Body, Politics and Molecules.

Maddalena Fragnito

↑ Life & Death. by Daniel Friedman, CC BY NC 2.0.

The biopolitical history of hormones is longer than one might expect. As early as the end of the 19th century, serums made of animal hormones were used to treat males who were considered too "feminist"[1] and females seen as too "masculine". In the laboratories of that time, hormones were already seen through gendered lenses: estrogens were considered feminizing, while testosterone was seen as masculinizing.

↓ Transfeminist manifestation in Verona on 29th March 2019. Source: Radiosonar.net


THE STRAND MAGAZINE. 3

SEQUARINE

THE MEDICINE OF THE FUTURE.

THE one great remedy of the future will undoubtedly be the Serum. The mere fact that Scientists are now able to transfer energy from one animal body to another is sufficient to arouse enthusiasm among Doctors.

The perfection of the Sequarine Serum (which embodies the very essence of animal energy) in a form for everyday use, places animal therapy far in advance of other branches of medical science. This Serum is being used with astonishing success in treating:—

Nervousness, Neurasthenia, Anæmia, Rheumatism, Gout, Kidney Disease, Diabetes, Dropsy, Dyspepsia, Liver Complaints, Paralysis, Locomotor Ataxy, General Weakness, Influenza, Pulmonary

BROWN-SEQUARD, F.R.S., F.R.C.P. (London)

↑ Advertisement of Brown-Sequard's elixir called "Sequarine". New York: Raven Press, 1993.

From these early experiments, an industry using animal extracts began to develop in order to treat whatever was defined as a behavioral issue, such as masculinity, femininity, homosexuality or depression.

The development and reinforcing of these kinds of somatic fiction go hand in hand with the commodification of specific molecules: the very definition of depression would not even exist without the synthesis of serotonin, while the "feminist" pathology would not be there without the synthesis of testosterone. These "pathologies" then spread and began to be treated by pharmaceutical and petrochemical companies—such as Ciba, Organon and Shering—who were able to foresee their potential profitability.

Early experiments related to these new illnesses were conducted on animals, but also on women, poor and indigenous populations. For instance, from 1940 to 1970, a petrochemically derived drug named Diethylstilbestrol was given to pregnant women in order to prevent spontaneous abortions. This was done before knowing the drug was carcinogenic and produced genetic modifications that could have an impact across the following three generations.

The contraceptive pill, regularly administered from the 1960s, was later discovered to have several not negligible pathological implications (obesity, depression and cancer, among others), even though these were seen as less "dangerous" than childbirth mortality (especially in countries with poor access to reproductive healthcare).

However, hormones do not just concern the reproductive sphere; they surround and contaminate us whether we are aware of it or not. Indeed, the petrochemical industry is the biggest producer of synthesized molecules through the diffusion of agricultural pesticides. For instance, Atrazine (a substance capable of modifying the sex of frogs and fishes[2]) is found in 94% of American drinkable

1 –In 1871 the word "feminism" was first used by a young French doctor named Ferdinand-Valère Fanneau de La Cour, in his doctoral thesis *On Feminism and Childishness in Tuberculosis Patients*. Feminism here is understood as a pathology of men suffering from tuberculosis that produces a feminization of their body. Later the term "feminism" was used as a term to accuse the men who supported women's battles for the right to vote. Cfr. Preciado, Paul. 2019. "La Rivolta nell'Epoca Tecnopatriarcale." *Kabulmagazine.com*, May 11. Translation by the author. http://www.kabulmagazine.com/paul-b-preciado-rivolta-epoca-tecnopatriarcale/#_ftn1 (accessed May 31, 2019).

2 – Sanders, Robert. 2010. "Pesticide Atrazine Can Turn Male Frogs Into Females." *Berkeley.edu*, March 1. https://news.berkeley.edu/2010/03/01/frogs/ (accessed May 31, 2019).

water.[3] PCB (a molecule patented by Monsanto)[4] is considered to be the most pervasive chemical compound in the world as it is detectable in all living bodies on the planet. BPA,[5] a fundamental molecule for the synthesis of some kinds of plastic, was first tested on women, even before Diethylstilbestrol, because of its estrogenic effects. Despite several studies confirming its toxicity, this molecule is still in circulation through BPS,[6] a new synthesis that it is not (yet) obligatory to trace.

In this context of "molecular colonization"[7] one wonders not only what is "normal" and what is "natural", but also what our level of awareness of our bodies and their relation is with the surrounding environment. Indeed, we are all contaminated by endocrine molecules that affect our reproduction, its related organs and, ultimately, our overall hormonal balance: we are battlegrounds for programs of "evolutionary" and control engineering.

3 – Pesticide Action Network North America. "Pesticide Residues Found by the USDA Pesticide Data Program", *Whatsomyfood.org*, http://www.whatsonmyfood.org/food.jsp?food=WR (accessed May 31, 2019).

4 – Servizio Interdipartimentale per le Emergenze Ambientali. Settore Studi e Valutazione (APAT). 2006. "Diossine Furani e PCB", *Salute.gov.it*. http://www.salute.gov.it/imgs/C_17_pubblicazioni_821_allegato.pdf (accessed May 31, 2019) .

5 – Konieczna, Aleksandra, Rutkowska, Aleksandra, Rachon, Dominik. 2015. "Health Risk of Exposure to Bisphenol A (BPA)." *Roczniki Panstwowego Zakladu Higieny*, 66(1):5–11. https://www.ncbi.nlm. nih.gov/pubmed/25813067 (accessed May 31, 2019).

6 – Qiu, Wenhui, Hongyan Zhan, Jiaqi Hu, Ting Zhang, Hai Xu, Minghung Wong, Bentuo Xu, and Chunmiao Zheng. 2019. "The Occurrence, Potential Toxicity, and Toxicity Mechanism of Bisphenol S, a Substitute of Bisphenol A: A Critical Review of Recent Progress." *Ecotoxicology and Environmental Safety*, May 30, 173: 192–202.

7 – Tsang, Mary. 2017. *Open Source Estrogen: From Biomolecules To Biopolitics... Hormones With Institutional Biopower!* (Doctoral dissertation, Massachusetts Institute of Technology).

Testosterone, disappeared (for the sins of others)[8]

How do we reconcile the fact that we live in territories contaminated by synthesized molecules but, if we want to use hormones to start or continue a transition,[9] we encounter difficulties that put our lives at risk?

Since the beginning of 2019, testosterone has disappeared from Italian pharmacies. In their latest bulletin,[10] he Italian Drug Agency (AIFA) announced an official "shortage" of medicines such as Nebid (Bayer), Testoviron (Bayer) and Sustanol (Aspen). As stated on AIFA's webpage,[11] the temporary lack of vital drugs for specific pathologies on the national market is monitored through an specific procedure. What is meant by a "shortage" is that a given medicine cannot be found throughout the country because the authorities cannot guarantee appropriate and uninterrupted distribution.

However, a real "shortage" of a drug has to be distinguished from its "temporary unavailability", which is due to market dynamics linked with its distribution. European regulations do not distinguish

8 – This paragraph of the paper was made possible by the contribution of Yuri S. D'Ostuni and Samuel Spano, who, starting from their own experience, helped me to understand why in Italy access to testosterone is never entirely guaranteed.

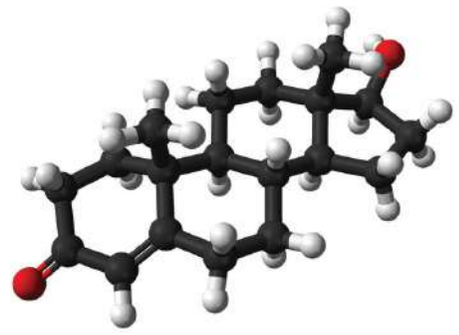
9 – Transition is defined as the path that leads an individual to stop living the role relative to their biological sex in order to arrive at living in the gender identity of choice. Wikipedia. 2019. "Transitioning_(transgender)". https://en.wikipedia.org/ wiki/Transitioning_(transgender) (accessed May 22, 2019).

10 – AIFA, Agenzia Italiana del Farmaco. 2019. "Elenco dei medicinali carenti." *Aifa.gov.it*, http://www.aifa.gov.it/sites/default/files/elenco_medicinali_carenti_03.05.2019.pdf (accessed May 31, 2019).

11 – AIFA, Agenzia Italiana del Farmaco. 2019. "Carenze e indisponibiltà." *Aifa.gov.it*, http://www.aifa.gov.it/content/carenze-e-indisponibilt%C3%A0 (accessed May 31, 2019).

between “shortage” and “unavailability”, even though the two are very different. Shortages are linked to productive problems and are often related to the non- profitability of a “out-dated” drug, whereas a temporary unavailability is related to the phenomenon of “parallel trade”, a practice that takes advantage of the price differences between different markets.

↓ Packaging of Testoviron Depot. Source: stronganabolic.com



If a pharmaceutical company makes more money from selling a given medicine in one country rather than another, it is inclined to sell the total amount required by both countries to the more profitable market. This forces the latter to buy the product—under emergency conditions and at an increased cost—through the public health systems that are granted “import authorization for similar uses abroad”.[12]

Parallel trade is the mechanism through which taxpayers from less affluent countries end up filling the coffers of the big pharmaceutical monopolies.

12 – Quotidiano Sanità. 2019. “Carenza farmaci Testoviron e Sustanon. Aifa ha autorizzato l’importazione dell’analogo medicinale commercializzato all’estero.” *Quotidianosanita.it*, April 19. http://www.quotidianosanita.it/governo-e-parlamento/articolo.php?approfondimento_id=12921 (accessed May 31, 2019).

Despite the fact that some countries have repeatedly brought lawsuit against companies such as Bayer, which has been specifically accused of this type of fraud[13], the company has always been acquitted for lack of evidence.

Beside fraud, the unavailability of medicines encourages the production and sale of testosterone of dubious origins[14], further limiting the possibility for transgender people to access safe pathways for hormone intake. Indeed, this type of drugs is only prescribed as therapy for hypogonadal[15] cisgender (when people feel their birth-assigned sex and gender match their gender identity) people; therefore, so-called “gender dysphoria” (when people feel their birth-assigned sex and gender do not match their gender identity) is not among the authorized conditions for the use of these medicinal products in Italy, as in most of the rest of the world.[16]

↑ Ball-and-stick model of the testosterone molecule, C19H28O2, 2009. Source: Wikipedia Commons.

13 – Desogus, Claudia. 2011. “Antitrust Issues in the European Pharmaceutical Market: An Economic Analysis of Recent Cases on Parallel Trade.” *Working Paper nº 60*. Center for Research in Health and Economics. https://www.upf.edu/ documents/3223410/3287206/wp60_desogus.pdf/dcff03ed-451b-4c79-a937-e54b98f8d038 (accessed May 31, 2019).

14 – Quotidiano Sanità. 2017. “Farmaci nel dark web. È allarme OEDT ed Europol. In Europa mercato da 80 milioni di euro.” *Quotidianosanita.it*, November 30. http://www.quotidianosanita.it/scienza-e-farmaci/articolo.php?articolo_id=56509 (accessed May 31, 2019).

15 – Hypogonadism is a pathology of the endocrine system that involves an inadequate secretion of sex hormones (e.g. testosterone and estrogen) by the gonads (ovary or testis).

16 – Smiley, Adam, Aisa Burgwal, Carolina Orre, Edward Summanen, Isidro García Nieto, Jelena Vidic, Joz Motmans et al. 2017. “Overdiagnosed but Underserved. Trans Healthcare in Georgia, Poland, Serbia, Spain, and Sweden: Trans Health Survey.” Transgender Europe. https://tgeu.org/wp-content/uploads/2017/10/Overdiagnosed_Underserved-TransHealthSurvey.pdf (accessed May 31, 2019).

Therefore, if on the one hand the recent depathologization of gender dysphoria[17] can be seen as a cultural and civil conquest, on the other it has left a definitional void that needs to be filled to guarantee access to medical care to everyone. In fact, this void pushes people who take hormones for gender transition to do so "off label", meaning that they become non-existent. Moreover, hormones are not refundable from the Italian National Health System and it is difficult to catalogue them as class A, meaning lifesaving, drugs. It is assumed that the life of a hypogonadal male is not a risk because of a temporary unavailability of testosterone, but its present classification (class C) does not protect trans people from the serious consequences that occasional testosterone intake can generate: a high risk of thrombosis and chronic osteoporosis, not to mention depression and suicide.

One of the factors that complicates this classification even further relates to the lack of data. Under the current legislation, AIFA can consider the introduction of a new therapeutic classification for a drug only if the pharmaceutical company that holds the marketing authorization (in Italy, AIC) submits a request for an extension of therapeutic indication, supported by related scientific evidence.[18] The problem

17 – Open Access Government. 2019. "WHO removes 'Gender Identity Disorder' diagnosis." *Openaccessgovernament.org*, May 28, https://www.openaccessgovernment.org/gender-identity-disorder/65852/" (accessed June 3, 2019).

18 – On the other hand, law n. 648 of December 23, 1996 allows medicines bought by the Italian health service to be used for a different therapeutic indication than the one authorized, following a request from the Technical-Scientific Commission of AIFA, from patient associations, scientific societies, health authorities, universities and scientific institutions for admission and care, after the careful evaluation of the scientific evidence in support. D.L. 23 December 2996, n. 648, "Conversione in legge del decreto-legge 21 ottobre 1996, n. 536, recante misure per il contenimento della spesa farmaceutica e la rideterminazione del tetto di spesa per l'anno 1996." http://www.camera.it/parlam/leggi/96648l.htm (accessed June 3, 2019).

is that there is no systematically collected data, because gender transition does not follow a specific medical procedure. There is no platform for sharing data on this "pathology" and this, in turn, affects medical research and access to care, as well as increasing the risks trans people face in emergency situations: for instance, during a serious accident, lacking access to patient's records and data, a physician could worsen their condition due to wrong therapeutic procedure.
Data collection is undoubtedly fundamental, but is made difficult by the lack of clarity about the therapeutic process. Perhaps if it is now universally clear that is not gender that has to be referred as dysphoric but the hormonal balance needed by a person to pursue a fulfilling life, what if instead we introduce an "hormonal dysphoria (or discrepancy)" for every individual who needs lifesaving drugs?

In summary, the temporary unavailability of testosterone in Italy, whose synthesis is a patent owned by Bayer, is the result of an illegitimate monopoly that guarantees large periodic investments paid for by taxpayers and trans people, because they find themselves buying the drug, which may fluctuate in price. But if those who pay taxes do not have any idea of these trends, those in need of hormonal treatment know exactly who the "sinners" are.

Furthermore, the problem that emerges following the story of testosterone reflects a more general problem, a pharmaceutical issue common to various pathologies. The phenomenon of a parallel trade, in fact, affects many other types of life-saving medicines, such as drugs for cancer therapies, cystic fibrosis and diabetes, as made clear by recent examples like

"Caravan for Canada",[19] groups of Americans with diabetes who form caravans of cars to go to buy insulin in Canadian pharmacies for 90% less than the US version (they are clinically identical), because in Canada pharmaceutical prices are set by a government agency called the Patented Medicine Prices Review Board. Further in the past, but perhaps better known, is the death of thousands of people from Aids in South Africa at the turn of the millennium, simply because people could not afford medicinal treatment costing 10.000 dollars per year.

These emergencies are generated by the fact that every new drug is patented and no one else can manufacture or sell that drug for a period of at least 20 years. Without competition, pharmaceutical companies can decide the price they want and, to date, they have defended themselves by claiming that the high costs are due to the research and development involved. However, as there is no transparency about how these companies invest their capital, no one can verify whether these claims are true.

Civil society groups, projects and organizations such as Fix the Patent Laws[20], Fair Pricing of Medicines[21], TAC[22] and Knowledge Ecology International[23] have been working for years on accessibility to medical treatments, while a final proposal delivered to the World Health Organization (WHO) comes from the health minister of the current Italian government, Dr. Giulia Grillo, which requires a resolution to improve transparency in the drug market. If this resolution is approved this year at the World Health Assembly,[24] governments could start asking companies to reveal the annual costs of research and development, their production costs and, finally, the profit margins of individual pharmaceutical products.

However, sticking to the current system will never bring universal access to drugs; some people will always survive and others will not. Instead of trying to regulate and modify the margins of a monopoly-based system, we need a different system, one more similar to the mission set out by Open Source Pharma: "Create a movement that includes existing initiatives and develop an alternative, comprehensive, open source pharmaceutical system driven by principles of openness, patient needs, and affordability."[25]

Among these topics, there is an argument within trans people networks about the need to become a spokesperson for more fragile categories—such as terminally or chronic patients—and to intervene in the European institutions to promote transnational laws for reducing the margin of companies playing with people's lives, as well as the desire to create new types of "safe and multipurpose" counseling spaces, and to build open-source platforms for data sharing.

19 – BoingBoing. 2019. "Americans with diabetes are forming caravans to buy Canadian insulin at 90% off." *BoingBoing.net*. May 9. https://boingboing.net/2019/05/09/life-or-death.html (accessed May 31, 2019).

20 – Fix The Patent Laws. https://www.fixthepatentlaws.org (accessed May 31, 2019).

21 – World Health Organization. "Fair Pricing of Medicines." https://www.who. int/medicines/access/fair_pricing/en/ (accessed June 1, 2019).

22 – Treatment Action Campaign. https://tac.org.za/ (accessed June 1, 2019).

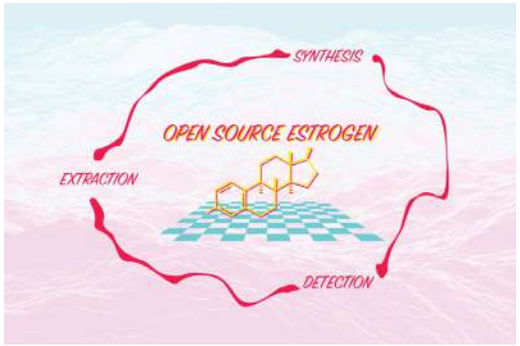
23 –Knowledge Ecology International. https://www.keionline.org/ (accessed June 1, 2019).

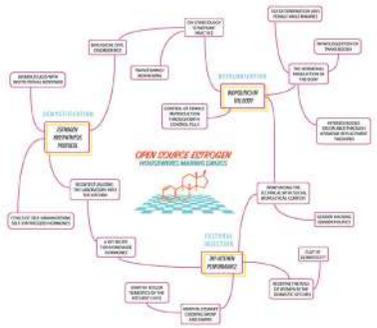
24 – World Health Organization. "World Health Assembly." https://www.who.int/about/governance/ world-health-assembly (accessed May 30, 2019).

25 – Open Source Pharma. http://www.opensourcepharma.net (accessed May 30, 2019).

Open source estrogen

Estrogen hormones are not so in the spotlight as testosterone; in fact, not being used for sport (and war), there is no such a lucrative black market for them.





↓ Pictures from Mary Maggic, Open Source Estrogen – Housewifes making drugs. Source: Maggic.ooo

An article entitled “Big Boring Bureaucratic Revolution”, published following the Istanbul Innovation Days, indicates that among the “six areas of experimentation” that the intersection between technological innovation and civic participation produce is one representing the encounter between art and science fiction: “There is a range of interesting initiatives looking at the arts, and in particular at science fiction, as a source of potential directions and lenses to understand the nexus of human and machine rights, emotional and genetic surveillance and human rights, impact of 4.0 technologies on human rights and law.”[26]

In this sense, Open Source Estrogen,[27] a collaborative project led by the artist Mary Maggic, stands between citizen science and speculative design and has the ambition to develop DIY/DIWO (Do it with Others) protocols for the “domestic” synthesis of hormones, as a response to the strong control by governments and institutions over human bodies.

If people do not receive adequate or sufficient drugs, can these be synthesized in a domestic environment?

How can we re-contextualize laboratory biochemistry into an open-source “recipe” that hacks estrogen to guarantee equity and accessibility?

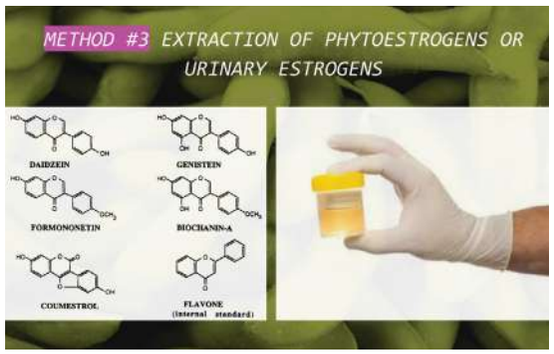
The project aims to hack hormones present in our body and the environment, creating non-institutional access to therapy, as well as raising awareness of how human bodies are regulated by the culture and the market. From estrogen detection and extraction to its synthesis, these recipes are forms of social resistance, awareness tools and DIY therapies that put gender hacking into practice. If institutions and medicine produce fictions about the way bodies should be divided by gender and how they should reproduce, heal and die, a domestic methodology of care, such as that promoted in Mary Maggic’s workshops, sees becoming molecularly mutant as a form of liberation of the body: “In our scientific methods, we do not seek techno-solutionism. With the creation of a DIY estrogen protocol, increased endocrinological know-how and body sovereignty, the project becomes a public platform for discussing the ethics of self-administered self-synthesized hormones. What physiological dangers have arisen through potential overdosing and exposure to impurities, and what will

26 – Johar, Hindi. 2018. “NextGenGov (the Big Boring Bureaucratic Revolution).” *Darkmatterlabs.org*, Jul 27. https://provocations.darkmatterlabs.org/nextgengov-the-big-boring-bureaucratic-revolution-39ccc3a6c9f8 (accessed May 30, 2019).

27 – Magic.ooo. 2015. “Open Source Estrogen”. http://maggic.ooo/Open-Source-Estrogen-2015 (accessed May 30, 2019).

people trade in return for wrestling greater control over their bodies?"[28]

Evidently, when practices of this type are disconnected from democratic political instances, they can produce horror laboratories, such as the rise of popularity among teens of DIY gene-editing kits bought and administered individually through the



↓ Pictures from Mary Maggic, Open Source Estrogen – Housewifes making drugs. Source: Maggic.ooo

web, but they become fundamental when contextualizing and promoting a framework against cultural stereotypes and the monopoly of patents and access to health. Discussing this with Yuri S. D'Ostuni and Samuel Spano, the idea of synthesizing their own testosterone dose would become interesting to the extent that it is a way of bypassing Bayer's patent and generating an open source synthesis of a drug in a more accessible way, creating life and shared knowledge.

A recent article by former UK civil servant Kit Collingwood-Richardson,[29] featured in an edition of Nesta's Lab Notes,[30] cites nine ways in which public services could respond more efficiently to ongoing social transformations. Point 7 is "Co-create policy with those impacted in the room" and—starting from the assumption that "Nothing About Us Without Us!"—discusses the need to include patients in the design of solutions that are sought, meaning listening to those who will be affected by these solutions for their entire lives: stop making (wrong) decisions in "white rooms" far from reality white rooms, and between people who do not have specific experience on the topic.

And yet, as long as government policies are unable to transform themselves from within, we will apply all our biopolitical powers to creating democratic and imaginative forms of social reproduction, resisting the commodification and privatization of the right to live.

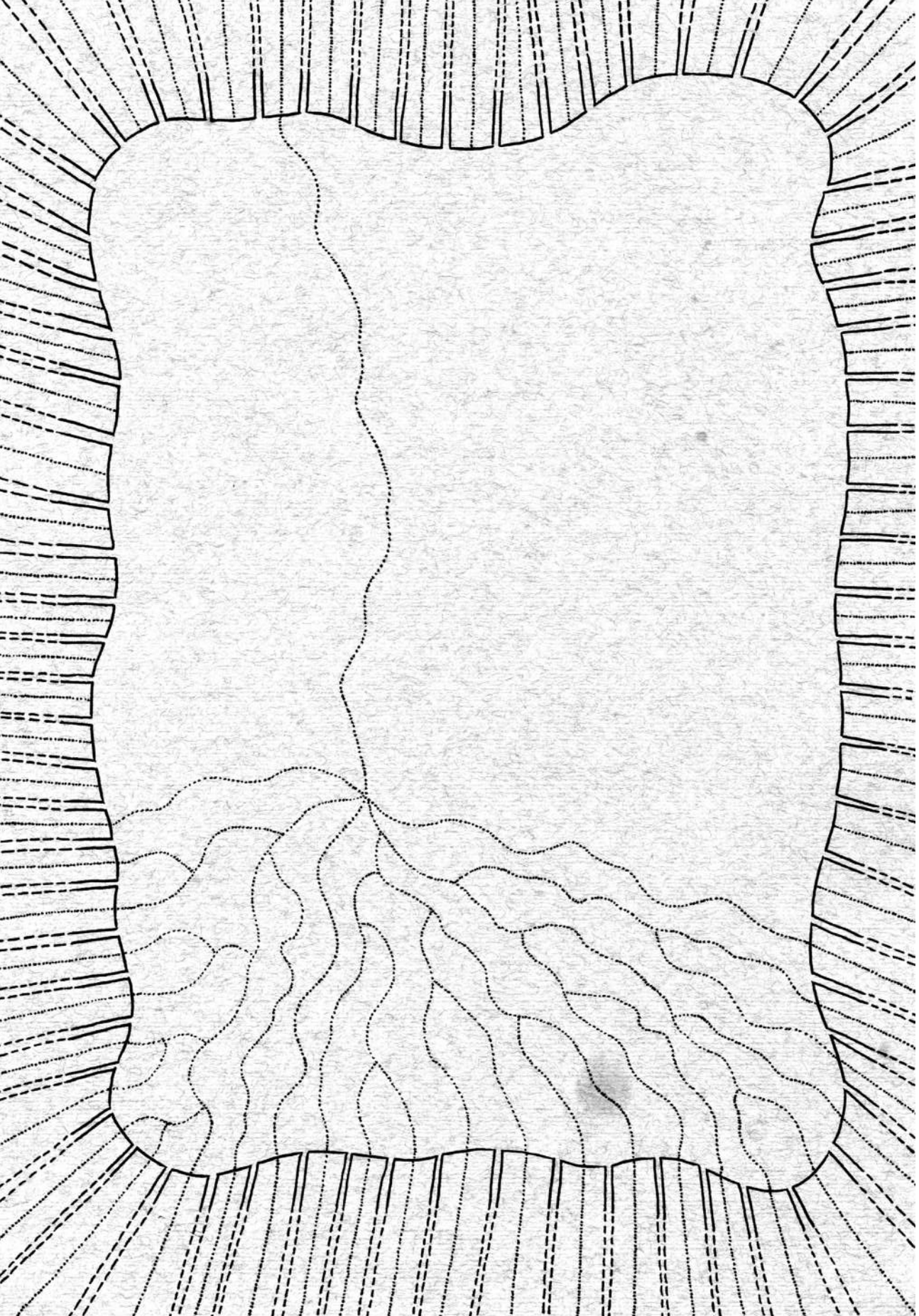
For this reason, "domestic" workshops such as Open Source Estrogen, which are synthesizing pharmaceuticals and sharing this knowhow in open source format, which could be defined as "alien" medical practices in the spirit of "opening the pill"[31] as well as representing a specific field of "digital social innovation" located between biohacking and open science, are also strongly connected with existing social movements that are demanding more affordable public healthcare systems, where autonomy, self-determination, access to medical data and open source can be guaranteed as rights.

28 – Tsang, Mary. 2017. *Open Source Estrogen: From Biomolecules To Biopolitics... Hormones With Institutional Biopower!* (Doctoral dissertation, Massachusetts Institute of Technology).

29 – Collingwood-Richardson, Kit. 2018. "Empathy and the Future of Policy Making", *Medium.com*, May 14. https:// medium.com/foreword/empathy-and-the-future-of-policy-making-7d0bf38abc2d (accessed May 30, 2019).

30 – Bass, Theo and Stokes, Matt. 2018. "Hacking Bureaucracy from the Inside." *Nesta.org.uk*, June 11. https://www.nesta.org.uk/blog/hacking-bureaucracy-inside (accessed May 30, 2019).

31 – Preciado, Paul B. 2019. "La rivolta nell'epoca tecnopatriarcale", *Kabulmagazine.com*, May 11. http://www.kabulmagazine.com/paul-b-preciado-rivolta-epoca-tecnopatriarcale (accessed May 30, 2019).



Caring for the Carers.

Valeria Graziano

↑ Revolution by Common Dissent. by Daniel Friedman, CC BY NC 2.0.

The last century accustomed us to consider care and technology as two opposing concepts. We are told that care is about affectivity and empathy, while technology is cold and rational. And yet, as Annemarie Mol explains, all care practices use technological tools.[1] Rather than imagining care as an innate faculty, therefore, we could begin to see it as a set of techniques and skills acquired in relation to the tools at our disposal.

Digital technologies in this sense are opening up many interesting scenarios. Their main promise is to automate the most strenuous or repetitive tasks of care work. In this sense, automation would allow caregivers to focus their attention and expertise on the more relational aspects of the role. Within this field, the specific trend towards open technologies aims to go further in transforming care by trying to respond to care needs that are extremely bespoke (and therefore not interesting enough for the markets) and to free care itself from the market-driven logics of technological innovation altogether.

Many DSI projects embrace such open ethics by focusing on the recipients of the services and their needs. As the slogan by the British innovation foundation Nesta has it, an alternative vision for "People Powered Health"[2] rightly emphasizes the benefits of redesigning health provisions and services by involving not only patients and their support networks, but also a broader communities of volunteers and other social stakeholders.[3]

1 – Mol, Annemarie, Ingunn Moser, and Jeannette Pols, eds. 2015. *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Vol. 8). transcript Verlag.

2 – Nesta. 2012. *People Powered Health: Co-Production Catalogue*. London: National Endowment for Science, Technology and the Arts.

3 – See Practices EchOpen, p. 102.

Beyond the enthusiasm for a less top-down conception of care and a more horizontal and active involvement of communities in their welfare services, it is nonetheless crucial to critically address too what the changes envisioned in the DSI approach can entail for all those caregivers who make a living out of their work, operating as professionals rather than on a voluntary basis. Even within some DSI contexts, we note a tendency to avoid tackling the thorny questions connected with care work head on, including the central issue of remuneration: who should pay for care work? And how much?

As Helen Hester put it (borrowing in turn a famous expression by John Naisbitt)[4], the rapid development and adoption of technological care equipment for remote monitoring, self-diagnosis and other forms of telemedicine risks splitting care work between "high tech" and "high touch" workers[5]: on the one hand, well-paid professionals developing or operating new technologies; on the other, much poorer and much less qualified assistants taking care of the operations that are not easily automatable, such as dressing, lifting or washing patients. The division of care labor is already uneven and racialized and relies on migrant workers, outlining what the sociologist Arlie Hochschild called a "global care chain"[6], referring to the impressive global network of workers, mostly women, who migrate to care for the elderly, children, disabled and sick persons in rich countries; these workers must in turn be replaced by other carers in their places of origin.

4 – Naisbitt, John, Nana Naisbitt, and Douglas Philips. 2001. *High Tech, High Touch: Technology And Our Accelerated Search For Meaning*. London: N. Brealey.

5 – Richards, Luke. 2017. "Automation and Healthcare: An Interview with Helen Hester". *Autonomy Interview 2*, Autonomy Research Limited, December. http://autonomy.work/wp-content/uploads/2018/08/Helen-Hester-Interview-02.pdf (accessed May 1, 2019).

6 – Hochschild, Arlie Russell. 2000. "Global care chains and emotional surplus value." *On the Edge: Living with Global Capitalism 3*, no. 5: 130–46.

By solely emphasizing the active role of patients and their informal support networks made up of friends and relatives (ironically, the so-called "dear" ones), we risk neglecting the problem of daily care work conceived as a private problem, as Melinda Cooper pointed out, avoiding the question of who is called to do it under such informal arrangements and under what conditions.[7] Free work thus risks returning (or continuing?) to be an implicit asset of the reorganization of care in the post-digital era.

The "dear" ones invoked alongside the empowered patients actually risk re-proposing a family-based model of care fundamentally organized according to coercive principles and mostly impacting women. Avoiding the issue of the remuneration of care work also risks neglecting the toll it takes on the caregivers, who can fall ill in turn. In the book *Forced To Care*, Evelyn Nakano Glenn highlighted how:

> *Many studies have documented high stress levels among family members who provide intensive care or who combine work and care for parents and disabled spouses and children. The demands of intensive care leave caregivers with little time or energy to look after their own wellbeing, so that their own health suffers. Numerous studies have shown that caregivers experience higher rates of heart disease, high blood pressure, diabetes, and depression. Other studies have documented the detrimental economic effects of caring for elderly or disabled family members.*[8]

7 – Cooper, Melinda.2017. *Family Values: Between Neoliberalism and the New Social Conservatism*. Cambridge, Mass: MIT Press.

8 – Glenn, Evelyn Nakano. 2012. *Forced to Care: Coercion and Caregiving in America.* Cambridge, Mass: Harvard University Press, 3.

Taking care of the caregivers

What would it mean instead to rethink the theme of care work in the light of the profound changes connected to its deeper technologization? In large part, the reactionary vision of the role of the family and of women in care, but also, in another sense, the outsourcing of care work as a service entrusted to categories of contractually weak workers, are problems that can only be tackled through far-reaching political processes. A central one would be the questioning of work itself as the main social mechanism for the redistribution of wealth, in favor of an unconditional universal basic income.[9]

However, here I want to explore two emerging aspects linked to the mutations of care and the possibilities supported by open technologies conceived from the workers' point of view. These concern both the possibility of overcoming the Fordist organization of personal services and the need to extend the ethics of care to the technological objects that support it.

Self-management as a social technology: Buurtzorg nurses

One of the obsessions of contemporary management is the use digital technologies for monitoring the performance of employees in real time. While in Ford's times, efficiency in production had become synonymous with the division of labor into increasingly simplified and abstract tasks, to be repeated ever more rapidly, nowadays digital management systems such as apps, badges and wearable trackers of all kinds have created an invisible but absolutely concrete control infrastructure for

9 – See for instance Basic Income Network Italia: www.bin-italia.org/

workers. In contrast, DSI could potentially be used to overcome the Fordist model of work within the care sector. The example of the nurses of the Buurtzorg association in the Netherlands shows that better results can be achieved when care is managed as independently as possible directly by those who dispense it.

↓ Jonathan Haeber, Jones Building Medical Equipment, 2014. CC BY-NC 2.0

Buurtzorg is a non-profit organization of neighborhood nurses founded in 2006 by Jos de Blok. Neighborhood nurses have been a specific professional figure in the Dutch healthcare system since the last century, acting as a link between hospitals, primary care physicians and patients visited at home. Since the 1990s, however, the role of the neighborhood nurse has been outsourced, along with many others, so that the nurses have had to establish themselves in autonomous sub-contracting organizations bidding for tenders with the public sector. Until the advent of Buurtzorg, the management of these organizations followed a classical organizational logic, based on competitiveness and efficiency: typically, the nurses' shifts would be planned centrally by a manager and then distributed daily to save time on the distance between appointments; nurses would use a badge to track the tasks performed with each patient, and each of these

tasks would be pre-allocated a given amount of time (10 minutes for giving someone an injection, 15 for giving a bath, and so on).[10] Furthermore, the tasks would usually be assigned according to the different levels of expertise of the caregivers, so that the most qualified (and therefore most expensive) nurses would find themselves managing only the most difficult interventions, while the less qualified ones would struggle to make progress.

This Fordist approach to home care (powered by technology) has produced very poor results. Not only do patients complain about the lack of a personal relationship with their nurses, who change constantly, but they get sick more frequently. The nurses also declare that they feel devalued in their professional competence in this mainstream managerial regime.

The birth of Buurtzorg revolutionized this system, proposing an organizational model inspired by totally different principles from monitoring, efficiency and standardization. While it does use coordination technologies, Buurtzorg has totally eliminated the figure of the manager. Here the nurses manage themselves in teams of 10–12 people. The whole team takes care of all the tasks, avoiding the fragmentation of the services offered. The teams also have full autonomy to decide on issues regarding shifts, holidays, and possible collaborations with rehabilitation centers or pharmacies. The performance of the activities is monitored and discussed within the nurses' assembly, and there is no one who evaluates it from above.

Furthermore, the staff of Buurtzorg promote an approach that supports a maximum decision-making

10 –Laloux, Frédéric, and Etienne Appert. 2016. *Reinventing Organizations: An Illustrated Invitation to Join the Conversation on Next-Stage Organizations.* Millis: Parker Nelson, 62–73.

autonomy for their patients, too, whom the nurses come to know in depth, because they have the time to stop and talk to them, to listen to their needs and those of their family members.

All this does not mean, of course, that conflicts do not occur or that difficulties do not arise. However, Buurtzorg supports nurses with specific training courses on subjects such as self-management and conflict mediation techniques. When a delicate situation requires it, figures with specific competences, such as expert coaches and expert nurses, offer teams support to resolve specific problems, although they have no decision-making or disciplinary powers.

The results of this different organization of care work are impressive. A 2009 study by Ernst & Young found that Buurtzorg requires on average 40% fewer hours of care compared to delivery through traditionally managed organizations. Patients remain in care for less time, and tend to have fewer relapses. Calculated in economic terms, the Buurtzorg approach saves the Dutch healthcare system about €60 million a year. Perhaps this is the main reason why the Buurtzorg model is currently being tested in nine other countries. To those who ask their founder if he intends to patent Buurtzorg and make a franchise, De Blok replied that he would rather prefer to see his model adapted to different contexts. "I'm not interested in money," he commented in a recent interview for *The Guardian*. "I see so many people searching for a new way of doing things in all the places I visit. It's all about creating something different from the bottom up".[11]

11 – Brindle, David. 2017. "Buurtzorg: the Dutch Model of Neighbourhood Care that is Going Global", *The Guardian*, May 9. https://www.theguardian.com/social-care-network/2017/ may/09/buurtzorg-dutch-model-neighbourhood-care (accessed May 30, 2019).

What remains more difficult to measure, as perhaps it should, is the impact of this approach on the personal wellbeing of the workers involved. However, recent figures provide indicators: the staff turnover at Buurtzorg is 33% less than in other organizations and, just like their patients, the nurses who work there get sick 60% less than the others. It turns out that the organization of care labor can be a technology of care in its own right.[12]

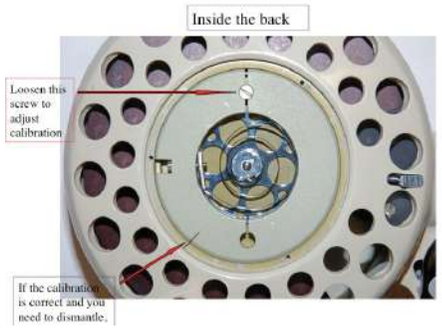
The approach to self-management and training developed by Buurtzorg (open and non-patented, in line with the DSI principles) foreshadows an ideal use of digital technologies in the healthcare sector, recasting the role of open technologies as tools for enhancing the capacity for coordination, autonomy and self-determination of workers and patients alike. Rather than harassing workers through the proliferation of intermediate managerial figures, the imposition of assembly-line work practices and continuous monitoring, the role of shared self-management technology in care processes could be re-designed, for example, through the creation of online cooperative platforms run by the workers themselves, replacing the many temping agencies in the sector.

... but what about non-human caregivers?

The DSI approach has a role in the ongoing transformations of an aspect of care which is perhaps more hidden, but no less essential: the maintenance and repair of technological objects used in treatment itself. The orientations of contemporary medicine point

12 – The links between workers well-being and forms of autonomous organizations are already well known; see, for instance, the experience of institutional analysis in France and the experiences of workers' self-management in Yugoslavia.

towards a future in which the body will become more and more intimate (not only outside, but also inside) with technological objects of various types, ranging from surgical meshes to cardiac defibrillators or deep brain stimulators. There are devices that connect the body to the network (such as pressure-monitoring clocks), those that administer drugs, and those that combine digital aspects with biological



components, such as the subcutaneous microsensors used by diabetics. Moreover, high-precision digital instruments are becoming increasingly indispensable tools in diagnosis and surgery.

In all these cases, caregiving and curing becomes, just as Mol suggested, the result of an ever deeper interweaving of human competences and the performance of technological objects, which someone will have to ensure remain in an effective and functioning state. So who and how should take care of the care machines? And under what conditions?

Although machinery has become an integral part of medicine since the 1970s and has a huge impact on treatment costs, laws governing the lifecycle of medical equipment have struggled to keep pace with the ongoing changes. In the United States (whose laws often influence the legal approaches

↑ Screenshots of the website Frank's Hospital Workshop. Source: frankshospitalworkshop.com

internationally), legislators have not yet come to develop a normative framework that clearly assigns responsibility for the maintenance and repair of the technologies implanted in the body, a situation that some researchers have denounced as alarming.[13] Yet complex devices such as surgical robots or 3D body scanners require specialized engineers and technicians who are not always easily available in hospitals. The growing intimacy between technology and the body requires extending the ethics of care to objects, because if even a simple common defibrillator is of no use if it is broken, we can well imagine that the complications that a malfunctioning pacemaker can have are of a completely different order.

Maintaining and repairing such technologies is often difficult, lengthy and costly for users due to manufacturers' desire to maintain total control over the products. Third-party technicians are denied information, problems are artificially made difficult to diagnose, and monopolies over spare parts are maintained.

This is a little-known limitation, but one that greatly impacts the capacity for intervention and care of hospitals with low budgets. In poorer countries and regions, the issue of broken or malfunctioning medical devices often has serious, life-or-death consequences for people. The data provided by the World Health Organization is discouraging: in some countries, 50% of medical machinery is unusable at any given time; in some cases, this figure is as high as 80%.[14]

13 – Davies, Dave. 2018. "Are Implanted Medical Devices Creating a 'Danger Within Us'?" *NPR.org*, January 17. https://www.npr.org/2018/01/17/578562873/are-implanted-medical-devices-creating-a-danger-within-us (accessed May 30, 2019).

14 – The Repair Association, "Device Companies are Cutting Hospitals Out of the Loop", Repair.org, https://repair.org/medical (accessed May 30, 2019).

↑ 'Wright's peak flow meter maintenance in pictures'. Slide by Mike Yeats, The Electric Squirrel , 2013.

Here, the care work of repairers and medical personnel in support of collective well-being clashes very clearly with the interests of a small number of powerful private businesses. Alongside organized legal battles for the right to repair (such as the one carried forward by the Repair Association in the United States), some technicians have chosen to react to the situation with bottom-up initiatives. This is the case with Mike, the retired biomedical technician who runs The Electric Squirrel site,[15] which is dedicated to the maintenance of the most common technical equipment in use across the southern hemisphere. It also applies to Frank Weithoener, another technician specializing in biomedical machinery, based in Tanzania. Frank, who has worked as an instructor and consultant in several so-called "developing" countries, claims to have opened his site because he was tired of meeting absurd obstacles to repairs everywhere he went.

On his website Frank's Hospital Workshop,[16] he collects and publishes all the maintenance and technical documentation manuals he can get his hands on, as well as providing his own tutorials. As expected, manufacturing companies such as Weyer, General Electric and others regularly threaten to sue Frank, telling him to take the manuals offline.[17] But fortunately he has thus far resisted pressure and continued in his mission: to take care of the machines we need to cure ourselves.

The barriers to maintenance identified by Frank are many and diverse: not only the difficulty in finding

15 – The Electric Squirrel. "Introduction." https:// theelectricsquirrel.wordpress.com (accessed May 30, 2019).

16 – Frank's Hospital Workshop. http://www.frankshospitalworkshop.com (accessed May 30, 2019).

17 – The Repair Association, "Device Companies are Cutting Hospitals Out of the Loop", Repair.org, https://repair.org/medical (accessed May 30, 2019).

spare parts, because the parent companies maintain their monopolies, but also the lack of attention from policymakers for financing technical support and allocating specific funds for preventive maintenance of equipment and the continuous training of technicians. This neglect highlights a clear continuity with an older trend: the instrumental invisibility attributed to more traditionally understood "care work".

We could then start from here to draw the contours of a different approach to care work, one which requires a joint reflection around its technologies and the reorganization of living labor, going beyond a mere techno-solutionist approach by insisting on the conditions under which the caring for human and non-human caregivers can take place in the best possible way.