“Being Informed About My Health Without Going to a Doctor’s Appointment”: Doctors’ and Patients’ Narratives About a Future with AI

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6.1 INTRODUCTION

Over the last several decades, the populations of Western societies have aged due to a continuous decline in fertility rates and increased life expectancy. This demographic change has been accompanied by a rise in people with chronic diseases, which are long-standing conditions that require daily management by patients, caregivers, and professionals to treat the symptoms of the illness and minimise its effects on the other

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spheres of daily life. This work has been made even more difficult by government policies that are often oriented by the principles of neoliberal ideology, resulting in a decrease in public healthcare spending, which affects healthcare organisations through staff reductions and underinvestment in new facilities and infrastructures (Dickenson, 2013).

Both in academic and non-academic debates, growing attention has been paid to the possible role of technologies in assisting people with chronic conditions by facilitating or replacing the work of informal (i.e. relatives, friends) or formal caregivers (i.e. care aides, social workers, health care professionals). A particular emphasis has been placed on technologies that can behave intelligently, that is, process large amounts of data, show problem-solving capabilities, and learn from experience (Bostrom & Yudkowsky, 2018). These technologies, which generally lead back to the broad field of artificial intelligence (AI), are governed by sophisticated algorithms that can learn from their experience. Unlike traditional algorithms, those that govern AI technologies can create and move data, learn from them, and make decisions without any human intervention. AI faces growing expectations about the potential benefits of intelligent machines in enhancing the health and quality of life of patients and simplifying and empowering the work of health care professionals. The spread of AI in healthcare has been supported by substantial economic investment from public institutions and private corporations. These investments aim to renew healthcare infrastructures and facilities by giving digital technologies a crucial role in the assistance of citizens with health issues. This chapter aims to shed light on a still under thematised issue: the ways in which professionals and patients depict a future with AI in healthcare.

Until now, the social sciences have mainly opted for a critical perspective on AI, highlighting how intelligent machines could strengthen preexisting inequalities (Owens & Walker, 2020), enable pervasive surveillance processes, and de-personalise doctor–patient relationships (Iliadis & Russo, 2016). However, contributions rooted in STS, traditionally interested in how society shapes (and is shaped by) new technologies in practice, have rarely addressed the topic of AI in healthcare. Moving away from a deterministic perspective, for which algorithms are external entities that can impact positively or negatively on healthcare systems and on society, this chapter seeks to contribute to exploring the socio-material assemblages through which algorithmic systems are produced, designed, and made to work in practice (Schwennesen, 2019).

This chapter's aim will be to show how socio-technical imaginaries transmit "moods and sensations" (Bucher, 2017, p. 41) about algorithmic technologies in healthcare, generating different and competing ways of thinking about what algorithms are and affecting how these systems are used (ivi: 32). These reflections will be developed by drawing on an ongoing European project aimed at designing and testing an AI-based remote monitoring system to detect patients with advanced Parkinson's disease (PD) at an early stage to allow for early intervention and treatment. The considered technology fits perfectly with the above-mentioned trends. It gathers data from various sources (e.g. electronic health records, wearables, clinical examinations) and different kinds of data from patients (e.g. medical histories, treatments, hospitalizations, frequency of visits, symptoms, signs, measurements) to help clinicians detect or forecast the advanced phase of PD. The chapter is organised as follows: after an introduction to the concept of socio-technical scenarios, it will present the methodology and the setting of the study. Subsequently, the empirical sections will focus on the convergences and divergences between the considered actors (in particular, neurologists and patients) in defining the future role of AI in the management of PD. Finally, the discussion will present the results and compare them with the existing literature on intelligent machines in healthcare.

6.2 Socio-Technical Imaginaries During the Time of Artificial Intelligence

In the so-called late and advanced industrial modernity, the expectations for technological innovation have dramatically grown due to phenomena such as the elevation of science to a leading authority in the solution of the problems of contemporary societies, the development of explicit national and supernational research policies aimed at defining the priorities of scientific innovation, the mounting investments of private companies and corporations in innovative programmes, and the growing attention paid by the media to the potentialities of technoscience (see Neresini et al., 2020; Selin, 2007). In parallel, a growing number of social science studies have developed theoretical concepts and approaches aimed at exploring how expectations can be generative since they guide activities, define roles, provide mutually binding obligations, legitimise novel objects and processes, attract interest, and foster investment (Borup et al., 2006).

In this heterogeneous field of study, often labelled the sociology of expectations, one of the most successful emerging concepts is that of socio-technical imaginaries, here defined as "generally future-oriented visions of connected social and technological orders (…). These visions need to be stable enough that they are not just read into, but can be seen to have the possibility of shaping terrains of choices, and thereby of actions: they are infrastructures of imagining and planning futures" (Sismondo, 2020, p. 505). Providing a detailed and exhaustive analysis of the debate on socio-technical imaginaries, mainly rooted in STS, is not one of the goals of this paper. Nevertheless, it is necessary to discuss the three key feature dimensions of this theoretical construct (see also Breuer et al., 2023). The first is *performativity*: Imaginaries are both performed (they are an effect) and performative (they have an effect). Most scholars who have analysed the relationship between expectations and technological innovation under a sociological perspective (Vezyridis & Timmons, 2021) have noted how imaginaries (both positive and negative) are the products of innovation practices and also function to drive the formation of the networks that constitute those ones. Consequently, imaginaries provide a framework for technoscientific *interventions* (such as innovative research policies and projects, technological objects, and infrastructures); they provide new ways of imagining the relationship between people and technology, stimulating the construction of new technological objects. The third dimension is *sociocultural*: imaginaries are embedded in wider cultural and political contexts. As argued by Breuer et al. (2023), scenarios developed by people involved in designing a new care technology are irremediably influenced by the visions that circulate in the public debate, thanks to powerful actors such as research institutions or policymakers.

In the public sphere, the recent hype around the concept of AI has been accompanied by an intense circulation of metaphors, myths, and rhetoric about the future role of intelligent machines in various fields of public (e.g. defence, education, welfare services, work) and private life (e.g. entertainment, housekeeping, daily care of older people).[1] Consequently, the concept of socio-technical imaginary has recently been used by various STS scholars to explore how expectations about a future with

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[1] See, for example, "Large, creative AI models will transform how we live and work" (The Economist, 22 April 2023) or "The A.I. hype cycle is distracting companies" (Harvard Business Review, 2 June 2023).

AI are circulating in our societies and how they shape (and are shaped by) politics, programmes, and practices that involve various actors.

Several authors have explored the role of the state in structuring future expectations about AI and how states may combine the powerful measures of regulation and the allocation of resources with their own narratives and visions (Beckert, 2016; van Lente, 2016; van Lente & Rip, 1998). Bareis and Katzenbach (2022) have analysed governments' rhetoric about AI in China, the United States, France, and Germany, observing how governments portray AI technologies as (i) an unprecedent and inevitable rupture that transcends any former societal experience, (ii) bearers of a shiny future in which the most important problems of the present will be solved, (iii) having features and goals consistent with cultural, political, and economic peculiarities of national contexts, and (iv) aligned with policies aimed at establishing normative principles, allocating funding and, more generally, transferring ideas about the future in practical interventions.

In other studies, scholars have tried to understand the relationships between AI technologies, imaginaries, and daily practices by analysing how these elements relate to each other. Schwennesen (2019), for instance, starting from an ethnographic study about the production and use of an algorithmic system at a rehabilitation centre, observes how this system was founded on a socio-technical imaginary of the possibility of replacing professional work with advanced algorithmic codes. At the same time, the author shows how the process of transferring professional expertise to algorithmic codes is not straightforward, as it involves a variety of humans (e.g. physiotherapists, IT workers) and non-humans (e.g. algorithmic imaginaries, policies, sensors, parameters, computers) and, with them, various judgements and assumptions about patient motivations and behaviours. In parallel, patients arrange and put human and non-human actors in place (e.g. reconfiguring spaces at home, defining when and where the technology must be used), start to interact with the new technology, experience frustration and anger due to their betrayed expectations, and, finally, redefine their imaginaries about AI.

To summarise, imaginaries are produced by individual and collective sense-making activities that result in shared ideas about technology, including fears, hopes, and expectations (Kazansky & Milan, 2021) that, in turn, influence the policies aimed at funding research and innovation activities, the features of technological objects, and the daily practices that emerge around these objects. However, the emergence of a certain vision about the future is certainly not a linear process. Imaginaries can contain incoherence, ruptures, and tensions; consequently, the depicted socio-technical futures are often controversial and debatable. As observed by Gardner (2022), considering the case of a data-driven hospital socio-technical imaginary, defining the features of an innovative technology produces various tensions about specific aspects (e.g. the nature of data collected or the adopted criteria for authorising researchers access to patients' data) that reflect the discords among different interests and aspirations. Such tensions can function to invigorate, rather than undermine, the emerging socio-technical imaginary, stimulating providers to solve these tensions and translate them into a specific socio-technical arrangement.

6.3 The Study

This chapter draws on a qualitative study on the expectations of neurologists and patients towards AI applied to the monitoring of PD, a chronic, progressive, and degenerative disorder of the central nervous system that, in 2016, affected approximately 6.1 million individuals worldwide. Based on statistical predictions, in 2040, this number is expected to increase to more than 12 million. PD is regarded with particular social concern for two reasons. First, it is characterised by various debilitating features that involve motor (e.g. tremor, rigidity, bradykinesia) and non-motor symptoms (e.g. anxiety, depression, sleep disturbances, cognitive impairments). Consequently, with disease progression, patients with PD often lose the ability to work and require the assistance of formal and informal caregivers, with major consequences for patients and their families, as well as for society and healthcare systems. Second, current therapies do not prevent PD progression. Consequently, much attention has been paid to the development of intelligent monitoring systems, useful for steering patients towards effective therapies to alleviate advanced disease and its symptoms (e.g. deep brain stimulation, neuroprosthesis). As a result of close monitoring, patients can experience significant improvements in their motor control and mobility and carry out daily activities with greater ease and independence.

This work is based on data gathered in Italy at two focus groups with six to eight patients each and during in-depth interviews with three neurologists and four patients with PD. The patients were recruited among the ones followed by the centre of the University of Padova specialised in the treatment of PD.[2] The semi-structured interview and focus group guides were based on a literature review and expert consultation and included topics such as detection of disease progression, current disease monitoring processes, and perceptions about AI and remote patient monitoring. For patient participants, to stimulate detailed expectations about a future with AI, demonstration materials were provided during the interviews and focus groups, including a slide show containing images of remote monitoring devices (e.g. wearables and social robots) and short videos explaining AI in simple terms. A qualitative content analysis with an inductive approach was employed by two of the authors (F.M. and C.G.) to extract meaningful themes from the data (Braun & Clarke, 2006). First, the two researchers rigorously reviewed the transcripts independently and used the interview guide questions as a provisory list of codes to analyse the data. Then, the three authors of the chapter developed, modified, and refined a coding frame composed of themes and subthemes established *ex-ante* and that had emerged through the analysis. To maintain the trustworthiness of the analysis, the resulting themes and subthemes were discussed among coders until a final consensus was reached. The analysis focused on two main topics that are at the core of this study: the dissatisfaction with current monitoring processes for PD and the convergences and discrepancies between actors' expectations about the future role of AI in the monitoring of PD.

6.4 An Unsatisfying Present Behind a Bright Future

The construction of a desired future starts from a strong dissatisfaction of patients and neurologists with the current monitoring processes for PD. In the management of chronic conditions, monitoring activities generally aim to gather information about the intensities of a disease's symptoms, tracking its progressions, and laying the basis for therapeutic decisions (see May et al., 2014, pp. 5–7). As we will see in this section, these actors produce narratives about the present that, on the one hand, pave the way for future ruptures and, on the other hand, are consistent with recent cultural, political, and economic trends in the Italian welfare

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[2] The study was approved by the local ethics committee of the University of Padova, and informed consent was obtained from all interviewees before participation.

system, which is characterised by the underfunding of public health care facilities and the consequent overloading of both formal and informal caregivers (see Giarelli & Neri, 2020). In particular, the current monitoring processes were evaluated by interviewees as unsatisfying for at least three reasons. The first reason concerns the troubles of public healthcare systems in following people with chronic conditions:

> I want to be really honest. I do not use it, [if] you are talking about UPDRS (Unified Parkinson's Disease Rating Scales) or also … I mean, actually it's my fault. I should start using it but partly because, considering I have 20 minutes per patient, it is unthinkable to apply certain scales and partly because 20 minutes per patient means to write, to collect the anamnesis, to ask what drugs he takes ….” (Neurologist 2, interview)
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> “'ll say something that may or may not be funny. My wife monitors me 48 hours a day. (Patient 3, focus group)

For many years, due to long-standing processes such as the growth in care demand and cuts in public spending, hospitals in Western healthcare systems have increasingly aimed to educate patients and relatives about the daily management of illnesses. Rather than treating them regularly in hospitals, they see patients during only the acute phases of their illnesses (Altenstetter & Björkman, 1997; Saltman et al., 2007). In the daily life of a physician, a high workload and the limited time dedicated to each appointment obstruct the possibility of using accurate scales that consider various aspects of PD, including non-motor symptoms and complications in applying the fundamental skills required to care for oneself independently (e.g. eating, bathing, mobility). Neurologists generally identify the onset of the advanced stage of PD by a decrease in the response to the drugs used for managing motor symptoms. In particular, the interviewed neurologists claimed that the advanced phase of PD starts when a patient needs increasing doses of Levodopa to reduce motor symptoms. On the other hand, the evaluation of non-motor symptoms is generally conducted based on interactions with caregivers, as they are considered more trustworthy than patients in detecting non-motor experiences, especially when patients experience cognitive decline or hallucinations. As we will see at the end of this section for the neurologists involved in this study, as well as for the experts involved in other studies (Dafsari et al., 2019), the evaluation of non-motor and motor symptoms carried out in these ways is unsatisfactory and leads to disarticulations between monitoring and drug administration.

The second reason for dissatisfaction with current monitoring is specular to the first. It concerns the heavy workload of patients and their families that, as mentioned above, is required to keep track of the symptoms connected with PD:

> So, I monitor if this tremor increases in intensity and frequency. Recently, I started to feel other symptoms, such as balance issues, a generalised slowing down of movements, some difficulties with wearing clothes, especially tight clothes, for example, to take off a t-shirt, I need my wife's help. So, the idea is to reveal them, to mention them at the next visit, apart from the fact that when the doctor visits me, he can see an eventual evolution of the disease …. I think that some telemedicine wouldn't hurt. The fact of having some contact outside the routine visits where you can freely say, 'It's been six months, three months since the last visit, and I'm noticing this.' It's a way of feeling a bit more cared for, and why not? Maybe the therapy can be adjusted earlier without having to wait for the natural course of events. (Patient 12, focus group)

This continuous engagement with symptoms can easily be labelled as the invisible work of patients and relatives, here defined as "the portion of their effort that remains hidden because it occurs behind the scenes (e.g. performed at home), between clinical encounters (e.g. scheduling, trouble-shooting side effects), or amidst multiple distributed actors (e.g. communicating with people in multiple roles or multiple people within a role)" (Unruh & Pratt, 2008, p. 41). As observed by Star and Strauss in their seminal article about invisible work, "the workers themselves are quite visible, yet the work they perform is invisible or relegated to a background of expectation" (1999, p. 15). In this case, between visits, patients and their caregivers keep track of information judged as relevant for understanding if and how the disease is progressing (e.g. slowdown of movements and tremors that obstruct daily activities despite prescribed medications). This work is deeply stressful for patients and their caregivers, since they are continuously engaged in detecting the emergence of new symptoms or the exacerbation of old ones. Due to the lack of continuous support by the healthcare system, patients and relatives feel alone in the face of illness, struggling to understand if changes in behaviours are indicative of a worsening health status or not. When they seek contact, via phone or email, to resolve these doubts in between the routine six-month visits, the response is unsatisfactory (e.g. consisting of a short answer) or, sometimes, missing.

The third reason for dissatisfaction with current care processes is related to the connection between monitoring and drug administration.

> Let's say that it is difficult for the specialist to manage Parkinson's at an advanced stage, but it is not difficult to diagnose it. So, the difficulty is in careful therapeutic drug administration based on a balance between the side effects and the efficacy of the drug itself, and, above all, it should be calibrated on what the priorities are, or, better still, on what the patients believes is important in their life. (Neurologist 1, interview)
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The existing monitoring processes are characterised by compressed timeframes in face-to-face visits and much delegation to patients for symptom tracking. Patients and relatives take notes about events and possible worsening of already existing symptoms and the onset of new ones. They transmit them via traditional communication technologies or during periodic visits. The outcomes of this exhausting invisible work are unsatisfactory for neurologists due to the features of the produced data, mainly qualitative observations integrated with interactions during visits, and the difficulties in analysing them using methods aligned with clinical and scientific guidelines. The main consequence is a disarticulation between the gathered data and decisions about therapies that seem delayed or grounded on incomplete data and analysis. Here, disarticulation is seen as a situation in which the different tasks that compose a certain process seem "discrete and conflicting bits of accomplished work" (Strauss et al., 1985, p. 151). This disarticulation seems to be frustrating for neurologists and patients who, as we will see in the next section, advocate for monitoring processes in which technologies can play a key role in articulating the different clinical activities, in other words, "putting all the work elements together and keeping them together" (Strauss, 1988, p. 164).

6.5 The Artificial Intelligence-Driven Monitoring Hospital

As observed in other cases (Bareis & Katzenbach, 2022), a strong dissatisfaction with the present is an inevitable premise for planning a radical rupture. Starting from these criticalities, interviewees draw future-oriented visions in which, thanks to AI-enabled remote monitoring technologies, data concerning patients' health are constantly produced and put in circulation, connecting them and their families with health care professionals. Here, this imaginary is called "the AI-driven monitoring hospital" and is characterised by two crucial features.

> Let's say as physicians, we really like graphs. So, if I had a graph of the patient's mobility, of his/her blood pressure, and how he/she moves at night; plus I feel his/her disability, I feel how he/she feels because then at the end what matters is also how the patient generally feels, whether or not the caregiver is happy with how things are going. These three things together would help me much more to manage the pharmacological therapeutic changes and eventually understand if there is something more that can be done, such as advanced therapy. (Neurologist 3, interview)
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> I'm currently in a position where I'm very interested in having certain monitoring tools to be more aware of my current condition, so I'd be very interested, if that's what you're asking." (Patient 1, interview)

The first feature is datafication, the conversion of qualitative aspects of life into quantified data. Following the classification of Ruckenstein and Dow Schüll (2017) of the different areas of datafication, the narratives enacted by neurologists and patients seem to imagine a future in which bodily experiences are folded into data that, in turn, increasingly shape experiences and mediate human agency.

With current monitoring processes, disease progression is mostly evaluated through measures and comments made by clinicians in face-to-face visits and the accounts of patients and their caregivers about their daily lives that, at least partially, are transformed into data by clinicians and stored in public healthcare infrastructures. A future with AI-enabled remote monitoring technologies is seen as an opportunity to construct, gather, and disseminate a great amount of health data that could become "a medium of connecting with others by offering a raw glimpse into one's intimate private life" (Sharon, 2017, p. 20). Wearables support the construction of data on disease progression (e.g. the intensity of dyskinesia, cognitive symptoms, number of daily activities, blood pressure monitoring) that is currently enacted mainly during face-to-face visits, with an intensity evaluated as insufficient by patients and neurologists. This desired scenario is in line with the so-called technoscientific objectification of bodies (Lock, 1993, p. 371) in which everyday activities, movements, and events are abstracted and converted into data flows. As observed by Lupton (2012), wearable technologies offer health care professionals remote access to individuals' lives in ways previously unimaginable by digitalizing the above-described invisible work of patients and relatives.

The second feature is augmentation, meaning that humans collaborate closely with machines to perform a certain process without complete automation, which is judged by interviewees as impossible and undesirable. As argued by Davenport and Glover (2018), "in contrast to automation, augmentation presumes that smart humans and smart machines can coexist and create better outcomes than either could alone. AI systems may perform some health care tasks with limited human intervention, thereby freeing clinicians to perform higher-level tasks."

> I can easily imagine that these devices will be capable of informing you of my health conditions without the need for a doctor's appointment, which is something that I really like because I feel like my condition doesn't yet require me to be constantly going to the hospital. (Patient 1, interview)
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> So, (the AI system) should be something that may be in a semiautomatic way tells me, 'Yes, look that this sick person has had at least five phases off a day in the last six months. If I have to watch the monitor 24 hours a day, well ´(the AI system would be useless)"… (Neurologist 2, interview)

For the interviewees, a future with AI-enabled remote monitoring technologies could simplify their daily lives, reducing the necessity for face-to-face visits (see the first quote above) or simplifying the analysis of clinical data (see the second quote above). As in other fields (see Kellogg et al., 2020), the use of AI is seen as a way to facilitate efficiency, improve communication exchanges, and reduce the amount of tedious and time-consuming tasks. If in the past public discourse in academic and popular culture arenas has focused on the possibility that AI synthetise the expertise of healthcare professionals (Oravec & Travis, 1992), replacing them partially or totally, recently, the common expectation is that AI can help respond to phenomena such as ageing populations and the crisis of the welfare state (Bareis & Katzenbach, 2022). From the perspective of the interviewees, AI is a response to the lack of resources of public welfare systems that has produced the dissatisfaction described in the previous section, supporting clinicians, relatives, and patients in carrying out their care work without substituting them.

> So, you would also have to try to correlate the motor data with whether or not the therapy was taken. And so the patients should still somehow let you know what time they took the medication that day because maybe they had motor symptoms because they forgot to take the pill. It's a little bit difficult to be able to imagine such a scenario in the sense that they have to be a very careful person, precise, and report everything to you. But if patients wear bracelets that records symptoms for five days a week, showing they have blocking symptoms, or conversely, severe dyskinesias causing falls …then yes, it would make sense. (Neurologist 1, interview)
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> Artificial intelligence has kind of exploded and is working more or less in almost all areas of knowledge, so it's definitely a direction to take to improve predictions. In my opinion, it might be especially useful to analyse potential patients before the actual symptoms arise thanks to traits, algorithms that come out from artificial intelligence. (Patient 13, focus group)

Augmentation is also a concept used in the literature to underline how AI can enhance human capabilities (see Davenport & Glover, 2018; Raisch & Krakowski, 2021), establish a mutual support relationship between humans and machines, and create better outcomes than either could alone. As underlined in the above quotes, AI-enabled remote monitoring technologies could support health care professionals in gathering and analysing different sets of data to support diagnostic or care processes. Making earlier diagnoses or having a more in-depth understanding of the stage of the illness are goals that from the interviewees' perspectives are unreachable without scientific and technological innovation. Therefore, augmentation is a perspective that could solve the dissatisfaction with the daily workload and the quality of care by supporting professionals and patients in their tasks.

6.6 EMERGING TENSIONS ABOUT ARTIFICIAL INTELLIGENCE IN PARKINSON'S DISEASE

While the depicted socio-technical imaginary is grounded in a deep and shared dissatisfaction with the current healthcare system and, in particular, with the monitoring process, the gathered narratives about a possible future with AI contain various tensions about the specific ways in which data should be gathered, analysed, and transmitted. The tensions emerge, in particular, between the aims of the considered projects, defined by researchers along with clinicians and patients.

> But do you have to keep these on all the time, day and night? If it doesn't affect my sleep, I can keep them on at night. (Patient 3, interview)

The first tension concerns the possibility of incorporating remote monitoring technologies into patients' daily lives. As is well known in STS, to be used, new technologies must be placed in the spaces and in the routines that are part of the daily lives of patients, giving birth to complex care infrastructures in which care is conciliated with working and mundane activities (Langstrup, 2013; Miele, 2022; Oudshoorn, 2012). When the interviewed patients were asked to imagine a scenario in which they wore technologies to monitor their health status on a daily basis, it emerged that the acceptability of the new object strongly depended on its compatibility with their daily lives. During the interviews and focus groups with patients, the researchers presented some of the devices used for gathering data for analysis by AI to monitor the progression of PD. Some of these devices request continuous interaction with a patient (e.g. filling in assessment questionnaires about their cognitive status), while others are bulky to wear and risk obstructing self-care, mundane, or working activities, which are important for patients' well-being. This is the case, for example, with an electronic abdominal belt that detects important data, such as the gait of patients and their body posture, that are useful for measuring the increase in specific symptoms associated with PD (e.g. bradykinesia and rigidity). For many patients, this high-tech device, evaluated as an object reliable for data gathering by the clinicians and researchers behind this project, seems to be problematic because it is perceived as incompatible with daily activities, such as showering or swimming. The compromise proposed by patients is to wear it for a limited time and not all day.

> If it's very flashy, I think certain wearables might bother. It [the wearable] becomes an object subject to – not discrimination – but curiosity, which leads to continuous questioning. 'What is it?' 'What is it for?' It could be more annoying, but when you have explained it once to your circle, the chapter is closed. If then it becomes an obvious thing even in everyday life, then it may result in discrimination. (Patient 16, focus group)
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> I would always wear long sleeves, so that they [colleagues] cannot see [if she wears a clinical wristband]. (Patient 17, focus group)

The second tension emerges around the possible reactions of people to the remote monitoring devices. People with PD, as well as patients with other chronic conditions, enact attempts at normalisation, intended as a process that enables individuals with a chronic condition to resume their pre-illness roles and responsibilities, find ways to live a "normal" life, cope with symptoms, avoid the negative meanings associated with their conditions, and minimise the disability (Joachim & Acorn, 2000). For example, people with a manual job negotiate therapies with clinicians aimed at decreasing tremors during working hours, while other patients note having disclosed their illness only to their closest friends and attributing the most visible symptoms to something other than PD. When the proposed devices are similar to technologies commonly used by people for managing their health (e.g. fitness trackers), interviewees were generally positive towards them. In contrast, when the devices acquire certain sides, shapes, and colours (e.g. the above-mentioned electronic abdominal belt or large white wristbands), the reactions were more diverse. Some patients affirmed that they would hide or not wear these devices, while others said they would use them because they do not think that people would notice them. Finally, others are willing to wear any kind of device because most of the people in their networks already know about their condition.

> It's clear that if I'm reliably told that it is a method that could give excellent results in terms of knowledge for the treating doctor etcetera, I would wear it on my ear as well, just to say. But if, on the other hand, it's part of something experimental, we don't know what it is, etcetera, maybe I'm a little bit more careful about using it on my body. (Patient 12, focus group)
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> I am definitely persuaded that a monitoring activity either brings positive benefits or no benefits at all. It will certainly not bring negative benefits. The fact of knowing in time, of making these forecasts …I am certainly in favour of something like this, at least from the point of view of 'research'. (Patient 2, interview)

The third tension relates to the perceived usefulness of AI-enabled remote monitoring technologies, traditionally intended in computer research as "the degree to which a person believes that using a particular system would enhance his or her performance" (Davis, 1993, p. 320). In particular, patients with PD are more or less willing to be involved in the use of these technologies following a cost–benefit approach in which the benefits generally concern an improvement in the quality of received care and the professional knowledge of clinicians (e.g. making suitable predictions about the future or detecting the early symptoms of PD), the possibility of living a "normal" life (e.g. doing the activities of the past), and slowing down the progression of the disease. Some patients believe that the considered technological intervention does not have a cost for them (see the second quote above); for others, the costs include possible harm to the body (e.g. wearing an experimental device that is unsuitable for long-term use), the impossibility of incorporating this technology into their daily lives, or an obstruction to their attempts at normalisation. Consequently, whereas AI-enabled remote monitoring technologies are often presented as positive for the health status of patients, patients imagine the possible ways in which this technology could (or not) improve their conditions, balancing out the positive and negative effects of technological innovation.

6.7 Discussion

Drawing on the presented research, the chapter will now focus on three final considerations concerning the narratives produced by the interviewees.

6.7.1 The Continuum Between the Current Shortcomings and the Desired Future

The depicted socio-technical imaginary of AI-driven monitoring is surely ascribable to the wide trend of defining enchanting digital-enabled future scenarios in which healthcare is more predictive, personalised, timely, efficient, and effective (Petersen, 2018). On the one hand, the enthusiasm for AI is nothing new; since the 1950s, public opinion and scientific debate have cyclically been enthusiastic (and, at the same time, frightened and disillusioned) about the potentialities of AI for solving the current problems of our societies (Natale & Ballatore, 2020). On the other hand, the presented work shows how the relatively recent renaissance of AI in healthcare is characterised by hope grounded on dissatisfaction connected to the cultural, political, and economic peculiarities of our time. The welfare cuts that have happened in Italy and other Western countries, along with the burden on informal caregivers and healthcare facilities, have laid the foundation for renewed trust in the potentialities of intelligent machines. The growing interest in the application of AI in healthcare, with particular reference to the considered care for PD, gives rise to convergences and tensions among the actors that should incorporate these intelligent machines into their daily lives. The emerging tensions seem to arise from the different hopes and fears stimulated by the possibility of having a future with AI, but the considered actors are far from being totally hostile or indifferent to this issue. Even in this case (see also Gardner, 2022), tensions seem to invigorate, rather than undermine, technological innovations connected with AI, showing the strong commitment of social actors to defining how a certain imaginary could be translated into practice.

6.7.2 A Delegation with Less Responsibilization

In a healthcare system characterised by the growth of care demand and the reduction in public spending, the monitoring of disease progression is increasingly delegated to people with PD and their caregivers, who keep track of motor and non-motor symptoms. This invisible work is judged as important but unsatisfactory by professionals and as extremely stressful for patients and their caregivers who suffer the effects of the delegation of symptom tracking. Starting with their dissatisfaction, patients ask for AI-enabled remote monitoring technologies that support them in making sense of their health conditions and softening the stress and loneliness associated with monitoring activities. As observed by several sociologists (LeBesco, 2011; Petersen & Lupton, 1996), in contemporary Western healthcare systems, delegation has been increasingly associated with self-responsibilization; this process has often been empowered by the availability of wearable technologies aimed at supporting people in the monitoring of their health statuses (Lupton, 2013). In contrast, the sociotechnical imaginary of AI-driven monitoring is represented as a scenario in which delegation is supported by innovative technologies, reducing the responsibilization of patients and their relatives. Patients and professionals imagine intelligent machines that can monitor patients and define if pre-existing symptoms are worsening and/or if new ones are emerging. In this way, the individual responsibility of patients and relatives decreases or, at least, is shared with the technology that should alert them and the professionals if the situation is worrying. This imaginary is also desirable for professionals who could obtain more granular and systematic data and thereby be supported in the decision-making process concerning pharmacological and non-pharmacological therapies.

6.7.3 A Prudent Coexistence Between Humans and Non-humans

If the public debate about AI has been dominated by technological myths in which emergent technologies have been depicted as "intelligent brains, smarter than people, unlimited, fast, mysterious, and frightening" (Martin, 1993, p. 122), the discourses enacted by end users of intelligent technologies are more prudent. Indeed, in the depicted scenario, the above-described delegation does not happen through an automatization process, but thanks to the so-called augmentation in which machines collaborate closely with humans without replacing them. This prudence has various underpinning reasons, such as the traditional fear of health care professionals losing power because of digital innovation (see Mørk et al., 2010), the centrality of human contact in the past experience of patients and professionals (see Fairhurst & May, 2001), or the fear of patients that the massive entrance of technologies into care processes impoverishes care (Pols & Moser, 2009). Beyond possible interpretations, a future with machines that augment human capabilities is characterised by a key role for patients who must adopt digital devices to gather data that can help doctors in decision-making. As shown in this chapter, patients are willing to play this role if AI technologies are compatible with their daily routines, bring sufficient benefits for their health, and do not clash with their attempts to be considered "normal" by the rest of society.

6.8 Conclusion

This chapter, adopting the concept of socio-technical imaginary, has explored the expectations of healthcare professionals and patients about AI-enabled remote monitoring technologies, taking into consideration the case of PD. Starting from a theoretical approach grounded in STS, the work has explored the narratives produced by these actors, focusing on how the expectations generate a future with technologies that behave intelligently to solve current problems. This chapter has overcome the widespread deterministic perspective on AI by conceiving professionals and patients as actors that can contribute to shaping future technologies, converging or conflicting around the desired future. In this way, the chapter has contributed to a shift from the study of algorithms intended as entities to an exploration of algorithmic systems intended to be socio-material assemblages produced by discursive and material practices.

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References

Altenstetter, C., & Björkman, J. W. (Eds.). (1997). *Health policy reform, national variations and globalization*. Macmillan.

Bareis, J., & Katzenbach, C. (2022). Talking AI into being: The narratives and imaginaries of national AI strategies and their performative politics. *Science, Technology, & Human Values, 47*(5), 855–881. https://doi.org/10.1177/01622439211030007

Beckert, J. (2016). *Imagined futures: Fictional expectations and capitalist dynamics*. Harvard University Press.

Borup, M., Brown, N., Konrad, K., & Van Lente, H. (2006). The sociology of expectations in science and technology. *Technology Analysis & Strategic Management, 18*(3–4), 285–298. https://doi.org/10.1080/09537320600777002

Bostrom, N., & Yudkowsky, E. (2018). The ethics of artificial intelligence. In *Artificial intelligence safety and security* (pp. 57–69). Chapman and Hall/CRC.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Breuer, S., Braun, M., Tigard, D., Buyx, A., & Müller, R. (2023). How engineers' imaginaries of healthcare shape design and user engagement: A case study of a robotics initiative for geriatric healthcare AI applications. *ACM Transactions on Computer-Human Interaction, 30*(2), 1–33. https://doi.org/10.1145/3577010

Bucher, T. (2017) The algorithmic imaginary: Exploring the ordinary affects of Facebook algorithms. *Information, Communication & Society*, *20*(1), 30–44.

Dafsari, H. S., Martinez-Martin, P., Rizos, A., Trost, M., dos Santos Ghilardi, M. G., Reddy, P. et al. (2019). EuroInf 2: Subthalamic stimulation, apomorphine, and levodopa infusion in Parkinson's disease. *Movement Disorders, 34*(3), 353–365. https://doi.org/10.1002/mds.27626

Davenport, T. H., & Glover, W. J. (2018). Artificial intelligence and the augmentation of health care decision-making. *NEJM Catalyst, 4*(3).

Davis, F. D. (1993). User acceptance of information technology: System characteristics, user perceptions and behavioral impacts. *International Journal of Man-Machine Studies, 38*(3), 475–487. https://doi.org/10.1006/imms.1993.1022

Dickenson, D. (2013). *Me medicine vs. we medicine*. Columbia University Press.

Fairhurst, K., & May, C. (2001). Knowing patients and knowledge about patients: Evidence of modes of reasoning in the consultation? *Family Practice, 18*(5), 501–505. https://doi.org/10.1093/fampra/18.5.501

Gardner, J. (2022). Imaginaries of the data-driven hospital in a time of crisis. *Sociology of Health & Illness*. https://doi.org/10.1111/1467-9566.13592

Giarelli, G., & Neri, S. (2020). Politiche sanitarie e sistemi sanitari. In G. Giarelli & G. Vicarelli (Eds.), *Sociologia della salute e della medicina*. Il Mulino. https://doi.org/10.1485/2281-2652-202016-5

Iliadis, A., & Russo, F. (2016). Critical data studies: An introduction. *Big Data & Society, 3*(2), 2053951716674238. https://doi.org/10.1177/2053951716674238

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243–248. https://doi.org/10.1046/j.1365-2648.2000.01466.x

Kazansky, B., & Milan, S. (2021). "Bodies not templates": Contesting dominant algorithmic imaginaries. *New Media & Society*, *23*(2), 363–381. https://doi.org/10.1177/1461444820929316

Kellogg, K. C., Valentine, M. A., & Christin, A. (2020). Algorithms at work: The new contested terrain of control. *Academy of Management Annals, 14*(1), 366–410. https://doi.org/10.5465/annals.2018.0174

Langstrup, H. (2013). Chronic care infrastructures and the home. *Sociology of Health & Illness, 35*(7), 1008–1022. https://doi.org/10.1111/1467-9566.12013

LeBesco, K. (2011). Neoliberalism, public health, and the moral perils of fatness. *Critical Public Health*, *21*(2), 153–164.

Lock, M. (1993). Cultivating the body: Anthropology and epistemologies of bodily practice and knowledge. *Annual Review of Anthropology, 22*(1), 133–155.

Lupton, D. (2012). *Medicine as culture: Illness, disease and the body*. Sage.

Lupton, D. (2013). Quantifying the body: Monitoring and mea-suring health in the age of mHealth technologies. *Critical Public Health*, *23*(4), 393–403.

Miele, F. (2022). On care infrastructures and health practices: How people in health promotion programmes try to change their everyday life. *Health, 27*(6), 13634593221093503. https://doi.org/10.1177/13634593221093503

Martin, C. D. (1993). The myth of the awesome thinking machine. *Communications of the ACM, 36*, 120–133. https://doi.org/10.1145/255950.153587

May, C. R., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., Mair, F. S., May, C. M., Montori, V. M., Richardson, A., Rogers, A. E., & Shippee, N. (2014). Rethinking the patient: Using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Services Research, 14*(1), e281.

Mørk, B. E., Hoholm, T., Ellingsen, G., Edwin, B., & Aanesta, M. (2010). Challenging expertise: On power relations within and across communities of practice in medical innovation. *Management Learning, 41*(5), 575–592.

Natale, S., & Ballatore, A. (2020). Imagining the thinking machine: Technological myths and the rise of artificial intelligence. *Convergence, 26*(1), 3–18. https://doi.org/10.1177/1354856517715164

Neresini, F., Giardullo, P., Di Buccio, E., & Cammozzo, A. (2020). Exploring socio-technical future scenarios in the media: The energy transition case in Italian daily newspapers. *Quality & Quantity, 54*, 147–168. https://doi.org/10.1007/s11135-019-00947-w

Oravec, J. A., & Travis, L. (1992). If we could do it over, we'd... Learning from less-than-successful expert system projects. *Journal of Systems and Software*, *19*(2), 113–122. https://doi.org/10.1016/0164-1212(92)90062-O

Oudshoorn, N. (2012). How places matter: Telecare technologies and the changing spatial dimensions of healthcare. *Social Studies of Science, 42*(1), 121–142. https://doi.org/10.1177/0306312711431817

Owens, K., & Walker, A. (2020). Those designing healthcare algorithms must become actively anti-racist. *Nature Medicine, 26*(9), 1327–1328. https://doi.org/10.1038/s41591-020-1020-3

Petersen, A. (2018). *Digital health and technological promise: A sociological inquiry*. Routledge.

Petersen, A., & Lupton, D. (1996). *The new public health: Health and self in the age of risk*. Sage.

Pols, J., & Moser, I. (2009). Cold technologies versus warm care? On affective and social relations with and through care technologies. *Alter, 3*(2), 159–178. https://doi.org/10.1016/j.alter.2009.01.003

Raisch, S., & Krakowski, S. (2021). Artificial intelligence and management: The automation–augmentation paradox. *Academy of Management Review, 46*(1), 192–210.

Ruckenstein, M., & Schüll, N. D. (2017). The datafication of health. *Annual Review of Anthropology, 46*, 261–278. https://doi.org/10.1146/annurev-anthro-102116-041244

Saltman, R. B., Bankauskaite, V., & Vrangbaek, K. (Eds). (2007). *Decentralization in health care, european observatory on health systems and policies*. Open University, London Press.

Schwennesen, N. (2019). Algorithmic assemblages of care: Imaginaries, epistemologies and repair work. *Sociology of Health & Illness, 41*, 176–192. https://doi.org/10.1111/1467-9566.12900

Selin, C. (2007). Expectations and the emergence of nanotechnology. *Science, Technology, & Human Values, 32*(2), 196–220. https://doi.org/10.1177/0162243906296918

Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity, and authenticity in an age of personalized healthcare. *Philosophy and Technology, 30*, 93–121.

Sismondo, S. (2020). Sociotechnical imaginaries: An accidental themed issue. *Social Studies of Science, 50*(4), 505–507. https://doi.org/10.1177/0306312720944753

Star, S. L., & Strauss, A. (1999). Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer Supported Cooperative Work, 8*(1–2), 9–30.

Strauss, A. (1988). The articulation of project work: An organizational process. *Sociological Quarterly, 29*(2), 163–178. https://doi.org/10.1111/j.1533-8525.1988.tb01249.x

Strauss, A. L., Fagerhaugh, S., Suczeck, C., & Wiener, C. (1985). Social organization of medical work. In *La Trame de la Négociation: Sociologie Qualitative et Interactionnisme*. Université de Chicago Press.

Unruh, K. T., & Pratt, W. (2008, November). The invisible work of being a patient and implications for health care: "[the doctor is] my business partner in the most important business in my life, staying alive". In *Ethnographic praxis in industry conference proceedings* (Vol. 2008, No. 1, pp. 40–50). Blackwell Publishing Ltd. https://doi.org/10.1111/j.1559-8918.2008.tb00093.x

van Lente, H. (2016). Forceful futures: From promise to requirement. In N. Brown, B. Rappert, & A. Webster (Eds.), *Contested futures: A sociology of prospective techno-science* (pp. 43–64). Routledge.

Van Lente, H., & Rip, A. (1998). Expectations in technological developments: An example of prospective structures to be filled in by agency. *De Gruyter Studies in Organization*, 203–230.

Vezyridis, P., & Timmons, S. (2021). E-Infrastructures and the divergent assetization of public health data: Expectations, uncertainties, and asymmetries. *Social Studies of Science, 51*(4), 606–627.