Managing Uncertainty in Biomedical Innovation from Below

Exploring Tensions and Contradictions in Oncology and Pregnancy Cases*

Barbara Morsello
University of Padua

Veronica Moretti
University of Bologna

Abstract: The contribution originates from Track 1, "Genetics and biomedical innovation: Between risky and promising scenarios", held within the VIII STS Italia conference. The session was intended to promote reflection on the implications of the latest innovations in genetic research and molecular biology for the formation of new care practices, as well as new surveillance and risk management. The objective of the paper is to highlights the contradictions and ambivalence that may rise from biomedical innovation through analysing two specific cases: 1) off-label practice in the context of rare disease in oncology and 2) pre-natal screening technology and surveillance practices. In both cases, these biomedical innovations, although very promising, produced high uncertainty, and the technologies and/or processes developed to cope with the 'unknown' were challenging. However, at the same time, tensions and contradictions were observed that originated unexpected practices 'from below'. In particular, the following section is focused on the ambivalence that has increasingly taken root in the management of risks related to health with respect to individual contributions and to research and scientific work practices.

Keywords: Biomedical research; genomics; digital pregnancy; self-surveillance; off-label.

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Corresponding author: Barbara Morsello, Biomedical Science Department, via Ugo Bassi 58/B, 35131, Padova, Italy. Email: barbara.morsello@unipd.it.

1. Introduction

The session "Genetics and biomedical innovation: Between risky and promising scenarios" was held in Trieste, Italy, at the VIII STS Italia Conference "Dis/entangling technoscience, vulnerability, responsibility and justice", and focused on the rise of new practices related to biomedical innovation. New screening techniques are profoundly related to emerging knowledge that shapes patients' experiences. Furthermore, reconfigurations of the infrastructures of biomedical innovation have also led to new practices. The common thread in this development is the management of some health-related risks, ranging from top-down forms of regulation and surveillance, traditionally realised under medical dominance, to the recent 'from below' forms of participation in clinical practices, usually expressed by the self-determination of and self-surveillance by patients. The following paragraphs aim to explore numerous different gazes (medical, patients and digital) in the identification and mitigation of some health-related risks, sharing the perspective that even healthy situations can be treated as pathological.

Highlighting the role of human and non-human actors in the reconfiguration of knowledge produced by innovation, the present contribution reflects on two specific cases in which the ambivalences of risk management by laypeople and clinicians were addressed.

Specifically, the first case study concerned how biomedical innovation is shaped by risk management in the clinical context and biomedical research. As emerged during the conference, the tension between 'adventurism' and 'securitism' is particularly visible in the case of oncogenetics and rare diseases, a highly experimental context, where protocols and off-label drugs play a specific role in fostering (or not) innovation. Protocols are conceived as infrastructures that – in certain contexts – must be reassessed, as in the case the prescription of off-label drugs that seems to favour a 'wild' de-regulation process.

The second case addressed new surveillance practices in the pregnancy arena, ranging from screening technologies to online foetus visualisation. This topic was examined to illustrate how pregnancy and birth have been included in the process of self-surveillance and data-sharing. Risk management in the everyday lives of pregnant women continues to use traditional screening practices, but also utilise the ability of subjects to negotiate this type of knowledge in public arenas such as social networks. The medicalisation of pregnancy and birth helps in understanding the surveillance of daily risks faced by pregnant women. Finally, as a consequence of extended medical surveillance, research dedicated to lay strategies towards risks suggests that the possibilities of sharing online ultra-

sound images of the baby-to-be should be critically analysed among scholars.

2. Dis/entangling Biomedical Innovation in Oncology: Between Boundary Infrastructure and Therapeutic Anarchism

This section focuses on the tension between protocols, understood as boundary infrastructures, and off-label clinical practices with the aim of reflecting on 'bioclinical adventurism' as a resource for biomedical innovation, as well as the deep limitations of this approach. Biomedical research is a prolific field of experimentation; thanks to the greater availability of information and new diagnostic biotechnology, a radical evolution in patient care is underway. Predictive medicine, neo-adjuvant therapies, which have recently become widespread in major health institutions, convert a patient's body into a theatre of medical-scientific experimentation, opening new possibilities of care.

The field of precision medicine seems to be a promising way for discovering correlations between DNA mutations and the risk of developing different diseases, helping patients to acquire new practice of self-care and illness-identity, perhaps simultaneously establishing a new regime of proto-illness (Gillespie 2015). Moreover, screening, self-diagnosis, and predictive tests are just some of the practices and tools now employed to gain greater control over disease (Timmermans and Buchbinder 2010). As in the case of genetics, the rise of knowledge acquired by biomedical research and translational medicine have modified and shaped both the experiences of patients and scientific and clinical practices. Genetic screening was envisioned to identify risk factors by creating new bio-clinical entities (Keating and Cambrosio 2003), and such diagnostic approaches are essentially focused on prevention and managing uncertainty. Oncology is a field of great experimentation with new techniques and care practices, involving knowledge from molecular biology, genomics, and informatics, as well as innovating diagnoses and stadiation processes (Huber et al. 2018). Thus, the production of biomedical knowledge concerning the cytogenetic characteristics of the disease and medical treatments is no longer confined to scientific laboratories (Martin et al. 2008; Cox and Webster 2013) but is strongly connected to clinical practice (Crabu 2014; Cambrosio et al. 2018). In line with this, oncology is an assemblage of practices and knowledge where specific 'oncopolicy' may rise to norm clinical and research activities that are also designated to reshape health policy.

Looking at pharma for cancer treatments, drugs have very long and complex trials where data are sources of legitimacy about off-label use, Pascale Bourret (Aix-Marseille University), Alberto Cambrosio (McGill University, Montreal), Jonah Campbell (McGill University, Montreal), Peter Keating (University of Quebec at Montreal) and Jessica Polk (McGill University, Montreal) underlined how physicians play a pivotal role in constructing the legitimacy of off-label uses instead of pharma companies or researchers. Overcoming data legitimacy by physicians imply to reconfigure authority of the data, by posing clinical experience with patient on a new light and this may lead to what the authors call 'therapeutic anarchy' or 'therapeutic adventurism.'

However, several studies have documented the proactive and critical engagement of patient associations in therapeutic and biomedical research in various contexts as a solution to patients' exclusion from health systems (Epstein, 1996; Rabeharisoa and Callon 1999; Panofsky 2011). Notably, patient associations are interlinking the rareness of diseases, the 'politics of numbers,' and patient's involvement in research (Rabeharisoa et al. 2014), playing leading roles in the legitimisation of new care practices.

A striking example of this is 'off-label' treatment. Off-label is defined as the use in clinical practice of drugs or treatments that have already been registered but are used in a way that does not comply with the requirements of the authorised product. The drugs used off-label often include already known molecules that are used in clinical situations for purposes not explicitly approved from a regulatory point of view. This practice is widespread in various areas of medicine where off-label prescriptions make up a conspicuous proportion of prescriptions. The off-label prescription of drugs is therefore allowed and regulated in some cases, even if not explicitly approved, representing an important opportunity that could lead to significant advances in the knowledge and treatment of certain diseases as cancer. On the other hand, the off-label use of drugs exposes patients to potential risks, given that the efficacy and safety of these drugs have been evaluated in populations other than those being prescribed. In contrast, patient organisations argue that such 'exceptional' programs should be thought of and eventually redesigned as appropriate insofar as they bring in 'real-life'-based evidence on the clinical efficacy of the orphan molecules and on their medical and social values. Indeed, the 'off-label law,' from the patient's perspective, take debates out of the strict realm of economic evaluation to issues of unmet medical needs, accessibility, and social justice.

In France, for example, rare disease patient organisations have pushed for RTU (temporary recommendation for use) as an appropriate option for orphan drugs. They argue that there are numerous molecules that have

already passed a series of toxicity tests that could thus be used for rare diseases if they have shown some 'real life' bio-clinical impact on certain aspects of the diseases (Rabeharisoa and Doganova 2016).

However, the wide diffusion of this practice has created new 'alliances' between clinic, laboratory, and pharma. The wide availability of personalised drugs from molecular profiling services – public and private – means that physicians can provide highly personalised off-label treatments. Nevertheless, many of these drugs are introduced with very little information about their effects. This is often the case for cancer treatments, which are becoming increasingly precise and targeted, but there is also poor bioclinical evidence of their efficacy. Finally, failures and successes are not routinely detected when off-label drugs are prescribed. In this regard, it can be problematised if off-label is the only suitable alternative to produce innovation within highly experimental settings and to overcome the stiffness of biomedical protocols.

On the one hand, off-label use can be interpreted as a break in the infrastructural assumptions enshrined in protocols that could be interpreted as boundary infrastructures (Mongili and Pellegrino 2014). Repositioning off-labels in the context of rare diseases transforms treatments and care practices, disentangling patients from protocols giving them more agency about their conditions and experimental treatments.

Rare diseases, in fact, are settings where knowledge is not sufficient to implement new treatment, and therefore protocols are rigid and there is difficulty in producing innovation. This situation takes on the features of a paradox. In keeping with this, off-labels can be perceived as a source of innovation and the way for patients with rare diseases to 'break' the infrastructure.

As remarked by Giuseppina Pellegrino (University of Calabria) in our track, protocols are more than boundary objects. As pointed out by Star and Ruhleder (1996), infrastructures are based on specific relational ecologies and are built around particular works and social practices. Assuming this perspective, protocols become a relational concept, the generator of a set of heterogeneous techno-scientific contexts where data can be produced by all actors involved in clinical settings. Indeed, today we are data citizens and our data are an integral part of our lives, especially related to health and wellbeing. In this vein, the need to explain natural phenomena in formal terms – to make knowledge available to the relevant scientific community and actionable to laypeople – reveals a strong tension between local knowledge, tacit knowledge (Collins 2010), and public knowledge (Knorr-Cetina 1981). This is also because knowledge and innovative practices in biomedicine are increasingly interconnected between clinical practice and scientific research following the model 'from bench to

bed' (Neresini and Viteritti 2014), where patients are simultaneously sources of knowledge and fields of experimentation. The tension between protocols and off-labels in producing biomedical innovation indicates a gap between aspiring to a highly desirable future, in which many serious illnesses will finally have a cure, and the daily organisation of clinical practice and laboratories. The collective dimension of biomedicine shows some limitations, while it also reveals hidden asymmetries and deep inequalities in the so-called post genomic and proto-illness era.

3. From Pre-natal Screening to Digital Foetus: The Surveillance Course Perspective

The main objective of this section is framing modern surveillance practices as they apply to risk management in the pregnancy arena. More broadly, considering the genomic turn of biomedicine addressed in the previous section, being 'at risk', as a new social condition, presupposes the control of individuals through screening practices that can estimate, in numerical terms and through statistical modelling, the chances of getting sick or, in the case of pregnancy, to prevent diseases for foetuses. Over time, as claimed by Foucault (1963), the evolution of clinical practice, as well as the growing development of new technologies, have brought about a change in what is observed, what is found under the microscope of medicine, shifting from a surveillance of symptoms to a surveillance of illness and to the lifestyles of the subjects. Unable to trace a radical clinical distinction between healthy and sick, everyone, according to Armstrong (1995), must be placed in a surveillance network. This Shakespearean limbo produced by the medical surveillance of risks generates a subject suspended between 'to be ill or not to be ill' that has redesigned the boundaries and interests of medicine and, above all, of surveillance. This extension to medical surveillance has been applied to gestation over the years.

Nowadays, in what has been defined as a post-genomic society, risk anticipation surrounding pregnancy has become increasingly pervasive, including not only recommendations on appropriate lifestyles regarding smoking, alcohol intake, and food, but also medical technologies, invasive screening, and numerous genetic tests, thus shaping motherhood. This is interrelated to the concept of intensive mothering (Reich 2018), namely the idea of mothers as able to prevent risks, pursue success, and manage their (future) children's health.

Following Armstrong's (1995) assumption, pregnancy is situated today in an intermediate space between health (normal pregnancy) and disease (pathological pregnancy) (Burton-Jeangros 2004), meaning that mothers-to-

be must control and regulate every single aspect of their pregnancy pathways. If being at risk is often interpreted as a predictor of future disease (Gillespie 2015), we should mitigate the uncertainty (Giddens 1991) through risk anticipation. On the basis of Crawford's definition (1980), healthism is defined as 'the preoccupation with personal health as a primary – often the primary – focus for the definition and achievement of well-being; a goal which is to be attained primarily through the modification of lifestyles' (p. 368). In the pregnancy arena, a dominant view considers the foetus's health of higher importance than the pregnant woman's health and well-being, and this hierarchy makes 'maternal sacrifice' legitimate (Bessett 2010).

The development of new technologies in reproductive health has opened new opportunities for prenatal diagnosis and, at the same time, have contributed to the medicalisation of the prenatal period with the 'normalisation' of prenatal foetal screening (Ettorre 2007). This is in line with the prolific experimentation in biomedical research, as highlighted in the first section. Various studies on the technical surveillance of pregnancy and birth have described future 'mothers' contrasting experiences and expectations regarding risk management surrounding prenatal screening and delivery' (Burton-Jeangros 2004 p. 420). As highlighted by Alice Scavarda (University of Turin) prenatal screening is often intended to function to facilitate selective abortion in case the foetus presents some abnormalities. Therefore, parents who refuse prenatal testing or choose to carry the pregnancy even in presence of a defect or a genetic disorder are deemed responsible for the birth of their disabled child. Motherhood thus becomes a perfect target for medical surveillance and actions taken to define legitimate and illegitimate maternal practices (Ehrenreich and English 1978; Murphy 2003).

On another level, recent developments in mobile technologies are making this practice more user-oriented, as different channels (apps, sensors, and social media) offer new ways of monitoring and measuring the human body and the maternal experience (Lupton 2012). As reported by Adams and Niezen (2015), identifying risk fits the paradigms of individualised and personalised health, where health risks are considered to be manageable and controllable via self-monitoring and self-care.

Surveillance practices and the management of new biomedical risks can be considered an integral part of our ordinary pregnancy routines. They are becoming an everyday activity, routinely performed. In addition, the rapid growth of self-surveillance pregnancy apps raises critical questions about the commodification and surveillance of personal data (Barassi 2015). Based on these premises, it can be argued that the use of the Internet and social networking to present the prenatal experience acts on two different fronts. On the one hand, it encourages what has been defined by Andrejevic (2005) as 'lateral surveillance,' which concerns peer-to-peer monitoring and the use of

surveillance tools by individuals rather than public or private institutions. This form of horizontal control, exercised among peers, is particularly widespread in the pregnancy experience. It involves subjects' (mostly voluntary) self-exposure on the internet and concerns three forms of routinised social monitoring and self-expression, which are integrated into the technological architecture of many contemporary social media platforms: (1) watching and judging (morally, aesthetically, etc.) networked Others; (2) watching Others watching oneself – that is, sensing and anticipating the gaze of strangers as well as of fellow group members; and (3) watching one's own data double – that is, the hypermediated Self in the form of (for instance) geographical positioning or personalised publicity offers (Christensen and Jansson 2015, p. 1480).

However, the representation of pregnancy in the online sphere also acts on a second level. Following Oviatt and Reich's (2019) work, posting status updates, pictures, and events of the prenatal experience could help one to make decisions regarding pregnancy and/or parenting. Already in 2010, Rideout, Foehr, and Roberts presented how groups and channels for prenatal and postnatal periods that appeared to provide visual and textual information about pregnancy, parenting, social support, and humour were popular among future parents, considering the different levels of expertise, community networks, and of course cultural understandings. This constant sharing of the future parenthood experience can impact the practices and representations associated with pregnancy.

Additionally, as Ilenia Picardi (Federico II University of Naples), Sole Alba Zollo (Federico II University of Naples) highlighted during the conference, the dissemination of foetal images on the web through the analysis of a corpus of pregnancy websites/blogs/social media range from weekly development guides to personal birth stories. As a result of the short circuit of the use of the new diagnostic technologies and new communication practices on the Web, pregnant bodies, conceived in the field of biomedical diagnostics as the site of control of pregnancy, become the site for the social construction of the digital foetus.

The extensive sharing of foetal images by parents has enabled a situation whereby corporations have access to important data regarding the unborn. The datafication of the body and this new form of 'foetus-veillance' blurs the boundary between private and public control. Some research (Barassi 2015; Lupton and Pedersen 2016; Ley 2016) has shown that some mothers not only endorse medical definitions of health risks but are also particularly eager to share images and data of the unborn. This creates a digital environment in which participation is often incentivised, and a variety of information is increasingly commercialised.

We do not know whether such data will be lost in the digital ecosystem or whether it will be integrated with other data, effectively impacting children's digital profiles and fuelling other surveillance practices. However, we know that 'data policies do not address this problem and collect children's data by relying on an ambiguous discourse that directs the responsibility, once again, to users' (Barassi 2017, p. 6). Quoting a famous song by the Rolling Stones, "Fingerprint File": 'Keep on the lookout / Electric eyes / Rats on the sell out / Who gonna testify / You know my habits, way ahead of time / Listening to me, on your satellite.'

4. Conclusion

Population screening, self-diagnosis, and predictive tests are just some of the practices and tools now employed to gain greater control over the development of disease, reinforcing the intersection between health, risk, and technology. As Jasanoff (2003) pointed out, risk is part of the modern human condition, woven into the very fabric of progress.

The present contribution proposes a reflection on the tension between new forms of negotiation and participation in biomedical research. Patients' participation in the processes of biomedical innovation is multifaceted; they are both the subjects of clinical experimentation and the sources of genomic data in diverse fields, from oncology to neurodegenerative, metabolic, and cardiovascular diseases. But individual forms of participation as biomedical innovation are also located in other fields, such as pregnancy. Risk management is particularly encouraged in pregnant women, where their everyday lives represent a central feature of the experience of pregnancy.

Through self-surveillance, pregnant peoples' bodies cease to be objects of medical knowledge and become a mode of knowing (Mol and Law 2004). Collecting data about different conditions could increase the set of knowledge and know-how showed by mothers-to-be. Conversely, in highly experimental settings, technological innovation produces new forms of knowledge, as in the case of oncogenetics; however, at the same time, it can become challenging to translate innovation into stable clinical practices. While protocols act as patient safety devices, in the case of rare diseases, they become highly constraining infrastructures for innovation. This tension can lead to the emergence of borderline practices, such as off-label treatment prescription, presenting scenarios that are potentially harbingers of innovation but where the risks of therapeutic adventurism are still poorly under-stood.

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