

A FRENCH HEALTHCARE SCHOOL?

ANALYZING TWO CASES OF SOCIO-THERAPEUTIC INNOVATION: THE UNIVERSITY OF PATIENTS AND THE CHAIR OF PHILOSOPHY AT THE HOSPITAL

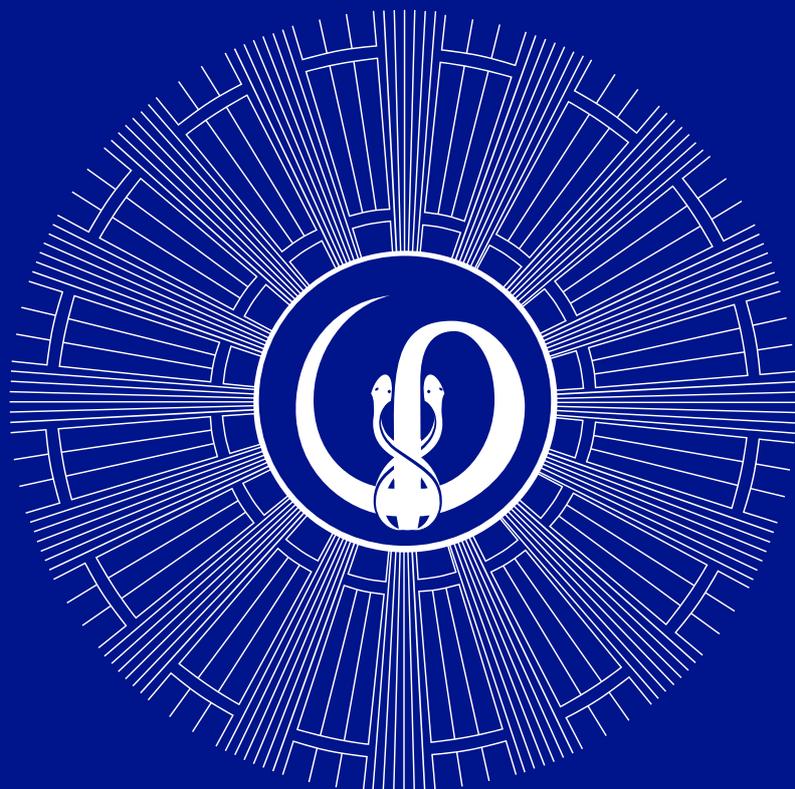
Abstract: This article shows—through two emblematic examples: the University of Patients (Faculty of Medicine, Sorbonne University Paris) and the Chair of Philosophy at the Hospital (GHT1 Paris “Psychiatry and Neurosciences”)—how the creation of two innovative socio-therapeutic mechanisms fits in to what we shall call the French School of Care (“French Care”). The fact is, France differs from Anglo-Saxon initiatives by the specificity of its public offer and organization of healthcare and by a unique theoretical corpus based on human and social sciences in which philosophy, institutional psychotherapy, and psychodynamics play a leading role.

Keywords: care, healthcare, university of patients, chair of philosophy at the hospital, vulnerability and capabilities.

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1 GHT: Groupements hospitaliers de territoire

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Since 1945, France has been advocating a health model based on universality and equality, founded on mandatory social protection, financed by social security contributions, co-managed by employer and employee organizations and controlled by the State (Nay *et al.*, 2016). In 2000, this model was still identified by the World Health Organization (WHO)³ as the most efficient general healthcare system in the world, according to five indicators: the general health of the population, health inequalities (or disparities) in the population, the general degree of reactivity of the healthcare system (satisfaction of the patients in line with the proper operation of the system), the level of responsiveness among the various categories of the population (the level of satisfaction of patients from various economic backgrounds with services provided by the healthcare system), and the breakdown of the system's financial load across the population (i.e., who bears the costs). However, other studies (by the OECD, the World Bank, Bloomberg, the IHME, and *The Lancet*) have long revealed numerous dysfunctions in the access to care, such as low investment in prevention, excessive increase in chronic diseases, hospital-centered healthcare and still insufficient outpatient offer, the irrelevancy of some (diagnostic and surgical) acts, high consumption of antibiotics, and too few generics. According to these studies, France ranks 20th to 30th in the world. France also falls periodically in the European rankings (from the ECHI, Health Consumer Powerhouse, and the HCSP). Still, for over 30 years, France has been developing an ethical and philosophical approach by integrating the humanities in its initial and continuing training programs, as well as in hospital practice. The system places the patient at the center of its therapeutic initiatives. The first university of patients was created in 2009 (Tourette-Turgis, 2013a); it delivers diplomas to expert patients and, by doing so, creates new jobs in the healthcare environment.

THE OTHER SIDE OF CAPABLE VULNERABILITY

The notion of “expert patient” is not new. It was born with the first self-study programs for patients by patients developed in English-speaking countries in the early seventies. The patient's experience is developed along with their activity, within interactions with their environment, specifically in situations that are new, urgent, problematic, extreme, or unexpected. These situations are significant events that force a patient to transform part of their acquired skills and contribute to the development of their expertise by their continuity. When their expertise is assessed or recognized by the community, they become “expert patients,” or a new type of potential professionals who will share knowledge on the chronic disease experience. The emergence of this concept coincides with that of social emancipation movements, specifically feminist movements or those that tackle the exclusion and social disqualification they undergo because of their status as minorities (whether due to their cultural diversity or to some kind of link with a “stigma” related to a norm). The inception of the University of Patients addresses, among others, three primary topics: feminism, early childhood, and HIV patients; these three areas and conceptual fields will be at the source of the modeling of patient care and the professionalization of the expert patient at the University of Patients. (1) In 1969, the Boston group, who initiated the “Our Bodies, Ourselves” (OBOS) movement defending women's full ownership of their bodies, promoted this approach in which women formulate stories based on their experiences and grievances with the medical profession, determine a form of self-awareness and societal experience, and share their knowledge on feminine health and body. (2) Another area of clinical practice and educational

3 The WHO no longer issues rankings following strong criticism of its indicators and methodology. However, it publishes world health statistics annually.

response is early childhood. Following the works of Françoise Dolto and Brazelton (1983), Stern (1981), Spitz on “hospitalism” (1946) and Bowlby (1978) on “attachment,” the infant was recognized as a being of language, vulnerable and capable, who needs the guidance, support, and care of others to be able to develop their greatest potential. To recognize the uniqueness of a baby’s activity and experience (Stern, 1981), one must analyze the intersubjective and environmental interaction in situations of physiological and motor dependency and vulnerability. (3) In the 1980s, healthcare providers, particularly psychoanalysts, faced a new disease that severely destabilized their practice:

The main concepts of psychoanalysis that are threatened are the treatment away from the couch, the analyst’s dilemma of facing their patient’s deteriorating health and impending death, and transference and countertransference that are dominated by death, a powerful third party. As young analysts, it is difficult for us to remain in the position we learned in school. We must invent a practice framework with enough content enabling us to carry out our work as psychotherapists. We must learn to provide care with immediate effects. For example, it is unreasonable to offer HIV patients an analytical cure while they may die within eighteen months; we must offer them a support mechanism that works over a short period of time and is essentially designed to support the ‘Me’ functions. (C. Tourette-Turgis, 2013b, p. 15)

In fact, AIDS patients and their families themselves started asking for listening and support systems. However, their request was very creative. While AIDS was an exceptional social phenomenon, it also triggered the emergence of innovative practices in terms of support: the need to incorporate new issues, never before addressed in this matter, such as the question of death by sexually transmitted infection, change in sexual behaviors, a new erotic use of the self, and risk management pertaining to emotional and sexual relationships. As a result, AIDS caused clinicians to question the definition of the care relationship as well as the practical modalities of their usual actions. Moreover, the absence of a medical response to AIDS has led to the emergence of another reorganization of care which, in the absence of therapeutics, made listening and support the only type of care available for several years.

THE UNIVERSITY OF PATIENTS MEETS THE CHALLENGE OF INCLUSIVENESS

The process of academic certification for patients is partly in line with the work of Rogers, who laid the theoretical foundations of a support relationship which, by counting on the other person’s potential, meets the needs of the sick who struggle with their own potential and with their own resources to face adversity. Carl Rogers is the author who had the heaviest impact on the theories and practices of support by denouncing all patterns of support, intervention or help aiming at guidance and control of the other person:

Therapy is not a matter of doing something to the individual, or of inducing him to do something about himself. It is instead a matter of freeing him for normal growth and development, of removing obstacles so that he can again move forward. (Rogers, 1942, p. 49).

Even though there is a “patient-partner” model in Montreal, France is the only country offering first-line training programs leading to a diploma for patients, in a professionalization approach that meets the demand of over 30% of its public. More than 15 million French individuals of all ages, almost 20% of the population, are living with a chronic disease (HIV, diabetes, cancer, MS, inflammatory bowel disease, etc.). In the case of HIV/AIDS, hemophilia, and certain rare diseases, patients have demonstrated their ability to improve the healthcare system’s organization. Clearly, improving the healthcare system’s organization cannot be done without the patients’ participation. The University of Patients is a response to a direct demand from individuals who live with a chronic disease and wish to leverage their experience and share observations with the communities in the areas of health and education, as well as in other areas where their skills could be of use.

The University of Patients is not a mere delivery process for a diploma in health education. Obviously, it aims at transforming a chronic patient into an actor in their own treatment, but it also invents a new phase in building patient expertise: it turns patients into professionals able to support other patients and, subsequently, care providers. There are several different DUs (university diplomas) such as therapeutic education, health democracy, and guidance in oncology or short gut syndrome. The first diploma, “Guidance mission for the patient journey in oncology,” is based on the patient-partner model. It was created and deployed in partnership with the Institut Universitaire en Cancérologie (IUC). Each diploma is backed by a legal mechanism. Therapeutic education diplomas are based on the 2009 law on hospitals, patients, health, and territories (Hôpital, Patients, Santé et Territoires, HPST, 2009, p. 12184), the oncology guidance diploma is based on the Cancer Strategy, and the health democracy diplomas are based on the law on health modernization. The “Grand Bleu” survey (2016)⁴ revealed data on student profile, expectations, social status, and qualifications: 30% of students are living in poverty and report income under €600/month; 56% are in a phase of stabilization or remission of their illness; 80% report discrimination at work, at banks, or with friends; 31% state that their friends and families admired their desire to attend the university; 60% want to pursue additional studies. The students, made vulnerable by their illness, say that they wish to increase their legitimacy by obtaining a diploma and explore new paths to professionalism.

A HOLISTIC APPROACH TO HEALTHCARE FOCUSING ON ITS SUBJECTIVE, INSTITUTIONAL, AND POLITICAL ASPECTS

On the other hand, the Chair of Philosophy at the hospital (Hôtel-Dieu, Paris; Hôpital Sainte-Anne) envisions a brainstorming process in line with the works of Canguilhem (1943, 1978) and Foucault (1963), Pollack (1990, 1991) and Goffman (1968) or, more generally, the Frankfurt School, from Adorno to Axel Honneth. This is the movement that deconstructs the transformation of instrumental and calculating rationality and questions the concretization of the subject, as also described by Guattari, Tosquelles, Oury, and all who seek to analyze the institutional aspect of care by showing how a care function that is not shared cannot produce care, and to provide an ethical response to the various challenges raised by medicine.

“To keep from falling asleep, here is a simple exercise you should try every morning, the same way a pianist practices scales: dissociating status, role, and function.” (Oury, 2014). The person who recommended such practices (scales, spiritual, or mathematics) was actually a physician: psychiatrist Jean Oury, one of the

4 Annual survey questionnaire issued by the University of patients to better understand its audience.

key figures of La Borde⁵ and of institutional psychotherapy. In line with the works of Tosquelles and Saint-Alban⁶, he clearly understood that caring for the patient without caring for the institution is nothing but pure “imposture”.

The methodology applied by the Chair of Philosophy at the Hospital refrains from dissociating the subjective, institutional, and political approaches of care. Care does not belong to a caste of providers who dispense it, as others dispense fine words, to patients considered unable to be active in the care process. The function should be shared; it pertains to a dialectic and creative alliance between the “caregiver” and the “care-receiver”, who together generate a unique momentum, crafted, among other things, by their specific features as subjects. We are not saying that subjectivity alone will do the job; it is an active part of successful, operational care. Care is central to the subject—meaning that it is a matrix for establishing individuation and a specific form of personal well-being—but the subject is also central to care. The “unique conversation” or the quality of intersubjective relationships between caregivers and patients, or between patients (this opens the institutional issue; we will come back to it), is essential, as is reciprocal subjective recognition between caregivers and patients. Care and subject(s) are indivisible: forcibly separating them endangers both care and subjects. Although many physicians, patients, and families are intuitively understanding, or even practicing and improving this know-how and these life skills of care, the fact is that the relatively minimal role of the humanities in the initial and continuous education of doctors, as well as the still-timid emergence of therapeutic education, do not facilitate the sharing of this knowledge. Nonetheless, it is a key element of caregiving, as are state-of-the-art technologies, and could even claim ownership of the latter.

The initial objective of the Chair of Philosophy at the Hospital is to create a critical environment for comparing teachings from human and social sciences and medicine as extensively as possible, even though the chair’s nodal is philosophy, as its name suggests. The focus is on philosophical questioning and methodology, to show how the hospital is a “common,” a common, even scientific, property, a place for sharing knowledge and recognition. Obviously, the chair wishes to connect with all interested entities related to ethics and the humanities: the University of Patients (Sorbonne University), the “La personne en médecine” program (Paris VII), the Hospinommics Chair, the Ethics School of la Salpêtrière, the ILumens Laboratory (Paris V), the Fédération hospitalière de France, IHEIE (Institute of Higher Education for Innovation and Entrepreneurship, Mines-ParisTech), the 42 School, etc. The chair is bringing together this constellation by offering a hybrid space, open to all—patients, physicians, citizens, families, and all types of care providers—to join forces and design a healthcare as humanistic as possible and address the technological challenges faced by today’s health and the internal revolutions threatening the institutional system and its partners. Here is an example, typical of such transformation: the hospital turning into an outpatient clinic, combining a need for cost reduction with the expectations of patients who demand different, faster care, undoubtedly with a deeper feeling of continuity between the various periods of life characterized by illness and the absence of illness. The exponential increase of chronic diseases is generating a need to establish this sense of continuity in the lives of patients and care providers, since illnesses—even cured—do not disappear. It should be noted that the “outpatient shift” is primarily linked with consideration and recognition of the patient as a subject and holder of specific knowledge necessary to understand their ailment. If the patient is not considered an “agent,” an actor of their treatment, the shift will fail. Today, everyone, including hospital physicians, city physicians, and social security administrators, agrees to the need for implementing this shift. However, again,

5 The Cour-Cheverny clinic (in Loir-et-Cher), aka La Borde clinic, is a psychiatry facility founded in 1953 by Dr Jean Oury.

6 As of 1940, the Saint-Alban hospital (Lozère) became the center of the renewal program for psychiatric hospitals.

if the patient is treated as a child and as an object, this innovation will remain unrealized despite its high level of technicity. More than a partner, the patient must be an expert patient, a competent patient, supported by a medical team who assists them in a human way. At the hospital, the patient is still too often deprived of their status as a subject. In the outpatient environment, this will no longer be allowed. To ensure operational outpatient care, the patient must no longer be objectified and must become a full-fledged actor in the care process. This is the shared care function we need to invent and teach.

The humanities, philosophy in particular, promote a more holistic approach of care in which the patient's vulnerability is taken into consideration without being accentuated or seen as a synonym for incapacity. In fact, vulnerability is a component of the human condition, shared by all and not only by those who specifically experience illness. Yes, vulnerability weakens the subject, but we should also remember that it can be, and often is, an opportunity for a person to transcend suffering and recover their individuality by building on the existential challenges they are facing. The life stories of creators often reveal the troubles they suffered before transforming them into style, art, work, progress and knowledge to the benefit of other humans. The point is not to promote a doloristic approach of truth where experiencing pain would be a source of truth and human improvement. However, it is important to remember this essential aspect of vulnerability: it can be a generator of capabilities, particularly when it is subject to care. In healthcare, ensuring the creation of a "capability-building truth" that provides the sick subject with physical and psychological means to go beyond the limitations of their illness is a goal of utmost importance for a physician. Although it is necessary to tell a patient the truth, it is also crucial to ensure that the truth does not weaken the subject and the caretakers, but strengthens them in their search for treatment and cure. Moreover, the uncertainty of the medical environment requires some humility towards the perception of what is truth. Teaching the humanities makes it possible to consider "truth" in its full complexity, including in terms of relations, and its polysemy.

The issue of sharing the care function suggests we should study social and health institutional organizations to verify whether they are compatible with the ethics of care. The case of burnout among healthcare providers, particularly in hospital environments, and among students (whether nursing students or future physicians), the ever-large number of suicides among healthcare providers, and the excessive number of patient complaints regarding unfairly *objectifying* practices are of course not only relevant to healthcare organizations. In the last few years, all public sectors, including companies and associations, have suffered from dehumanized management, vacillating between arbitrary pressure and contradictory orders, making a lot of employees sick. This is not a unique situation. However, if healthcare itself is sick, the consequences are of a different nature: the impact of lack of care, in an environment specifically designed for care—which is not the case for, say, an ordinary administration or a company—is much more damaging for the patients, the citizens, and the global world of healthcare. This is what Jean Oury called, in 1957, the "ambiance" at the hospital, a term, although rather innocuous, was trying to facilitate the comprehension and sharing of the concept of "*pathoplasty*": the pathogenic aspect directly related to the surroundings. Or, to express it in a simpler way: how an environment can make a person in it sick. In 1927, psychiatrist Hermann Simon was already talking about "healing the hospital" with the specific purpose of providing quality care to patients; Tosquelles, in Saint-Alban, had dedicated his work to this mission.

Jean Oury commented:

Obviously, if a manager is sadistic, phobic, paranoiac, everything and everyone is impacted. Using state-of-the-art techniques, group psychoanalysis, etc., will bear no result. However, the hospital infrastructure, with its habits, prejudices, etc., maintains a pathology (Oury, 2009, p. 13)

This the context in which Tosquelles said that in psychiatry, we are over one hundred years late compared to medicine or surgery: we have not yet invented asepsis. And how every institution must combat not only the “physical” nosocomial but also the “psychological” nosocomial, in the sense that there is an equally deleterious contamination for the care structures, which is not material but immaterial, relational, and intersubjective, which refers to the persistence of domination, contempt, and discrimination in social relationships. Again, the Chair of Philosophy at the Hospital hopes to actively contribute to the implementation of this critical attention to the operation of organizations and institutions so that they can upgrade their practices and provide the best possible care for patients and practitioners.

The significant expansion of chronic diseases is also causing the chair to consider a more societal analysis of the definition of illness and its social meaning. If we refer to the definition of the WHO, a chronic illness is a health issue that requires several years of care and has a significant impact on the quality of life of patients and their family and professional environment. This definition shows how much the definition of illness has changed. Illness no longer tilts to death, but to life: more often, being ill means to live with an ailment rather than to die from it or live poorly with a living ailment. “No healing is a return to physiological innocence, because the biological normativity is irreversible,” Canguilhem wrote (2007 [1943], p. 156) in his *Essai sur quelques problèmes concernant le normal et le pathologique* (An essay on some issues related to what is normal and what is pathological). Grieving for healing defined as a return to the previous state is no more, having given way to a type of demystification of healing. However, the very harsh reality of chronic diseases has created a new grieving process for healing, as if it were about healing from the very idea of healing. This was actually Canguilhem’s opinion in a 1978 article titled “Une pédagogie de la guérison est-elle possible ?” (Is it possible to teach healing?).

The unambiguous awareness that healing is not returning helps the patient pursue their search for a state of the least renunciation possible by freeing them from the focus on the previous state [...]. Learning to heal is learning about the contradiction between hope for one day and failure in the end, without saying no to hope for one day. (Canguilhem, 2002 [1978], p. 99)

Chronic diseases are not the only challenge faced by the medical community, far from it. They generate very intense life experiences in terms of physiological and metaphysical questioning, in the sense that they call for a reset of all categories of well-being, happiness, and relationships with others and with one’s own body. What is this sick health, this long-lasting illness that can hide behind its ability to go unseen? What is this invisibility of disease that leaves traces everywhere and spreads, sometimes very deleteriously, to the environment? How can we better cure this and support these subjects? Again, the chair remembers the primary truth that there are no diseases, only subjects who fall ill, and that recognizing this subjectivity is the only viable way to provide care.

CONCLUSION AND OUTLOOK

Did patients need a university? Did hospital staff, physicians, and care providers, as well as patients and families, need a chair of philosophy at the hospital? Since the late 1980s, with the critical health tragedy of AIDS, medicine and the human sciences have been joining forces to try and solve some of the issues of epidemics and chronicity. As a result, clinicians in charge of patient support are confronted with unexpected challenges: what is the point of surviving one's own announced death if nothing is provided in terms of social reintegration? To whom, or for what will my death be beneficial? Does biological survival have meaning if this existence or survival is not considered by the community? Hence, deploying a space for listening and guiding patients through four epidemiological journeys facilitated experiments in various clinical situations: (1) assisting patients in the absence of medical treatment; (2) assisting populations in a voluntary effort to discover their serological status; (3) assisting patients who struggle in following a treatment; (4) assisting the return to health. This dive into the assistance universe revealed a need to build an academic structure, develop a space in which patients who wish to do so can study, integrate their personal journey into a collective narrative, create—at their own pace—a new skills portfolio, and take some time to reflect on, theorize about, and share their experience. As long as there is no institutional framework for such teachings, all therapeutic mechanisms and all healthcare communities deployed in this type of exceptional circumstances run the risk of being short-lived, even though they are within the realm of *techne* while also bearing promising *episteme*, particularly for other illnesses. One option was to create a mechanism at the periphery of the institution; however, this carried the risk of establishing a reception facility for people already exposed to intense marginalization outside of the institution. Both projects had to be implemented at the core of the academic system and of the hospital. Protecting democracy and institutional functions means multiplying connections between citizens and existing institutional components. One of the issues highlighted by the University of Patients and the Chair of Philosophy at the Hospital is that of epistemic authority, i.e., the question of who is authoritative in terms of knowledge, proficiency, and skills. In this sense, developing patients' epistemic authority as "public" in the sense expressed by Dewey means creating conditions that will allow them to deploy their right to exercise their freedom of investigation, and creates new relationships among healthcare providers and with patients. When acquired in an adverse situation, a skill has the same value as one acquired in a vertical knowledge transmission mechanism. Just because a skill is acquired in a peer group does not make it less valuable or less legitimate than a skill acquired in a traditional educational setting. This assumption raises the question of classification of the ways in which skills are acquired according to the legitimacy of the acquisition environment. It shows the persistent confiscation of the qualification of expertise by those who claim to manage, help, protect, and care for the weak, the outcast, the vulnerable, and the sick.

The University of Patients and the Chair of Philosophy at the Hospital follow the tradition of the Age of Enlightenment, adding a few critical breaches (Adorno, Bourdieu, Deleuze, Guattari), in that we must take into account differentiated intellectual tools and create teaching programs aiming to reduce and fight against the feeling of illegitimacy of students who do not dare to challenge the academic *doxa* because they acquired expertise through self-education or from associations without real authority. It is important to identify knowledge transmission systems that integrate the issue of their acquisition by students and do everything possible to avoid intimidation effects and techniques in the offering of knowledge. The University of Patients and the Chair of Philosophy at the Hospital are also in line with the pedagogical and psycho-sociological clinical trends in adult education described by Dewey, Freinet, Freire, Tosquelles, Oury, Ardoino, Lapassade, Winnicott, Cifali, Lewin, and Rogers. These trends and authors all insist on the fact that the teacher or school

should not become a main obstacle in the access to knowledge. Since existing legal mechanisms such as the validation of acquired experience (*Validation des acquis de l'expérience*, VAE, 2002), the validation of professional achievements (*Validation des acquis professionnels*, VAP, 1985), and the right to life-long education and training (*droit à l'éducation et la formation tout au long de la vie*, 1995) state that anyone should have access to education at any time of life, the Chair of Philosophy at the Hospital and the University of Patients are concretizing these principles by offering them a space they did not have before, in a climate of innovation conducive to new theoretical and practical developments.

Therefore, we should ensure that the patients' experience is acknowledged by showing that their insights are not only as valuable as professional expertise and recognized in other professions, but, more important, can be used as resources enabling us to find solutions for other problems in our society. When a person is able to make decisions in a situation of uncertainty or is ultimately capable of managing recurring risky situations or facing the news of their impending death, the skills acquired through this experience could be applied to other situations, such as those exposing people to fear, to risk, and to terror, just to name a few examples. Skills acquired by humans in situations of dire adversity are socially undervalued and are rarely taught (Tourette-Turgis, 2015).

Following these new systems for a French school of healthcare, it is essential to create and structure a recovery clinic (Tourette-Turgis, 2018). In medicine, we have moved from the medicine of acute illness to the medicine of chronic illness; we must now examine the paradigm of passing from the medicine of chronic illness to the medicine of recovery. American epidemiological data have confirmed that this is a public health issue; in France, 3 million cancer survivors still have specific needs. Another new experimentation must be implemented: a patients' hospital, managed by expert patients; in other words, an entity where patients are the administrators and managers and the care providers dispense their fundamental and traditional knowledge while focusing more on social innovation and appropriation of care paths and new therapies. If hospital users become decision-makers in terms of the organization of medical work, surely they will implement practical recommendations toward optimization, in cooperation with medical and administrative teams. Patients are already user representatives and, in this capacity, attend hospital meetings. However, the scope of their participation is too often restricted to mediating conflicts and issues generated by hospital dysfunctions, even though they could make creative suggestions to transform the hospital into a space designed from the patient's perspective instead of from the perspective of those who work on their bodies.

Simple and symbolic arrangements considering the real distribution of medical tasks between care givers and patients would optimize the medical and paramedical actions. Instead of being a downward space for an act on a passive patient, care would be a co-intervention in which each actor oversees their own part of the care. In the past few years, healthcare providers have lost hospital management and administration to managers who stole the heart of healthcare. It is entirely possible that thousands of them would prefer returning hospitals to patients and share the management with them to better preserve the core of their job and its requirements.

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