Simulation Lab, University of Toronto.

particular condition of the patient and will possibly lead to a correct diagnosis. While data included in the simulation are selected to serve a specific set of goals, other less useful data are discarded. In this case, the visualization zooms into the object simulated: the viewer is not provided with a picture of the entire organ; just a disembodied section of the artery, which the observer is not obliged to contextualize for the sake of understanding.

Visualization can also help zoom out on a general trend, providing a bird's-eye, general and all-encompassing view of a given phenomenon, disease or set of diseases, or a genetic map or epidemiological study. One may recall the classic epidemic maps popularized in the nineteenth century by John Snow (Koch 2011). Thanks to their visual clues, these maps famously fostered impressive breakthroughs in the understanding of epidemic outbreaks in certain areas, or were instrumental in finding their cause (Lynteris 2016). Epidemiological data and statistical forecasts are usually anchored to geographical maps which illustrate the spread of an infectious disease over a territory, or the effects of environmental and social conditions in causing certain diseases in certain regions. These maps often accompany studies such as the rise of cancer in polluted areas or the specific incidence of the diabetes epidemic in a specific location (Serlin 2010).

Recently, innovative applications and ingenious design methods have been devised to contain larger amounts of abstract data, or data that are not

anchored to a geographical area. Strategies include placing data in circular formations, as in the case of Circos (Introduction to Circos 2017; Yang *et al.* 2013, see fig. 2), a layout model which allows the researcher to upload and order large amounts of data onto a single circular graph. Skilfully partitioned and colour-coded, these circular maps are relatively easy to decipher, providing reading clues that direct the reader to understanding general trends generated by particular phenomena and circumstances.

Using these new methods, data from research into complex diseases can be extracted, collected and curated into viable visual artifacts. In turn, these artifacts can help communicate the nature and progression of a condition across a variety of disciplines. They can also spark (or so it is assumed) new research and boost the understanding of previously obscure conditions. Finally, they can facilitate a patient's grasp of the nature of a disease, thanks to the immediacy afforded by the image (Anderson 2008).

However, when we stand in front of the visualization of a medical condition, or the pictorial rendition of a genetic map, something always appears to be missing. In their aim to depict medical research as accurately as possible, many of these visualizations come across as impersonal and self-contained. In their attempt to explain a phenomenon correctly and precisely, they end up omitting the multiple relations and cooperative exchanges occurring between the various practitioners working on the same subject (Bollier 2010). In their effort to eliminate personal judgments in favour of detached, unbiased objectivity, they not only efface any sign of the patient and their personal experience of the disease, but also isolate their subjects from the surrounding context. It is as if the organs portrayed in these images and animations were separated from the body of the patient and taken out of context.

While this observation is in no way meant to be a criticism of the effectiveness or the efficacy of visualization in a medical context, these examples tend to make us forget that the medical practice (and the research connected to it) is very much based on personal relationships, involving often uneasy relations between the practitioner (or whomever is responsible for constructing the visual artifact) and the patient, as well as those elements that reveal the extent of the patient's suffering or the stigma that certain conditions may entail. In fact, there exist both contextual and affective features that make every condition

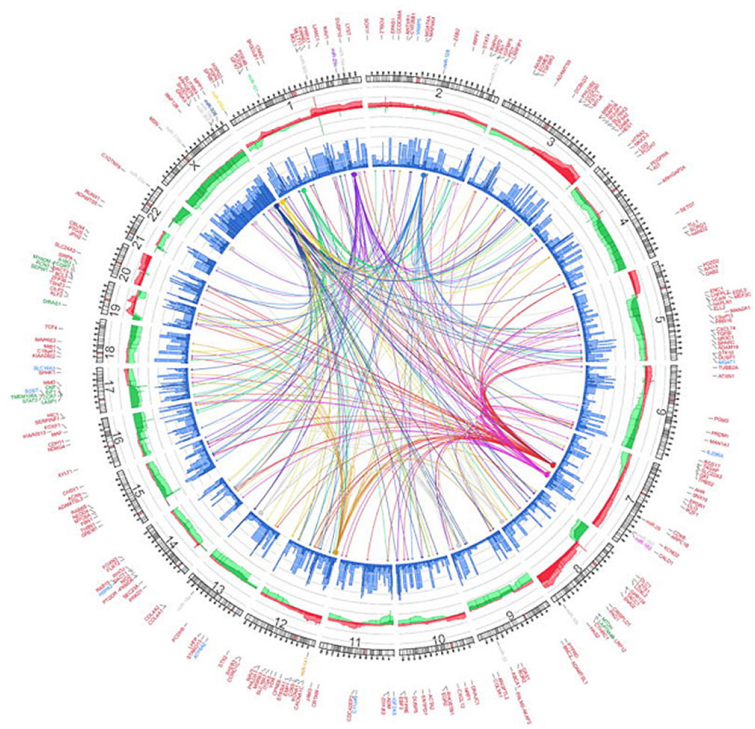


Fig. 2. Integrated analyses identify a master microRNA regulatory network for the mesenchymal subtype in serous ovarian cancer. Yang *et al.* 2013.

unique; a particular condition will be experienced differently, both physically and emotionally, by different patients (Parsons 1951, Wilde 2007).

These considerations are suppressed by an often exaggerated confidence in new technologies and methods of display that claim to provide sharper and more precise – and thus supposedly more accurate, content. However, these features are not of marginal importance. The suffering of the patients and their personal experience of a condition, the technological, social and personal layers implied in any scientific and medical practice, are all elements that add complexity to the work of the clinician and the medical practitioner. For instance, the latter may struggle to understand why the development of a disease reproduced on a map, or simulated using normalized data do not always succeed in accurately anticipating its course; they may be puzzled as to why individual patients react differently to certain drugs; they may be wondering why a particular condition should not be treated as an anomaly in certain patients (Mol 2002). Does the often fragmented and disembodied view of hyper-specialized illustrations inhibit the achievement of a more comprehensive (though less specialized) grasp of the complexities that underlie a

disease? As today's visualization techniques become increasingly filtered by technologies and increasingly rely on Big Data to formulate diagnoses and to understand human conditions, they don't seem to be willing to take into account the relational and affective aspects of medical research and practice outlined above: is there a way to bring them back? And how important is it to bring them back?

In examining this issue, it is important not to think of the advances in visualization as a failure. Visualization may or may not help us improve and communicate medical research; it has certainly facilitated advancements in scientific and medical research (Steinman and Steinman 2011, Smelik 2008). However, in this paper, I am less interested in what visualization communicates, than in how this information is communicated. Specifically, this essay asks whether reassessing the hierarchical status and the infallibility of the data that disease maps, visualizations and medical illustrations manifest and rely on (Cartwright 1995), may actually change the way we understand those data; whether such a shift might encourage the researcher to look at the context that surrounds these data and the ecologies that modulate them; whether we may devise a more holistic approach that uses different methods and techniques to seize the complexities of a condition or a disease; or to establish better and more humane relations between practitioners and patients, or between different professional figures (Mol 2002).

Info-scientism: quantity, quantification and mechanization

Despite their invaluable richness of detail and their accuracy in portraying either one specific occurrence, or a whole set of interconnected phenomena, today's increasingly extensive body of visualizations explicitly omits a variety of aspects from the phenomena examined: namely, their contextual significance and their relation to other external phenomena or individuals that may affect the objects under examination (Dalton and Thatcher 2015). The area of medical visualization (that is, visualizations aiming at illustrating the presence of a disease, as well as its development and associated interventions for the purpose of research or therapy) is no different from any other areas in which visualization is heavily employed (Cartwright 1995). But while contextual elements may be missing in today's digital and

quantified artifacts, for a long time previously they did seem to accompany medical illustrations. The expulsion of these elements has coincided with a gradual erosion of the role of human judgement in favour of mechanical reproduction, as direct observation has given way to technologically enhanced observation and digitally filtered renditions via data collection (Dror 1999, Daston and Galison 1992, Stafford 1993). An exaggerated trust in the superiority of quantity, quantification and mechanization has led to what I'll refer to in this paper as 'info-scientism'.

In examining scientific and medical images of the body disseminated in the seventeenth and eighteenth centuries, Lorraine Daston and Peter Galison (1992), and Barbara Stafford (1993) have each observed how the illustration of medical conditions, as well as natural and scientific phenomena, gradually turned towards quantification as a means of validating research, and towards mechanization as a strategy which renders human observation obsolete. This tendency, Jonathan Crary clarifies, likely arose as the result of a simultaneous transformation of the way technological devices allow us to find and record information, and the way that the '...plural forces and rules composing the fields in which perception exists' (Crary 1990: 6) change over time and thanks to a number of other socio-economic factors. There is an increased faith in quantification, as the ability of technological devices to improve the knowledge of a human body now perceived as fragmented and multiple. At the same time, the resulting improved knowledge about the body is imperative to 'the formation of an individual adequate to the productive requirements of economic modernity and for emerging technologies' (*ibid.* 81). In this formulation, life emerges as object of power; as a biopolitical entity.

Daston and Galison suggest that objectivity in the form of quantification and mechanization did not substitute 'subjectivity' as a former and opposite approach. In the seventeenth century in fact, 'epistemology aspired to the viewpoint of angels; nineteenth-century objectivity aspired to the self-discipline of saints' (Daston and Galison 1992: 82). Here angels and saints stand for a divine, thus indisputable authority, based on knowledge inherited from tradition rather than on current observation. The rise of objectivity is not a way to 'efface the features of the scientist' (that is, their subjectivity) but substitute a former authoritative, religious higher order to aspire to with another authoritative order, this time

represented by mechanical objectivity. As with saints and angels before mechanization, the 'ideal of objectivity ... attempts to eliminate the mediating presence of the observer: some versions of this ideal rein in the judgments that select the phenomena, while others disparage the senses that register the phenomena' (*ibid.* 83).

Stafford (1993) points out that the iconographic tradition of the seventeenth and eighteenth centuries pertaining to the medical illustration of diseases, while keen on accurately portraying how a disease would manifest or how it would affect the patient, contained elements that exceeded simple visual 'recording'. Stafford uses the term 'unseen' to refer to what cannot be expressed with words or images, or by using any language that precisely addresses it (visual, written or spoken). Illustrators of this period had a keen interest in capturing and transmitting elements such as fear, pain and discomfort, insidious danger and terror. These only to a certain extent constitute subjective or aesthetic interpretations of the effects of a disease over an individual. They are also attempts to record and to map the symptomatic course of a disease.

Being at that time the only observable indication of the presence of an ailment, these visual accounts retained scientific value to help diagnose and identify current and future similar diseases. Besides their scientific merits, these early medical chronicles did not shy away from reproducing the practitioner's personal interpretation of the suffering of the patient, distaste for the grotesque manifestations of the disease and anxiety concerning a disease that could be potentially dangerous both for the clinician and for other individuals. The obsessive attention to morbid details and the physical degradation that these diseases caused, both unlocked pity for, and stigmatized, the victims, as if they were somehow responsible for their own ailments. By focusing on bodily manifestations, and by fostering the construction of collective and medical narratives that helped the understanding of various diseases, the illustrations considered by Stafford function as a primitive form of human epidemiology.

For Stafford, 'unseen' is a term that reminds us of an early visual incarnation of the notion of 'affect'. According to Gilles Deleuze and Félix Guattari, affect is an ability to affect and be affected. As opposed to 'feelings' which belong to the sphere of the personal, and 'emotions' which are primarily social, affect

comprises pre-personal intensities 'corresponding to the passage from one experiential state of the body to another and implying an augmentation or diminution in that body's capacity to act' (Shouse 2005). Considering this definition, the unseen can be interpreted as simultaneously what we don't, we can't, and we are not allowed to see, a pre-existing and preconceived, but not-yet-revealed sign of perception unraveling an area of exploration that unsettles any scientific aspiration towards establishing clear or indisputable conclusions; a relative and generalized certainty. The gradual introduction of scientific instruments partially mechanized the process of seeing, visually reproducing and recording. These enhanced processes could collect an increasing amount of information. Along with these new additions, came a tradition that progressively trusted mechanization as the ultimate solution to the shortcomings of subjective judgment, or, as Daston and Galison argued, a tradition that uses '... mechanically reproduced images in order to avoid suspect mediation' (Daston and Galison 1992: 81).

This approach also originates from an overall trust in quantity and quantification, two connected but distinct qualities that have dominated many scientific disciplines since the seventeenth century. For Cray, it is crucial that we do not separate mechanization/quantification as technological innovations devoted to improving empirical research, and as an epistemological transformation in perception itself. In fact, much of the visual innovation has an empirical function not only to cope with and to understand the complexity of the subject examined, but also to comply with new epistemologies of power and new conceptions of perception (Crary 1990).

Today, there is a certain insistence (biopolitical in its nature) in excavating as many precise details from a complex phenomenon as possible, as if collecting more information helped us not only to see it (thus understanding it) more clearly, but also to control it. This translates into a general belief that the larger the amount of data collected and aggregated from a given phenomenon, the more accurate the solutions to its quandaries will be. A widely held idea is that visualization is simply a 'transformer directing a deluge of data' rather than 'a form of data in itself' (Turnbull 2015: 73). Second, quantification has been interpreted as a way of providing specific details about phenomena that other non-quantifiable disciplines could not provide, and a way to separate them from

non-exact disciplines such as poetry, or the arts (Dror 2001). This tendency is often intensified by the sectorial divisions that define different, yet connected medical practices, and by the methodological differences that define the researcher, the clinician and the technologist (Steinman and Steinman 2007).

The quantitative approach and reliance on quantitative and semi-automated research require that one makes selections, eliminates noise, as well as other elements that may obfuscate important findings because they are thought to be ‘unnecessary’. Any aspect deemed superfluous simply doesn’t make it into the illustration. Operating various degrees of selection in this variety and volume of data is, for Edward Tufte, a necessity that supersedes all forms of visualizing and mapping. Refusing to do so would indeed make data illegible, as they would be too rich and thick in detail to be deciphered in any appropriate way. Scientists have to make compromises and choose the amount and type of data to highlight (Tufte 1991). Yet, these compromises ‘assume that every object has the same importance as any other and that everything is, or can be, connected to anything else’ (Manovich 2001). In other words, data are assumed to be originally neutral and can be collected, modulated, and recombined infinitely. As a result, it becomes epistemologically difficult to transcend the ‘legacy of Cartesian ontology and post-Cartesian rationalism within the knowledge systems that have informed the rise of computation’ (Munster 2006: 3) and, furthermore to understand affect as a fundamental concern that should not be dismissed, but rather be given a high degree of attention, especially when interpreting medical data.

Recuperating affect

Craig Dalton and Jim Thatcher explain that data ‘are necessarily situated and partial’ (Dalton and Thatcher 2015). According to Thomas Turnbull (2015), data only make sense when they are examined in their context. By relying exclusively on quantity and quantification, we create a gap between the information collected and its context, resulting in a progressive loss of connection, as context becomes superfluous and all the attention becomes focused on data conceived of as ‘pure’ and impartial. This leads to a failure to critically read data, or to ‘contest [their] creation, commodification, analysis and application’ (Dalton *et al.* 2016). Sadly, recuperating some form

of critical approach is hindered in two apparently contradictory ways: on the one hand, the increased reliance on mechanization and quantification has led to ‘info-scientism’, that is, the belief that data are more impartial than qualitative observation – not only that are data more reliable, but also superior to qualitative findings. On the other hand, information is believed to be well-communicated only when it is trimmed down and curated into a comprehensible form. Thus, while a large amount of data may be collected, not only will only the most relevant be included into the visualization but they will also be arranged according to established principles.

This approach seems to be no different from looking into a petri dish: in the same way the scientist isolates a microbe in order to protect and examine it in its pure form and without external interference, medical visualization isolates, selects and displays its data in a delimited space, promoting a detached observation. Similarly, when a large amount of information is gathered onto the same map or graph, data are aggregated in clusters and classified according to established principles, and in order to answer particular research questions. This selective approach feeds the viewers the details according to what they should be focusing on. As a result, many of the questions that visualization claims to tackle are destined to remain partial, as the view of the object observed is mainly directed to fit specific goals. This curated, petri-dish approach is exclusionary by nature: despite claims of impartiality it nevertheless provides a partial view; despite assertions that it isolates and separates an object of inquiry as if to divest it of contextual detritus, it ends up incorporating other arbitrary elements deriving from one’s professionally and culturally informed interpretations of that object. Thus, while the explicit function of visualization is to offer information devoid of any contextual (relational) and affective (emotional) hints, it does contain other elements that anchor it to a specific environment, professional structure, epistemology.

Natasha Myers defines the act of visualizing as an act of ‘rendering’. Rendering is not just a matter of reproducing an object that stands in for something else, but a combination of gestures that she defines ‘performative’ by nature. In fact, these gestures do not merely refer to ‘the object that is rendered, but also to the subject, the one who renders, and the activity of rendering’ (Myers 2014: 154). The complexity of the phenomena resulting from the data mining process

are 'renderings'; they are selectively 'curated' to make space for consistent results, or to give rise to plausible and easily readable outcomes. Here, richness and diversity are tamed in favour of clarity. In fact, the process of reduction (Lynch 1988) produced by digitization and visualization is a metaphoric necessity and not just an 'aesthetic flourish' (*ibid.* 159). The metaphors comprising this process are lures that direct practitioners' imaginations and experimental inquiry' (Stengers 2010). Visualization then is '...like the materialized refiguration that corporealize(s) life in the form of information systems' (Myers 2014: 142).

As Gina Neff points out, people and professionals come to imagine data in very different ways, according to their public and target audience and to the meanings they want to communicate. This practical strategy, she argues, 'neglects key aspects of the social interoperability or integration of data into health solutions. How will such data be integrated into care providers' work practices; through the complex routines of clinics and hospitals; and into existing legal, social, political, and economic frameworks' (Neff 2013)? Collecting and aggregating increasing amounts of information leads to the discovery of new, previously unseen connections, as data-intensive health becomes an exciting research frontier for the benefit of the public good. But these data escape us, as analysing the intricacy that characterizes them doesn't necessarily lead to better clarity. Single procedures claim to reproduce a phenomenon as self-contained. However, they only succeed in focusing on limited aspects of a phenomenon. In fact, the attempt to govern by encapsulating data within the range of a single graph, an image, or a delimited space ends up neglecting and thus misrepresenting the relational aspects (environmental and contextual aspects, personal experience, pain, etc.) that also contribute to these images. In addition, the 'liveliness' of emerging knowledge is channelled through institutional and practical narratives and the necessity of simplifying and reducing all 'politics' (Esposito 2008: 28) lurking behind the production and representation of visualized artifacts.

For Neff, 'a computer usually looks at one small aspect of the patient's problem but doesn't get the context. An expert doctor can understand the huge picture of what's going on with a patient' (Neff 2013). However, as most doctors or expert professionals are generally not trained in working across disciplines,

the medical illustrations and the visualizations they read tend to reproduce the same reductive and heavily quantified landscape they should be questioning. In fact, as medical visualization has gradually acquired a more specialized appearance and function, so the role of the medical practitioner has transformed from that of an interpreter who claims a special (if authoritarian) relationship with the patient (Wilde 2007) to a disinterested figure whose professionalism is in fact measured according to a somehow detached, and therefore un-biased and impartial approach. Nonetheless, both the medical practice and most research in the medical field are distinctively relational and deal with and produce affect: they require intensive exchanges and frequent dialogues with patients and other practitioners; they sometimes involve personal and emotional work; they often produce experimental and tentative work that does not always fit every patient or produces fixed results and scientific certainty. The mapping and visualization of medical conditions promotes an appreciation for discrete data and digitized, quantified items. One wonders, then, what kind of visual (and non-visual) solution could help recover the relational aspects and complex affective elements I have mentioned above.

The tendency to reduce and isolate, celebrated in the field, has also triggered many creative attempts to re-imagine the potential outcomes of visualization as a practice, by activating affective and relational qualities through the visual arts and socially driven interventions. I contend that these strategies may foster new approaches in the field of visualization and beyond, aimed at looking at the phenomena researched as ecologies and as complex clusters of events with far reaching outcomes, rather than as self-contained objects; as uniquely and temporally situated, rather than strictly determined and frozen in time. A strategic modulation of aesthetics and cultural references shared across different individuals and professionals may also lead to an affirmation of medical imaging and visualization as relational practices; that is, as practices that facilitate the relationship between the researcher, the clinician, and the patient, and that are not only able to hybridize and transform, but also to recuperate, the complexity of life.

Ron Wild and Joseph Geraci's *Oncomap* (2013) is the product of a collaboration between a mathematician and medical physicist (Geraci) and an



Fig. 3. Oncomap. Wild and Geraci 2013.

artist/engineer (Wild). It consists of a large visualization map spanning several disciplinary areas. The goal is to address the scientifically complex and bureaucratically intricate world of oncology research as a whole, rather than as a fragmented constellation of microactivities and practices. The map exists in analogue form (on a canvas) and as a Gigapan map, a digital technology that allows the viewer to magnify and explore an image at extremely high resolutions (fig. 3). According to the authors, the complexity characterizing the field and the bureaucratic engine governing it damage the human relations between doctor and patient and between the different professional figures involved in studying, diagnosing and curing cancer. In addition, they contribute to intensifying the feeling of loneliness and lack of empathy endured by both scientists researching in the field and by people who have to undergo any treatment.

The Oncomap was created with the aim readjusting traditional understandings of the scientific practices in oncology research and to make manifest those elements that cannot be measured and recorded through a scientific process or through ad hoc visualization. These elements include the relation between clinician and patient or technician and researcher; the emotional labour which characterizes cancer management; the bureaucracy involved in the big machine that is oncology as a diverse area of research, and so forth. These relations and subtly yet firmly intertwined items underscore the relational aspects of oncology and reveal its affective qualities.

But Oncomap also works as a critique of info-scientism: the prominence of data and models, as well as the sheer amount of data presented in the map in their very specific and very different forms, cause a sense of disorientation in the observer. In addition, they inevitably raise questions about their complexity and their complicated management, the lack of real connection and dialogue that often characterize research, even when it is geared towards a particular disease. Finally, they make us question today's obsessive faith in the efficacy of data and quantification in the face of poor human communication.

Drawing on Geraci's everyday research working at the Department of Pathology and Molecular Medicine (Queen's University) and at the Toronto General Hospital, the map contains a dense network of heterogeneous and interconnected items, ranging from mathematical equations, hard data and genetic maps interspersed with vignettes displaying moments from the everyday life of the medical practitioner. These heterogeneous items are not only located side-by-side, revealing each other's – sometimes unusual – interrelations, but they are also sitting next to other items that clearly show the relation between the practitioner and the patient, the procedure that the patient has to undergo, and the tools through which cancer care operations are transmitted and organized.

As an artifact, Oncomap is not easy to read. Items come without written explanations. As a result, to a person who has no scientific knowledge, the work

looks more like a colourful pastiche than a coherent map. Upon further observation, the observer may realize that among the items on display there are some very familiar elements: the doctor's badge, the image of the cancer patient undergoing therapy, the rat being used in drugs research, the protein folds visualization dancing before one's eyes, are all evocative of how intricate and difficult it is to navigate this field.

While *Oncomap* contains real data, such as protein models, mathematical formulas and genetic sequences from Geraci's own research, it could not be considered a scientific product to be studied by a practitioner or a medical professional for the purpose of training or research. It does not provide any specific information about any medical condition. *Oncomap* has a different pedagogical value. The map asks the viewer to pay attention to the difficult, often intense relationships between patients, clinicians and scientists: seeing how one's therapy or research is being directed may provide better awareness of the wider network that revolves around cancer care; it makes visible, and thus may improve, the relation between different individuals involved in this complex network (from the patient to the surgeon, to the geneticist); it reveals not only the intricacy, but also the volume of information that circulates in the field. Quantitative data visually reproduced in this map are repurposed to provide a qualitative understanding of a general context without dismissing the scientific content.

As a map combining scientific visualization, visual tropes and other non-scientific items, *Oncomap* does not seek to provide pragmatic information to be used in developing new research initiatives. The fragments it contains are re-contextualized to draw attention to the relational and affective aspects of cancer research and care. While it does not play a crucial role as a scientific product, nor is it made for scientific research, it does have a distinctive conceptual value. In fact, when positioned side-by-side with visualizations displaying parts of organs, data, or medical processes, it could play a significant role in reminding clinicians, researchers and patients alike that there is more to research in the medical field than quantified data and focused, self-contained imagery. By offering different views connected inside the same artifact and by encouraging the viewer to take note of the context surrounding a particular data, *Oncomap* has the potential to create a shift in the communication of

medical research and in the comprehension of its fragmented body of work.

The progress of a cult of quantification and mechanization, along with their claims to accuracy, is arrested and takes on new meaning once the context surrounding certain scientific visualized and statistical data is revealed. In the following example, the affective aspect of human experience with a disease and the medicalization of the human body as the result of a diagnosis become the beginning of a rebellious journey against the assumed authority of the medical practice. *La Cura* 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.

In 2012, Italian designer, artist and activist Salvatore Iaconesi was diagnosed with brain cancer. He suddenly found himself in a situation where he was no longer a human being but had become 'his own tumour'. As doctors dispensed advice that felt more like impositions to follow the typical path of many other patients with the same tumour, he was caught in a medical system intent on measuring, visualizing and examining his condition but did not seem to see him as a whole person (Iaconesi 2013). In Iaconesi's words 'the patient is a strange being that is, on the one hand, entirely made of data: blood exams, images of body parts, lab values, diagnoses' (Delfanti and Iaconesi 2016: 126). Not only did he realize that as a patient, he was no longer considered an individual, but a fragmented entity, but that part of this disembodied entity had been taken away from him. In fact, all the examinations that had been performed on him and that provided some important information had been stored in a format which it was not possible to share with him.

His response has now become *La Cura*, a long-term project that extends well beyond medical treatment or data sharing. In an attempt to rebel against the reductive constraints imposed by medicine, and to break free from an inflexible and impersonal medical system, that is, to de-medicalize his condition, Iaconesi obtained and released his medical data online and turned to its community to seek advice, medical and otherwise. His request was not exclusively of a medical nature but had a broader 'symbolic' value, drawn by a need to open up '... cancer's

“source code” as a biopolitical rite of healing, aimed at redefining concepts such as “disease” and ‘cure ... to reappropriate the condition of being ill, and to foster a society that recognizes disease as a complex experience – one felt by social bodies as much as individual bodies’ (Delfanti and Iaconesi 2016: 124).

Iaconesi describes his experience with the medical system as a ritual made of never-ending routine scans, repeated examinations, blood work, etc. ... during which both his body and his humanity were seen as fragments and as if they were simply a bundle of data: ‘...your body, personality, and social connections disappear, and are replaced by data and images’ (Delfanti and Iaconesi 2016: 128) (fig 4). The use of the term ‘ritual’ in defining this series of actions is telling: in fact, individuals performing a ritual are usually only partially aware of the meaning behind their gestures. These gestures are habitual, collective and symbolic, as if to honour an authoritarian dogma whose meaning is not always evident but is respected nonetheless. In the medical ritual Iaconesi was caught up in, everything is obsessively quantified and passed through body scans, software and digital models. By subverting the system he contravened the ritual, and became ‘a bad patient’: he not only refused to abide by the ‘machinery of medicalization ritual’, but also proceeded to share his data with unknown individuals.

The act of sharing in this case is not just meant to disseminate information with the purpose of receiving more. By turning to a community of friends and strangers, Iaconesi welcomed and eventually recovered human and affective elements that had been lost in the extreme operation of reduction he had endured during his experience with the medical system. This gesture is a gesture of care. As Maria Puig de la Bellacasa explains, caring is ‘everything that we do to maintain, continue and repair our world so that we can live in it as well as possible’ (Bellacasa 2017: 3). It is becoming aware that ‘studying and representing things have world-making effects’ (*ibid.* 30). It is a way of thinking and speaking beyond what we assume to be some social and ‘politically’ useful research.

La Cura (as a project led by Iaconesi and his partner Oriana Persico) has now evolved into a series of workshops revolving around social issues, installations reflecting on more-than-human relationships between the human, the social and the natural body and has as one of its mottoes ‘the cure does not exist if not in society’ (La Cura 2017). While critical of the objectification of the patient through a dispropor-

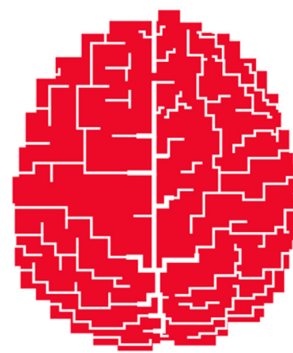


Fig. 4. La Cura. Salvatore Iaconesi and Oriana Persico: screenshot from <<http://opensourcecureforcancer.com>>.

tionate faith in data, La Cura does not reject data: it uses information and scientific visualization in combination with social dialogue and meaningful sharing as if they were all part of a complex ecosystem, within which data are only a bit-part, not the protagonist. In addition, La Cura draws attention to the impossibility of understanding disease as a self-contained item or as a conglomerate of data. The important presence of the social and the emphasis on human relations underline the added value that the environmental and material conditions surrounding the body bestow. These elements in fact always end up affecting the body in various ways.

Conclusion

La Cura and its long-term performative journey into the meanderings of cancer research and management emphasizes the role and use of affect in treating medical data (especially when it comes to personal medical data), and the necessity to regard such data as part of a very complex context (and therefore relational). Here, the visualization of medical data and cancer information, as well as other items used in diagnosing, curing and, importantly, comforting the patient, become part of an affective ecology that combines different practices and links different individuals, fostering not only dialogues and discussions, but also artistic interventions and political considerations concerning care and social responsibility.

The lesson to be learnt in this rather extraordinary situation is that a similar interdisciplinary strategy may be useful to initiate a shift in the priorities of the medical field from data to affect and from quantification and purification to contextual and

critical analysis. While its goal and reach lies more strictly within the area of visualization, the importance of this shift is also highlighted by Oncomap. In both cases, it is possible to observe a shared concern towards the disproportional role that ‘datafication’ – what I have called throughout this article ‘info-scientism’– directly deriving from quantification and mechanization has achieved. Specifically, this increasing reliance on data has brought about a decrease in our ability to critically approach data as elements of a whole diverse and highly complex system, rather than as autonomous items. The quest for objectivity has caused an increasing disbelief in human judgment and its consequent dismissal as subjective and inadequate at best.

The two cases presented as examples are not meant to substitute medical visualization as an advanced tool for envisioning, diagnosis and finding new cures. However, they work to shift our understanding of visualization from something which is delimited and isolated to something which is part of a whole ecology of relational and affective items. The two examples also function as warnings that unless we accompany these visual sources with an appropriately critical eye and an increased consideration for human complexity and uniqueness in its immersion into a specific context, we may miss much evidence and many solutions that are right before our eyes. ■



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when they are decontextualized, re-purposed and relocated through artistic and cartographic practices. Her artistic work is mobile, itinerant and collaborative. She has brought it to art festivals (Transmediale 2011, Hemispheric Institute Encuentro, Brazil 2013), community centres (the Free Gallery Toronto, Immigrant Movement International, Queens) and scientific institutions (RPI). Her recent Cabinet Project was an experiment in ‘squating academia’, a practice aiming at repopulating abandoned spaces inside the university with collaborative works in art and science. She holds a PhD in Communication and Culture from York University (CAN). Information about her publications and her upcoming book can be found at <<http://atomarborea.net>>.

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