
Editorial

Health democracy, from one crisis to another

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This year, France celebrates the 20th anniversary of 4 March 2002, law on 'Patients' Rights and the Quality of the Health System' that included the notion of 'health democracy' in the French Public Health Code. This term—which does not have a real equivalent outside France—was defined as a system that recognizes the capacity of each individual to know about, decide and act for his or her own health and for the health of the population.¹

Beyond this legal mechanism, this concept of health democracy is based first and foremost on a set of fundamental principles. First of all, there is the freedom of the patient to make the choices that concern him or her ('No medical act can be performed without the free and informed consent of the person and this consent can be withdrawn at any time'). It also involves the legitimacy given to the actors of the health care system (e.g. patients, professionals, etc.) to deliberate and issue opinions on health policy, and the definition, implementation and evaluation of the strategies and levers implemented. These principles thus converge with the foundations of health promotion and are the results of a strong mobilization of associations in the field of HIV. Indeed, the activism of these stakeholders has established the legitimacy of patients and patient groups to express themselves and participate in individual and collective choices, thus giving substance in France to the notion of empowerment.

This system is now integrated into the functioning of the French health care system. However, the health crisis has reshuffled the deck and put health democracy on hold. The annual report of the National Health Conference highlighted all the infringements of patients' rights during this crisis.² The collective dimension of health democracy has not fared any better. The public authorities have not referred matters to the consultation bodies. More generally, citizens have not been associated with decisions.

Thus, we are witnessing the paradox that a mechanism that was born of an epidemic (AIDS) died of a second epidemic (coronavirus disease 2019). It is obvious that the management of a health crisis may require exceptional measures; however, the debate in France has often been reduced to a dichotomy between health and freedom (i.e.

accepting restrictions of freedom for a better health). However, this opposition does not make sense from the point of view of public health. On the contrary, we argue that democracy and related freedoms is one of the conditions of health. Due to a lack of consultation of stakeholders, decisions that have been taken have often been difficult to implement and have given rise to strong and counter-productive opposition (e.g. the vaccination pass has led to an increase in opposition to vaccination³). Moreover, because of the uniform nature of these top-down decisions, they have not been able to take the diversity of needs, contexts and situations into account, with the result that social and territorial inequalities in health have been greatly aggravated: in France, those most vulnerable to the virus have also been those who have been the least well cared for. Moreover, we can hypothesize that the lack of consultation and transparent communication, and the lack of trust in the public authorities are all contributing factors to the deleterious impacts of the crisis, particularly in terms of mental health, for which France has seen the worst developments in Western Europe.⁴

Mann⁵ reminded us in his analysis of the HIV crisis how human rights and public health are inseparable. Let us hope that the lessons learned from this crisis will allow us to rebuild health democracy.

Conflicts of interest: None declared.

References

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