ELSEVIER

Critical Reviews in Oncology/Hematology 84S2 (2012) S5–S10

CRITICAL REVIEWS IN
Oncology
Hematology
Incorporating Geriatric Oncology

www.elsevier.com/locate/critrevonc

Constructing the Medical Humanities gaze

Marco Annoni, Giuseppe Schiavone *, Luca Chiapperino, Giovanni Boniolo

SEMM (European School of Molecular Medicine) & IEO (European Institute of Oncology), Via Adamello 16, 20139 Milan, Italy & Faculty of Medicine, University of Milan, Milan, Italy

Contents

Abstract

In the last few decades genomics has completely reshaped the way in which patients and physicians experience and make sense of illness. In this paper we build upon a real case – namely that of breast cancer genetic testing – in order to point to the shortcomings of the paradigm currently driving healthcare delivery. In particular, we put forward a viable analytical model for the construction of a proper decisional process broadening the scope of medical gaze onto human experience of illness. This model revolves around four main conceptual axes: (i) communicating information; (ii) informing decisions; (iii) respecting narratives; (iv) empowering decision-making. These four kernels, we argue, map precisely onto the main pitfalls of the model presently dealing with genetic testing provision. Medical Humanities, we conclude, ought to play a pivotal role in constructing the environment for competent decision-making, autonomous self-determination and respectful narritivization of one's own life.

Keywords: Medical Humanities; Decision-making; Autonomy; Narrative medicine; Information provision; Empowerment; Breast cancer; Genetic susceptibility

Prologue: The case of Mrs. Smith

"The real voyage of discovery
consists not in seeking new landscapes
but in having new eyes"
Marcel Proust

Mrs. Smith is a woman in her forties. Mother of three she lives in a quiet suburban neighborhood. Unlike other women, though, Mrs. Smith recently learnt that she comes from an Ashkenazi descent. This, her doctor said, entails being subject to a higher risk for breast and ovarian cancer. Overall, she is told, 12% of Caucasian women are at risk for breast and ovarian cancer; among these, 27% have an inherited genetic mutation [1], of whom 5–7% have a mutation in a single high penetration gene, such as BRCA1/2 [2,3]. A variety of options open up for women in such condition, all of which would put Mrs. Smith in front of difficult choices. First, she has to decide whether to undergo genetic testing for breast cancer susceptibility. Second, depending upon the test, she may face the choice of undertaking preventive therapeutic surgery. This procedure may amount to oophorectomy (the surgical removal of ovaries), hysterectomy (the surgical removal of womb), and – in the case of uterine fibroids arousal – myomectomy (the surgical removal of fibroids) [4]. This is

* Corresponding author at: SEMM (European School of Molecular Medicine) & IEO (European Institute of Oncology), Via Adamello 16, 20139 Milan, Italy & Faculty of Medicine, University of Milano, Milano, Italy. Tel.: +39 02 943 75022.
E-mail addresses: giuseppe.schiavone@ieo.eu (G. Schiavone); giovanni.boniolo@ieo.eu (G. Boniolo); marco.annoni@ieo.eu (M. Annoni); luca.chiapperino@ieo.eu (L. Chiapperino).

1040-8428/$ – see front matter

the toolkit of technical information and possible choices, indeed scientifically robust, that Mrs. Smith would be provided with.

But in which ways is her decisional landscape reshaped by medical information provided in terms of risk-percentage, susceptibility and genes-interactions? And to what extent is such communication adding value or displacing the way in which she can make sense of her prognosis?

Introduction

> "Do you see this egg?
> With this you can topple every theological theory,
> every church or temple in the world"
> Denis Diderot

In the last century medicine has undergone tremendous changes. From surgical procedures in organ transplantation to stem cell therapy and reproductive technologies, health-care provision has increasingly been technology-driven. In recent decades, some of the most significant advances have been accomplished in the light of the genomic revolution. Whole-genome sequencing, combined with high-throughput analysis of data sets, has opened up a host of new diagnostic tools as well as new therapeutic strategies. In a nutshell, the vision brought about by what we shall henceforth call the "molecular gaze" is that of making eventually visible the underlying molecular nature of phenomena such as cancer, thus rendering them explicable, diagnosable and curable up to an unprecedented degree.

Indeed, the adoption of a "molecular gaze" has been of tremendous importance for contemporary science, health care and people wellbeing. However, while such gaze can reveal new epistemic objects, it may also constrain their interpretation, potentially leading to a sort of 'peripheral blindness' that may conceal both their theoretical and normative assumptions as well as their implications for individuals, science and society.

As we argue in this short contribution, looking at the experiential landscape of medical subjects only through the lens of the molecular gaze leads to a higher, but substantially monoscopic, resolution of the objects of medical practices, be they diseases, therapies or prognosis. We suggest that there may be a way of opening a second eye – i.e. the eye of the Medical Humanities – onto those very same objects, rendering the vision of medicine, eventually, stereoscopic.

"Seeing things" versus "seeing things as"

> "I call our world Flatland, not because we call it so,
> but to make its nature clearer to you, my happy readers,
> who are privileged to live in Space"
> Edwin A. Abbott

Scholars in philosophy and history of science have been aware since long that scientific instruments not only provide new ways of seeing old phenomena, but also means of creating new epistemic and meaningful objects of observation [5]. Similarly, early 20th-century physics has taught us that technological progress is directly correlated with our capacities to make visible and visualize physical phenomena [6,7]. In both respects, the case of biomedical technologies, and in particular of molecular genetics fore-casts, is telling.

As with breast cancer single-gene mutations, genetic tests do not create *tout-court* new objects. Nevertheless, by making such mutations visualizable these tests reshape in multiple ways not only how we can think about our future – now as people "at risk" – but also how we decide to live in our present, e.g. by taking preventive surgical measures or by adopting healthy lifestyles. Though we are no more "genetic and molecular" beings than we were three decades ago, people are increasingly perceiving, representing and thinking about themselves in terms of risk factors, pathological molecular pathways and epidemiological findings. In order to understand the impact of molecular medicine on people and society, it is essential to question both the assumptions and the implications brought about by its distinctive gaze.

While there are several contributions that reconstruct the genealogy of molecular medicine [8], here we shall try to question some of its implications, asking which are the potential blind spots produced by such a stance, and how they may reverberate on patients' experience. Our aim is not that of providing punctual solutions but rather that of identifying areas of potential interactions between contemporary medicine and the bundle of scholarly practices that are now clustering under the umbrella term "Medical Humanities". We will do this by limiting our analysis to the case of information provision in genetic testing. How can the adoption of a purely molecular eye transform the very idea of one's prognostic future in such cases? In order to answer this question, a useful starting point, we maintain, is that of departing from the distinction between "seeing" and "seeing as" elaborated by the philosopher of science Norwood R.L. Hanson [9].

According to Hanson observation is always theory-laden. This implies that we never "see things" as purely optical phenomena; rather, we always "see things as", already filtered by our interpretative, linguistic and conceptual schemes. In order to illustrate this point, Hanson resorts to the example of Tycho Brahe and Kepler. Though the two astronomers "see" the same optical phenomenon – the sun –, they see it "as" diverse things because of their two different astronomical theories. In a similar way, optical illusions such as the well-known "duck–rabbit" illustrate how the same physical drawing can literally be "seen as" two different things. In both cases, increasing our power of resolution would not make much of a difference: having a more powerful telescope would not resolve the contrast between Brahe and Kepler, just as looking closer at the drawn image would not change our seeing it as a duck or as a rabbit. In seeing, no eye is innocent [10], and different