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Situated Responsibilities. Ethical Research and Care Practices Among Patient Communities in Italy

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Abstract

In the last two decades, there has been growing discourse – in and around institutions – on specific aspects of scientific research and technological innovation, particularly on the way they tend to be conducted «secludedly», without the possibility of scrutiny or intervention by people outside institutions themselves. The so-called «Responsible Research and Innovation» (RRI) approach aims to rewrite the relationship between scientists and their wider social context, focusing of conducting research «responsibly», which would ideally mean more attuned to societal needs and desires. This contribution tries to discuss what this idea of «responsible research» might concretely mean, and, drawing from empirical research on two patient and caregiver organizations in Italy, aims to show what happens when these ideas of ethical and responsible research are reappropriated by subjects usually excluded from these processes – with the explicit objective of tailoring research and innovation to the concrete need of patient-caregiver communities.

Keywords: responsibility, Responsible Research and Innovation, patient communities, care, biosociality.

Riassunto

Negli ultimi due decenni, si è progressivamente sviluppata una riflessione – all'interno e intorno alle istituzioni – su alcuni aspetti della ricerca scientifica e dell'innovazione tecnologica, in particolare sul modo in cui tendono a essere condotte in modo «isolato», senza la possibilità di controllo o di intervento da parte di persone esterne alle istituzioni stesse. Il cosiddetto approccio della «Ricerca e Innovazione Responsabile» (RRI) mira a riscrivere il rapporto tra gli scienziati e il loro contesto sociale più ampio, concentrandosi sulla conduzione della ricerca «in modo responsabile», che, idealmente, significherebbe più in sintonia con i bisogni e i desideri della società. Questo contributo cerca di discutere cosa possa significare concretamente questa idea di «ricerca responsabile» e, basandosi su una *ricerca empirica su due organizzazioni di pazienti e caregiver in Italia, intende mostrare cosa succede quando soggetti solitamente esclusi da questi processi – con l'obiettivo esplicito di adattare la ricerca e l'innovazione alle esigenze concrete delle comunità di pazienti e caregiver – si riappropriano di queste idee di ricerca etica e responsabile.*

Parole chiave: responsabilità, Ricerca e Innovazione Responsabile, comunità di pazienti, cura, biosocialità.

What is «responsible» about «responsible innovation»?

In the last ten or fifteen years, a new approach to conducting research and innovation has progressively taken root – maybe we could call it a new «paradigm», as it aims to radically shift the priorities of these processes. Responsible Research and Innovation (RRI), as this approach is called, wishes to go, quoting the title of an influential paper, «from science in society to science for society, with society» (Owen, Machnaghten & Stilgoe 2012), moving away from a strictly hierarchical way of doing scientific research (and technological innovation), and towards more horizontal and collaborative practices. This approach is increasingly popular in EU institutions, where from the early 2010s and especially with the Horizon 2020 program it has become an influential way of rethinking research projects.

In the RRI perspective, there is a «traditional» way of doing research and innovation that puts all the agency in the hands of a small number of subjects. From the decision about the problem to be solved or the issue to be explored, to the results produced, the entire process of «making» research or innovation is often hidden away behind the walls of institutions that usually show only the final product. And this process is entirely in the hands of experts, significantly limiting the input lay people (even those directly impacted by the results) can have. Ethical concerns, where they are present, are usually preoccupied with what we *don't* want science and innovation to do – with risks and unintended consequences (Owen *et al.* 2013). Underpinning this «traditional» way of doing research are a few key assumptions. First, a sort of instrumental representation of research and innovation: they are, in and of themselves, simply «tools» and as such morally neutral. They can be misused, and thus their diffusion and accessibility has to be controlled, but they don't have any innate ethical or moral content. What is innately moral (or rather, innately good) is scientific and technological advancement: «progress» gives us more tools to face structural and everyday challenges. The possibility of negative consequences doesn't invalidate the ultimate need to pursue progress. Lastly, and maybe most significantly, scientists and innovators should have the freedom to shape the direction of this progress, owing to their specific expertise. Institutions should intervene later, to eventually course-correct for unexpected consequences, but shouldn't substantially limit the autonomy of researchers. Society has a largely passive position in these processes: lay people are end-users or beneficiaries of research and innovation.

What is, then, the proposed paradigm shift? The core objective of the RRI approach is to invert these assumptions, and ultimately center the entire process of research and innovation on its ethical dimensions.

> Responsible Research and Innovation is a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view on the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow for a proper embedding of scientific and technological advances in our society) (Owen, Machnaghten & Stilgoe 2012: 753).

Rather than positioning progress as a value in itself, RRI focuses on its wider desirability. Ethical concerns are not just relegated to risks and unintended consequences – they should address what we *want* science to do as much as what we don't want it to do. As Owen et al. argue (Owen et al. 2013; Owen, Machnaghten, and Stilgoe 2012), a feature of the discourse on responsible research and innovation has its focus on their purposes, with how experts decide the «right» research agenda – and for whom it's «right». If the governance of science and innovation is usually closed down and restricted to specialized institutions, RRI aims to open it up to wider deliberation, involving the public as much as possible since the early stages of research and innovation processes. This involvement would inevitably foreground the political dimension of these processes, and of RRI in general: what is «right» can only emerge in a public, or hybrid, forum (Callon, Lascoumes & Barthe 2009), and with a public and participated debate. In this way, RRI re-frames what «progress» can mean: not simply additive of scientific knowledge or technological tools, but the answering to wider societal needs and problems – collectively and collaboratively defined.

A key aspect of the discourse on RRI is the reframing of what «responsibility» means. A concept that appears frequently in the literature is *responsiveness*: institutional actors that participate in research and innovation processes should strive to be attentive to societal needs, and formalize forms of public engagement to foreground these needs. Being «responsive» in this context means actively listening to a broad range of stakeholders, and not leaving the listening to the autonomy and initiative of individual researchers or innovators, but integrating collaborative practices and public engagement into the mechanisms that govern research and innovation in general. This means creating new responsibilities and new responsible subjects. In the RRI perspective, scientists and researchers become «responsible» in a variety of different ways, and most importantly to different people. If the «traditional» representation of scientific responsibility is mostly concerned with professional deontology, and as such is directed towards the scientific community and institutions, RRI's responsibility is mainly focused on society at large. Scientists are responsible of looking for and pursuing the «right impacts» for their work; they are responsible of engaging with stakeholders at all levels; they are responsible of being reflexive throughout their work. But it's not just scientists: all actors involved in research and innovation processes become responsible in the same way. Funders, policymakers, businesses should equally be responsive to societal needs, engage with stakeholders, be reflexive. The reshaping of responsibility widens both the scope and the subjects involved.

> The framing of responsibility itself is perhaps one of the greater intellectual challenges for those wrestling with the concept of responsible innovation. (…) Reframing responsibility in the context of innovation as a collective, uncertain and unpredictable activity is focusing attention on dimensions of responsibility such as care and responsiveness which are values- and not rules-based, allowing for discussion concerning purposes and accommodating uncertainty (Owen, Machnaghten & Stilgoe 2012: 756).

Care is the other keyword. RRI seems to articulate a sort of ethics of care (Tronto 1993) in its rethinking the how and the why of research and innovation. They become, in a way, care practices (Mol 2008), not simply adapted and adaptable to specific needs but actively attentive to the foregrounding of needs. In this perspective, doing research and innovation is a way of *taking care* of social ills or structural difficulties – and they should arise from a «collective duty of care» (Owen, Machnaghten & Stilgoe 2012: 756) that all institutional actors involved in these processes share.

This, at least, is the ideal representation of this new approach. Radically opposing the «ivory tower» attitude of scientists and innovators, RRI suggests the need to embed research in society, to make it more participated and align it to concrete social needs. However, concretely acting on this perspective can be significantly harder. What forms of engagement could, for example, actually rewrite the power imbalance between stakeholders in research and innovation processes? If institutions and experts remain the ones exclusively in charge of defining rules, parameters, and limitations of public engagement, if participation can only occur inside very specific borders, RRI could simply end up as a new name for the status quo. This contradiction is, I believe, evident in the way literature on RRI puts the burden of transformation entirely on institutional actors. While this is inevitable, up to a point – they currently have all the initiative and resources – this initiative is precisely what doesn't seem to change. Under RRI, lay people aren't able to proactively influence institutions and scientists; they have to wait for scientists and institutions to come to them. The contradiction seems entangled with the way we do research and innovation. It's already significantly difficult to abandon the so-called «deficit model» of the public understanding of science, in which experts assume a strictly pedagogical role towards lay people, communicating the «right» knowledge (Bucchi 2015). Even more difficult would be not just abandoning this hierarchical view of knowledge, granting equal legitimacy to the more experiential knowledge that lay people possess (Arksey 1994), but also integrating this knowledge and the practices it brings into the scientific process at all levels.

This doesn't mean that the discourse on RRI and its reframing of responsibility aren't worthy of consideration. Maybe, the debate itself is more significant, at least now, than its practical translations. It's not hard to imagine why discourses on the responsibility of scientific research and technological innovation are proliferating in this specific historical moment. The so-called «move fast and break things» attitude especially towards technological advancements has had unexpected and wide-ranging consequences – from the disruptive effects of social media to more recent doubts about large language models and generative AI[1]. Renewed attention to the processes and purposes of research and innovation signals a

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[1] LLMs and generative AI seem to be particularly significant contexts in which to explore meanings of «responsible innovation», to which I can only gesture at here. On the one hand, we've seen the proliferation of debate around «good» uses of AI, especially focusing on the sourcing of the training data and on the accuracy of answers produced by tools like ChatGPT. On the other hand, these preoccupations arrived after many of the problems of generative AI had already presented themselves – from the indiscriminate scraping of data without any considerations of attribution and

more generalized preoccupation towards the social meaning of technological and scientific progress. And, more importantly for us, this debate isn't confined to institutional spaces. Other actors have adopted a similar language to RRI, thinking about how research and innovation can be carried out outside the traditional contexts of institutions and businesses – and how it can be carried out in the «right» way (Arnaldi, Crabu & Magaudda 2022).

This paper will explore the work of two such actors, two patient organizations active mainly in Italy. It draws from a research project conducted between 2021 and 2023. Due to Covid-related restrictions spanning about half of the project, in addition to the specific structure of the organizations in question, a significant part of this research has been conducted online, participating to remote meetings and events and, where possible, observing the interactions that members of these organizations have in their own online spaces, sometimes specific websites, often social media. Interviews have also been conducted, partially online and partially in person. Participants have been recruited mostly through word of mouth, starting from the core members of each organization and widening the circle from there, to other members and to professionals (mostly in the healthcare sector) that have worked with these organizations. More specifically, observations in this paper are mostly based on conversations and interviews with caregivers in both organizations in question, on interactions on social media channels pertaining to these organizations, and on the documentation produced by the organizations themselves.

Literature on patient organizations has already shown different ways in which these entities question the «truths» of biomedicine and of healthcare institutions, both on the practical, therapeutic front and on the scientific knowledge front (e.g. Epstein 1996; Rabeharisoa & Callon 2004). Here, I wish to focus on how these two organizations articulate ideas of responsibility in their everyday activity, operating mainly outside the range of both public health institutions and biomedical or pharmaceutical companies. If ideas of responsible research are predicated on a more responsive and attentive relationship between scientists and society at large, do people who are both subjects and objects of research, who aim to produce knowledge and innovation that is immediately impactful on their own everyday life,

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compensation to authors, to so-called «hallucinations» of chatbots that confidently recite incorrect information.

embody these ideas? How do they act in an ethical way? If, as Veena Das argues, moral and ethical concepts don't have any inherent meaning, but they acquire meaning in their situated, everyday use (Das 2015), I aim to explore what specific kind of «responsibility» emerges from the care practices of these organizations.

Distributed knowledge, distributed care

The first case is that of a voluntary association that I'll call Libre[2], dedicated to the support to everyday care of diabetes, and specifically to the use of technological devices that facilitate care. The organization was founded in 2014 by a software developer, Francesco, after his daughter was diagnosed with diabetes.

> My daughter went into diabetic coma and our life radically changed. When we came back home, I started furiously looking for information on the Internet, about diabetes, about diabetes in children, about what I could do to take care of her. And I found out that most of the things that are available online are for adults, and the few I could gather about children with diabetes didn't give me any practical information that could be useful in everyday care.

One of the main difficulties that Francesco reported in the first weeks and months after his daughter's diagnosis was the unavailability of information about her glycemic levels. «Sensors and receivers[3] are relatively limited technologies», Francesco told me, «because I need to be close to my daughter at all times to check if everything's fine. I can't leave her at kindergarten, because I don't know if the staff is prepared to deal with a glycemic crisis». Looking around online, he eventually found a solution to his specific problem, particularly suited to his specific skills, in NightScout, an open source software that through the «hacking» of sensors and receivers allows these devices to automatically upload their data to the cloud, where it can be accessed even without specialized equipment.

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[2] This, like all other proper nouns of people and organizations, is a pseudonym.

[3] Sensors are wearable devices, usually attached to the arm or the thigh, that transmit blood glucose levels to specific receivers, often through radio waves. They are the main instrument that allows for a constant monitoring of glycemia, and as such are frequently used by diabetics. Another frequently used device is the microinfusor, another wearable device that periodically releases insulin and helps with the management of blood glucose levels.

NightScout development itself is an interesting example of user-led development of a tool oriented to the specific needs of caregivers.

> NightScout got its start in the Livonia, N.Y., home of John Costik, a software engineer at the Wegmans supermarket chain. In 2012, his son Evan was diagnosed with Type 1 diabetes at the age of four. The father of two bought a Dexcom continuous glucose monitoring system, which uses a hair's width sensor under the skin to measure blood-sugar levels. He was frustrated that he couldn't see Evan's numbers when he was at work. So he started fiddling around (quoted in von Hippel 2017: 2).

The software started with the encounter of a few caregivers (mostly parents) of diabetic children, that were looking for something that would help the former monitor the latter's condition – mainly, glycemic levels – without being overbearing. Most of the first developers were software engineers or programmers, individually working on jerry-rigged tools combining sensors and receivers with consumer-grade electronic devices, like smartphones and other smart home assistants. They met on social media, where many were talking about their problems, and sharing their discoveries and results. After a few of them started coordinating their efforts, NightScout ceased being only a homebrewed system and became a community, gathered mainly around a Facebook page of the same name, with not only a growing number of active developers, but a wider range of users without a technical background, but that were also looking around for this kind of tool to use in their everyday care. One of them was Francesco.

«When I found NightScout, it was a relatively new system, and I could find nothing in Italian about it or similar software. So I decided to use my technical knowledge to write a guide, and that's how Libre started». The association began as nothing more than a Facebook group, where Francesco could share his expertise and experiments in using NightScout to check his daughter's glycemia, and possibly involve other parents or caregivers in the process. «It wasn't hard, in the beginning, to find people who needed the help, who could benefit from something like NightScout», Francesco told me, «and the group grew quickly. And with more people, we started doing more things». After a few months, the Facebook group became a website, a space that could house a plurality of activities carried out by the members of the association. The core objective remained the dissemination of and support for the use of technological devices applied to everyday care for diabetes – NightScout, first of all, but also everything else that Francesco and the other members of the association deemed fit to test and recommend. However, the community around Libre grew not only through the joining of caregivers, but also of adult diabetic patients and professionals who work with diabetics, from doctors and nurses, to psychologists, to lawyers. This way, the association tries to complement its work on diabetes and technology with other aspects of everyday care, from strictly biomedical ones to psychological and emotional ones, to bureaucratic and legal ones. The website has, for example, sections on the Italian legislation on disability and how it applies to diabetics and their caregivers; or a section dedicated to psychological support for diabetic children and adolescents; or a section in which both adult patients and caregivers can talk about their experience with chronic disease or everyday care. «We are a voluntary association and we want to remain one» argued Francesco, «so we won't ever ask for money or any other kind of material contribution. What we ask for is that if you have any kind of skill or expertise that can be useful you share it with others, whenever you can».

Knowledge sharing is, in general, the main activity of Libre. The website of the association is structured as a database of information produced and freely shared by its members. The involvement of professionals has been useful to widen the range of support that Libre is capable of offering – through information that is legitimated by the authority of people with officially sanctioned expertise, such as licensed physicians and lawyers. However, the association's main interest, that of technology and specifically remote monitoring systems, remains the purview of amateur developers and researchers. And, in a sense, this compartmentalization of not only knowledge but legitimacy (both epistemological and moral) is something that Libre actively pursues.

> Often, doctors aren't aware of «unofficial» systems developed by the wider community of patients and caregivers. So, they can't help us spread the word around. We try, I try to explain as much as I can, especially when a general practitioner asks, but these systems remain unofficial, so they don't really promote them as much. It's mostly other diabetics or caregivers that promote the work of the association, and we like it that way. We don't want to become affiliated with health institutions or pharmaceutical companies; we like to be independent as much as we can.

The association is not directly antagonistic towards doctors and other healthcare professionals, nor is it critical towards the knowledge produced by «mainstream» science and its related actors. However, the members of Libre consider mainstream science incomplete: the perspective of doctors and scientists might be more accurate in regards to the biological dimension of the disease, but is unable to seriously consider the experiential dimension, and hardly even takes into account the material, relational, social aspects of everyday care. That is where Libre aims to intervene – even though some collaboration with «sanctioned» expert is present, most of the knowledge disseminated by the association is eminently experiential (Borkman 1976; Mahr 2021), acquired through the everyday process of caring for a chronic disease, or living with it. This experiential knowledge concerns mainly the minutiae of ordinary care, with again a particular focus on the uses of technological devices, both official and unofficial, and their possible consequences. Active, if controlled, experimentation with these devices is encouraged. Most of the times, «experimentation» means thorough testing of commercially available device: Libre is always looking for diabetics and caregivers that are willing to try new sensors, receivers, microinfusors. The first objective is a sort of verification of official information – again, the association isn't opposed to biomedical knowledge (and, as such, to the information provided by the manufacturers of these devices), but it always aims to independently check what, for example, a sensor can do and how it can be integrated into everyday care practices. But another important form of experimentation concerns the use of new devices in tandem with homebrewed systems such as NightScout. Being «unofficial» software, unexpected complications or errors might manifest in their use with different biomedical devices, and it's always up to the community of users – in the case of Libre, mostly caregivers but in some cases adult patients – to verify eventual problems and collaboratively search for solutions. This is, for example, how Francesco ended up developing his own remote monitoring system.

> NightScout is a very complex system to set up… you need some technical knowledge or to be very careful in how you connect the different devices to your computer or your phone. This is why I started with a step-by-step guide, but it still was a significant roadblock for many. So I started working on something different, something easier… and ended up making an app, basically. It's less capable than NightScout in terms of raw features, and being just me working on it it's also less compatible with sensors. But it's usable with the most common ones, and it's far easier for people with less technical skill. It's also easier to connect with other smart devices, not just your phone.

While we were talking, he turned around and asked a smart speaker for his daughter's glycemia. «See? This is what I mean. She's at school now, and I can be confident that she's ok». He showed me other devices that can give him the same information. «I'm trying to be thorough. If I can be informed whenever I need about my daughter's condition, I can intervene in any situation necessary».

Through the distributed production of knowledge about technology applied to diabetes, and especially about the care practices it allows, the members of Libre become «lay experts» on the disease (Arksey 1994; Rabeharisoa, Moreira & Akrich 2014), claiming a form of expertise that has a different epistemological foundation from that of mainstream science:

> The ability of lay people to identify changes in their bodies, as citizen scientists for example, rests on intimate bodily experiences. Their epistemic groundings is founded in the intimacy of bodily perceptions. It is not reason at work, but knowing one's own body; not objective facts, but subjective sensations; not cold experiments, but individual experience (Mahr 2021: 36).

This «epistemic grounding» on bodily, intimate experience works for the patients that reflect and act on their condition, that experiment with the instruments of care at their disposal, and that try to analyze the results of this experimentation (Barbot 2006); but it also works for caregivers. Taking care is not a disembodied experience – rather, it's a form of engagement *with* the body of someone else *through* our own (Puig de la Bellacasa 2017), and as such produces analogous forms of situated, intimate knowing.

> The aim is not so much to pursue a «counter-science», but to generate complementary knowledge, which on the one hand underlines one's own concerns and experiences, but on the other hand should also add a new facet to the knowledge of science (Mahr 2021: 124).

The case of Libre (and, similarly, the next case I'll talk about) underscores how much of the bodily experience of illness is shared in the dwelling of the everyday. In the discourse around diabetes, there's even a specific concept to indicate the way the disease affects the people around the patient: T3, or «type 3», is the primary caregiver for someone with type 1 diabetes (the most severe). It's particularly significant, in this case, the use of a language that explicitly refers to the biomedical categorization of the disease – it signals continuity with the «recognized» types of diabetes, it argues that this is also a social pathology, that it «infects» relationships as well as bodies. It forces caregivers to adjust and shape their everyday on the needs of the patient, to be constantly prepared, to negotiate with every other aspect of their life, to talk to (and argue with) doctors, public health administrators, teachers. But it also affect caregivers' bodies – going without sleep, or pushing through pain and illness to provide adequate care. Francesco defines himself as a «T3 father» first and foremost. His objective isn't to redefine biomedical categorizations of diabetes, but to use his specific knowledge – *experiential* knowledge, contingent on his specific care practices – to open up new spaces for care (Mol 2008). The epistemic grounding of Libre's practices is on the caregivers' status as T3 – not directly affected by diabetes as a disease, but still immersed in its consequences as an illness.

The specific attention that Libre gives to technology applied to everyday care, and not only to the *use* of technology but also to the *active shaping* of technological devices, defines a space of expertise and experience that the association claims as legitimately its own, and through which it aims to gain social capital in its interactions with healthcare professionals and biomedical researchers. This means trying – struggling – to see the use of unofficial devices and systems recognized as a legitimate form of care, even though it places both the patient and the caregiver outside (or at least on the border) of biomedical science and public health intervention. A particularly interesting aspect of this struggle concerns the safety of the «hacked» devices that members of Libre use. Biomedical devices have to undergo a process of evaluation and certification that assures doctors, patients, and caregivers that the risks are minimal, or at least controlled, and that the results are accurate and reproducible – in the case at hand, that sensors give accurate information about blood glucose levels. Regulatory bodies and their certification procedures aren't free of critical points: clinical trials, for example, have repeatedly shown their limitations, such as in the scramble to find enough subjects suitable for participation that has complicated the already existing biases in the selection of these subjects and in the inherently partial results they produce (e.g. Petryna 2006; 2013). The same is true for the testing of technological devices that are used for therapeutic purposes. Regulation and certification aren't a guarantee of efficacy of care; they are, however, a way that health institutions have of taking responsibility – through certification, «sanctioned» experts use their legitimate knowledge to support the adoption of specific drugs or devices, and thus make themselves accountable for it. By hacking sensors, receivers, and microinfusors, the members of Libre are, in a way, rejecting this assumption of responsibility, and taking it for themselves. Another member of Libre, Cesare, recounted of his experimentation with creating devices for everyday care.

> I made this sort of alarm clock […] that shows me my daughter's glycemic levels when I ask for it. And on these numbers I decide her everyday therapy. I mean, I'm confident of the usefulness of this thing, but on paper I shouldn't necessarily trust those numbers. Nobody *knows* if they are correct. But many diabetics and caregivers use devices like this in their everyday care, and most everything works out. These systems are made by people with diabetes and used every day by thousands. If problems arise, there's a community that gives support 24/7. I think this is worth as much as any official certification.

Francesco told me similar things. «We always make it very clear that the things we promote aren't certified», he said, «but also that there's an active community that is constantly helping with any problems that we might encounter». Especially where software is concerned, «the community of developers is always working on a new version, on correcting bugs. If an official device is defective, you might have to wait months for a new one». In rejecting the responsibility of health institutions, members of Libre make themselves *responsible subjects*, actively engaged in ensuring the «quality» of the care devices they promote. The «distributed» knowledge of the community around Libre becomes the assurance that is lost in manipulating and hacking mass-produced (and officially certified) devices.

From a wider perspective, the shifting of responsibilities also means envisioning forms of care that themselves have a different grounding from those based on «expert» biomedical knowledge. Forms of care that foreground the relational and social dimensions of diabetes, that account for the practicalities of caregiving and the ordinary obstacles to living a «good life» even with chronic disease, and that emerge first of all through the collaborative development of technology. As Annemarie Mol argues, «attuned» care for chronic disease necessitates non-linear and open-ended forms of support for patients (Mol 2008; Zigon 2017). «Attunement», in this case, doesn't simply stem from the possibility to «choose», to express a preference in everyday care – it's enacted through the opening of boundaries, through «mak[ing] space for what is not possible» (Mol 2008: 22). By focusing on the distributed knowledge of its community, Libre widens the possibility space for care practices, along the same distributed lines that cross and connect its members.

Producing knowledge, diversifying care

The second case I want to reflect on is that of Strike, a foundation that promotes scientific research and technological innovation concerning cerebral palsy (CP)[4] in children. As with Libre, the foundation was created by caregivers, specifically the parents of a child with CP – but in this case, it was created initially to share the experience of caregiving with other people, and to give support especially to parents in the same situation.

> It began in a kind of random way, in 2013. We had the opportunity to publicly talk about our experience with our son, who was two at the time. We, my husband and I, we were on stage, and started talking very honestly about our difficulties, how we couldn't find anyone who could tell us what we could do, even what CP could mean for our son in his future. The talk had some resonance, because after that other parents and caregivers started contacting us to tell us their own stories, often similar to ours. So we thought, we have to do something.

This is how Federica, one of the founders of Strike and its president during my research, recounted the inception of the foundation. Strike was founded in 2014, as a voluntary association, and, like Libre, was initially little more than a Facebook community, dedicated in this case exclusively to relatives and caregivers of children with CP. The group still exists in the same form, and it's still only for parents and caregivers. While the organization is now far larger than it was at the beginning, and – as we'll see – has a number of collaborations with physicians and academic researchers, that space has maintained the same objective and the same structure: a place of sharing, mutuality and self-help, where caregivers talk about their everyday experience with caring for their children, without necessarily involving doctors or any other kind of «expert». Amongst the transformations that Strike has undergone, many of which have sidelined the more grassroots and community aspects of its work, the Facebook group – together with other virtual spaces of everyday sharing – has remained mostly a *communitas* in the Turnerian sense (Turner 2004): a group of peers with a shared

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[4] Cerebral palsy is a complex neurological disease usually caused by perinatal stroke. Consequences can be wide-ranging, both in their nature and in their severity, but they usually entail either impairment in motor functions, in speech, or in cognitive functions. Rehabilitative therapy can mitigate these consequences, but the damage is often irreversible.

sense of their ordinary life, that identify with common (moral) values and stances and that actively participate in each other's lives. And in this kind of *communitas* the space for experts is minimal. As another member of the group, Alessia, told me, physicians are often quick to dismiss insights or observation made by caregivers, because they aren't validated by scientific knowledge or by rigorous research, but «only on personal experience».

> They will say, did Doctor Google told you this? And yeah, sometimes we look things up on the internet, but more often than not it's something we talked about among ourselves, it's the lived experience of another parent, or my own. What they don't understand, or don't want to, is that they have studied, but we live this disease on our skin, every day of our lives, so maybe we know a thing or two about it.

Again, this knowledge is legitimated by intimate, bodily experience (Mahr 2021), and struggles to be recognized as valuable by experts both in the definition of everyday problems connected to CP and in the discussion or implementation of possible solutions. This is why Strike still has a space dedicated exclusively to caregivers – a space where the experiential can be talked about without fear of judgment, of being labeled in some way «anti-science». But this very struggle for legitimacy is also the reason why a considerable amount of effort and resources of the foundation have gone, especially in the last few years, to projects that foster cooperation between patients, caregivers, and experts. If Libre asks for voluntary collaboration from experts, but sidelines their perspective in its main activity, Strike instead aims to push for hybrid spaces (Callon, Lascoumes & Barthe 2009) in which an intersection of expert and experiential can create new pathways for both scientific research and everyday care.

A specific project that Strike tried to realize a few years ago is particularly illustrative of where the foundation wants to take this intersection. One of the most significant problems that people with CP face is the profoundly unequal distribution of healthcare services across Italy, particularly where it concerns rehabilitative therapy for both motor and cognitive functions – something that caregivers in the community around Strike are particularly attentive to. Especially for those living in the Southern regions of Italy, finding suitable clinics is often an uphill battle.

> During pregnancy, when I discovered that my daughter had this problem… they advised me to move to Roma or Milano. With my husband we had just moved

> to Puglia, and we couldn't find anyone… so we moved to Milano for childbirth, and then went back to Puglia… after a few years, we decided to move to Milano for good. I know it's nobody's fault, but I can't risk my daughter's health.

Stories like this one, from Rosa, another caregiver of Strike's community, are the reason why the foundation expends considerable effort to create alternative pathways for everyday care, ones that don't necessarily rely on local public health services, or even, in some instances, don't expect people to move at all. This last one is the case of Symmetry, one of the main projects of Strike, that aimed to create a platform to remotely conduct a form of physical rehabilitation. «We read an article about mirror neurons», Federica told me, «and when we discovered that the research team was Italian, we went and talked to them. We were thinking about a way of taking these discoveries out of the lab». The best way, according to Federica, was trying to involve neuroscientists from the very beginning of the project, to ensure the scientific rigor of the entire process. Alberto, a neurologist that worked on Symmetry, recounted the beginning of the project:

> The initial idea was to create something that could remotely pair children with similar levels of motor function, and let them do rehab work together, under the pretense of play. […] Strike was very focused on the care and communication aspect of it all: they wanted something to give back to their community. We wanted to understand more about mirror neurons and motor rehabilitation. So there was some friction, especially at the start.

In the different perspectives of Federica and Alberto are visible the different, sometimes divergent, logics of research and innovation of patients/caregivers and institutions. For Federica, the guiding principle is that of care: Strike aims to represent the needs of people with CP and their caregivers, and to widen the spectrum of available care. Once again, this is a logic of open-endedness and attention (Mol 2008), that focuses on the specific and granular aspects of the act of ordinary caring. On the other hand, for Alberto the focus point is knowledge production, and «validated» knowledge at that. Therapeutic intervention is, in this perspective, secondary to the accuracy of the data collected and the rigor of their interpretation; for Strike, instead, it's the scientific validity of the results that's simply a means to an end, that of giving support and care opportunities to caregivers.

But it’s not simply an inversion of the priorities of research and innovation. Like Libre, Strike aims to frame the production of experiential knowledge as complementary to the work of sanctioned experts and scientists – but, as already noted, by creating an hybrid forum for discussion and collaboration (Callon, Lascoumes & Barthe 2009). Symmetry is a concrete example of such a forum: the project moves from what Strike (and, specifically, Federica) perceived as a need of the community, rather than from the wish to know more about CP. Not only that, the form that the project took was, again, strongly argued for by Federica and her husband because it could result in a different and more accessible way of doing rehabilitation. Expanding the boundaries of care, in this perspective, means not only creating new instruments and practices, but «attuning» these practices to a wider spectrum of needs. If the interests of experts and scientists is usually focused exclusively on the disease itself, as an organic entity, the interests of «experts of experience» (Viehöver, Wehling & Roche 2015) is often more holistic, and includes a plurality of trajectories of care (Mahr 2021). So, Symmetry was planned as an effective way of doing motor rehabilitation remotely – not only creating new possibilities for therapeutic intervention but also compensating for unequal access to institutional care. But the «remote» part aims to compensate for a wider range of structural inequalities, for example in being economically more accessible in addition to physically more accessible; or in lightening the work of primary caregivers – very often women who are forced to abandon their jobs to dedicate themselves exclusively to care.

This is the specific way Strike frames its own responsibility towards its community, and towards people with CP in general. The foundation rejects the monopoly that experts claim on legitimate knowledge on the disease, but they don’t see themselves as antagonistic or even alternative to what Michel Callon and others call «secluded research» (Callon, Lascoumes & Barthe 2009), research that is conducted only inside the walls of academia or of other institution, without contact or collaboration with (in this case, patient) communities. Instead, they aim to «open up» the space of secluded research and introduce different criteria for evaluating the utility, the impact, the accuracy of the data collected and the results produced. By pushing for a wider range of considerations in directing biomedical research and innovation, by centering attention to the complexities of everyday care, Strike tries to bring up issues that often remain outside the purview of institutional research, and involve experts and scientists in the search for solutions.

Active collaboration means access to more resources than the average patient organization. While, for example, Libre has to make do with voluntary work, from its community of patients and caregivers and from the experts that are willing to freely help, Strike can organize multiple research projects with full-time researchers – it's the case of Alberto, that was fully employed on Symmetry for the year he spent on the project. However, more intertwined collaboration means more opportunities for the different logics to clash, as we've already noted. And again Symmetry proves to be a significant example, in its conclusion and in the way it's narrated by Federica and Alberto respectively. The latter declared himself satisfied with the results: findings on the effectiveness of remote rehabilitation were significant, and the research also came with interesting results on the perception the children had of their own body. In both cases, neuroscientists involved managed to publish the findings in scientific journals. On the other hand, Federica was frustrated by the inability to keep going, to create something that could actually be used by caregivers and children with CP. After about a year, funds dried up and while on the research part the work of data analysis and publication went on, Strike found itself with an instrument for rehabilitation that seemed to be effective, but couldn't be made accessible to patients. «If we're not sustainable, if we're unable to give back, what's the point of doing all this?».

(Bio)socially responsible

In his landmark essay *Artificiality and Enlightenment*, Paul Rabinow describes a new mode of self-fashioning, that he calls *biosociality*:

> In the future, the new genetics will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduction will emerge, which I call «biosociality.» If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality nature will be modeled on culture understood as practice (Rabinow 1996: 99).

The circulation of biomedical knowledge, concepts, and representations allows, Rabinow argues, for the construction of social identities through their reappropriation – communities emerge not only through social-biological concepts such as race or gender, but through the sharing of biological characteristics that are re-signified in a cultural, situated way. In a context in which disabilities or chronic pathologies aren't simply biological facts but imply a complex network of social, economic, even moral positions, they can also become instrumental in the construction of social bonds and personal relationships. Patient communities can be considered and articulation of biosociality: they are created through the appropriation of biomedical knowledge, that is used as a basis not only for the shaping of one's social identity, but also to structure a (social, political) praxis. Rabinow himself identifies them as a salient example. «There already are, for example, neurofibromatosis groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on. That is what I mean by biosociality» (Rabinow 1996: 102).

Both Libre and Strike, I would argue, constitute biosocial communities. They are, in a significant part, *virtual* communities – neither organization has a geographically-situated base, and they mostly operate and share experiences on online platforms. This means mostly being active on social media: as we've seen, both had their start on Facebook, aggregating people who were struggling with similar problems on everyday care. But they both tried to shape their virtual spaces to accommodate the need of an actual community. On the one hand, they redefined the rules of engagement and interaction on social media, by – for example – restricting access to information posted on Facebook, and implementing informal vetting processes to control who can access private spaces, and who can consider themselves actually «part» of the community. On the other hand, while these «official» spaces are usually the main point of interaction between members, they are not the only one: members often establish smaller-scale relationships outside the organizations' main spaces, and through these relationships offer each other different forms of support in their ordinary care practices. While the use of online platforms inevitably shapes what kinds of relationships are possible, both Libre and Strike struggle to find ways of reappropriating these platforms and use them as instruments towards their own needs, prioritizing the connection between members and the sharing of experiences of illness and care.

The key point of biosociality, as Rabinow argues, is the centrality of a (bodily) condition in the shaping of the subjectivities of members of the community. And in the case of Strike and Libre it's evident that the conditions in question affect much more than only the people who are chronically ill. Even the lives of caregivers, even their social identity and self-representation, are profoundly shaped by chronic pathology. Riccardo, the other co-founder of Strike, was very explicit about how their son's condition was affecting their own:

> We were in a worse shape than [him]… you think there's something wrong with you, with what you've done, you think you're a total failure… the trauma is double, first because you can't process what happened, what your child has, and then when you're a bit better, and you think more about it, you see the shape of it… how will he do things when we're gone? From then, your life is preparing for that, ultimately is just preparing for that.

The same is true for Libre. As I've noted above, the notion of «T3» is used explicitly to mirror biomedical language and categories concerning diabetes, and to underscore the social and relational dimension that the disease has – going so far as to «infect» (relationally, morally) the people who take care of the sick person. Francesco's subjectivity is profoundly shaped by his being a «T3 father». And even his own expertise as a software developer is in large part dedicated to taking care of his daughter (and, by extension, to working on support for diabetic patients). If, from Rabinow's perspective, biosociality is the sharing of experiences, collective advocacy, education and reshaping of the everyday around a disease, then Libre and Strike – with all other caregiver organizations – are biosocial communities. Biosociality allows subject to actively re-signify, and even *choose*, what «biological facts» can mean, for as Ian Hacking argues biology is not a given, but is shaped by not only scientific knowledge and research, but also by the technology that acts on our bodies and our lives (Hacking 2006).

I would go one step further still. Strike and Libre are communities aggregated around caring for a specific disease, but they also follow in the footsteps of organizations that do research «from the bottom-up» (Rabeharisoa & Callon 2004; Epstein 1996), and that struggle for the recognition of patients and caregivers' rights (Rose 2007). As we've seen, these dimensions are inherently interconnected: relationships are formed through the sharing of care experiences and the imagining (and trying to realize) new care practices. Through this imaginative effort, and their shared and distributed work, both organizations enact different dimensions of the respective diseases (Mol 2002): CP isn't just damage to the brain caused by perinatal stroke, diabetes isn't just the inability of the body to produce insulin; they're both also prisms that redefine proximity and care relationships, and produce both in-group and out-group identity for both patients and caregivers. Per biosociality, biological facts are «modeled on culture understood as practice» – they are outside the body-as-object, and in the body as nexus of cultural and moral meanings. And, also, as nexus of (care) relationships.

Finally, I wish to go back to the issue of responsibility and responsible research. Strike has worked on projects that explicitly refer to the RRI discourse and mobilize its related methodologies, and they have contrasting feelings about them.

> Often it's a «project factory». You get a grant for one, maybe two years, and you do something, and then that's it. It's like with our latest project, with [a university in Northern Italy]. It's not sustainable, we've got a prototype and nothing else. And then they move on. We betrayed the expectations of our community, the families that we involved, and we went against our mission.

One of these projects, Movement, effectively illustrates the contradictions that RRI can fall into from the perspective of end-users (in this case, patients and caregivers). Movement was a project that Strike was involved in, coordinated by engineers and designers of an Italian university. The specific objective of the project was, once again, the prototyping and developing of an aid for motor rehabilitation for children with CP. However, Movement also had a wider objective: to experiment with different methodologies of collaborative innovation, explicitly referring to RRI's principles in the way research, development, and testing were conducted. Strike's founders and community members were involved in identifying which specific need could be addressed; they were involved in prototyping, iterating, and testing possible solutions; they got to try and use the final product of this process. But then, the project was over, and what remained was a few finished prototypes that couldn't be actually used for everyday rehabilitation needs, and mostly couldn't even be accessed outside the confines of the university in question. Even though Movement responded, at least in theory, to the principles and ideals of responsible innovation, in practice it still ended up not answering to the concrete care needs of Strike's community of patients and caregivers.

Symmetry, as we've seen, had similar problems. And this is in general the critique that Federica and Riccardo articulate against RRI as an approach: as long as it remains confined to discrete endeavors, as long as the initiative and resources stay with institutions, no space of research and innovation will be fully «hybrid». The expectation of institutions, in these projects, is usually to find «auxiliary associations» (Rabeharisoa & Callon 2002), that cooperate without necessarily claiming any kind of authority or ownership on the research and its results. The «responsibility» institutions have begins and ends with the involvement (often limited in scope and time) of a section of the community that will be impacted by their work. As we've discussed earlier, this is a structural issue with RRI – but the inherent contradictions of the approach don't mitigate the discontent of patient and caregiver organizations.

This is why Strike tries to reappropriate the idea of responsible research and innovation and redefine it along the lines of a logic of care (Mol 2008). Similarly, in its rejection of institutional responsibility, Libre argues that the community itself is the more legitimate «responsible subject». In both these cases, the constantly renewed process of *attunement* to the needs and perspectives of patients and caregivers is absolutely central to the re-signification of «responsible» and «responsibility». Libre and Strike both try to push at boundaries, make space for people, and take care of them. As Jarrett Zigon argues, attunement is one of the conditions for «being-with»: the ability to remain entangled in relationships, but also the struggle to maintain them, to *care* for each other (Zigon 2014; 2017). Here is where biosociality, responsibility, and attunement intersect: if biosociality is the sharing of not only conditions but experiences, it's a form of acting together – of being-with. The re-signification of biological «facts» is collective, creates the possibility of inhabiting the same world, of being responsible for each other through the act of caring. In the cases of Strike and Libre, being responsible means switching the logic of research and innovation, rather than simply «injecting» cooperation, and through this switch, it means arguing for a different idea of what «good care» can be. In other words, it means creating, and maintaining, a biosocial community.

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