Ethical issues related to the COVID-19 pandemic in patients with cancer: experience and organisations in a French comprehensive cancer centre

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ABSTRACT

Background The COVID-19 pandemic has aggressively reached the most vulnerable, not only the elderly but also patients with chronic conditions such as cancer. In this study, we present the outlines of ethical thinking and the measures implemented to try to respect our basic values of care, in the specific environment of an oncology hospital.

Methods Our ethics committee created an ethical watch system based on 24/7 shifts to assist practitioners in their daily decisions. We discuss the challenges faced by patients with cancer during the pandemic, such as access to critical care and ethical dilemmas in the context of resource scarcity, as well as the issue of isolation of patients. We also debate the restrictions in access to oncology care in a health context strongly ‘prioritised’ against COVID-19.

Results In all areas of an ethical dilemma, either for sorting out access to critical care or for the dramatic consequences of prolonged isolation of patients, our common thread was our attempt to protect, whenever possible, the principles of deontological ethics by strictly resisting utilitarian pressure. Respecting democratic health decision-making processes is a cornerstone of ethically relevant decisions, including in the context of a sanitary crisis.

Conclusion The role of an ethics committee related to real-life situations includes not only a reflexive perspective in respect of fundamental principles, but also the help to enlighten and resolve ethical dilemmas in complex clinical situations. This ethical watch team assists physicians in decision-making, promoting the supportive and palliative dimension of care with a holistic approach.

BACKGROUND

The COVID-19 pandemic, first identified in 2019 in China, has spread around the world within just few weeks, indifferent to borders and human constructions. Almost each country had to face the outbreak of this new epidemic, which led to hospitals, emergency rooms and intensive care units (ICUs) being overwhelmed, and sometimes death of several hundreds of thousands of people. While the virus blindly strokes entire populations, it fell more aggressively on the most vulnerable, such as the elderly and patients with severe chronic conditions (hypertension, obesity, diabetes, respiratory insufficiency and cancer).

Although the cancer-associated risk of developing a COVID-19 pneumonia appears to be lower than a specific age, obesity or hypertension, patients with cancer are not spared from the most severe forms leading to mechanical ventilation (MV).1 2 Thus, while a diagnosis of SARS-CoV-2 pneumonia might affect the chances of survival, it also leads to long periods of resuscitation and rehabilitation, compromising the possibility of continuing or resuming antitumour treatments for several weeks. Therefore, the usual criteria for the implementation of invasive resuscitation techniques in oncology patients were subsequently rapidly challenged by the occurrence of COVID-19 pneumonia. Simultaneously, facing the epidemic wave of rapid increase, resource allocation and medical demand questions were addressed, putting
stress on the means that were at that time available. Finally, the conditions for preserving the permanence of oncology care through the flow of infected patients led to emerging ethical dilemmas for health professionals and, beyond this, for society as a whole.

In moral philosophy, normative ethics helps to resolve ethical dilemmas, applied here to medicine. Schematically, besides the historical virtue ethics, the two main theories are currently deontology, inspired by E Kant (there are absolute constraints on our actions), and utilitarianism, a consequentialist theory (a moral action maximises utility for the greatest number of people). The two approaches were in competition during the pandemic.

METHODS
Facing challenges of a unique kind and dimension for most of our generation, we present the outlines of ethical thinking and the measures implemented to try to respect our basic values of care, in the specific environment of an oncology hospital. By its daily involvement in medical decisions, the common thread of our ethics committee was the attempt to protect, whenever possible, the principles of deontological ethics by strictly resisting utilitarian pressure.

In this study, we present how our local ethics committee created an ethical watch from the beginning of the pandemic to assist practitioners and teams in their daily decisions. We then discuss the various challenges faced by patients with cancer in the context of the COVID-19 pandemic, such as access to critical care and ethical dilemmas in the context of resource scarcity. We then debate on restrictions in access to oncology care and treatments in a health context strongly ‘prioritised’ against COVID-19, as well as on the issue of isolation of patients and the balance between health risk and inhumanity of care, including in palliative setting and for end-of-life patients. Finally, we discuss the challenges of respecting democratic health decision-making processes, including in the context of a sanitary crisis.

This article describes the actions taken by an ethics committee in response to the COVID-19 pandemic. This is not a research, but a descriptive account and reflection of our experiences.

RESULTS
Setting up an ethical support unit for helping caregivers in their thinking
The outbreak of the epidemic led to brutal, although anticipated, organisational upheavals in entire areas of the hospital: postponement or sometimes drastic reduction of scheduled activities, reorientation of surgical units especially towards the reception of patients with COVID-19, increased ICU capacity and so on. Anaesthesiologists abandoned operating rooms to reinforce the resuscitation team, and surgical units received ‘medical’ patients with infection, respiratory failure and often those in palliative situations. Confronted with these sudden changes, new organisations and an unknown disease, a cross-cutting support was needed: listening to teams, helping to adopt new types of practice, and solving complex medical and ethical cases appeared as fundamental both in assisting the teams and promoting the basic respect for the fundamentals of care during an extraordinary period.

Since 2012, our ethics committee has had both reflexive and embodied activities in the daily questions of oncological practice. This existing structure prompted us to create an operational unit adapted to the requirements of a crisis situation, responding to the request of the National Advisory Committee on Ethics. Twelve members of the committee, six practitioners and six non-practitioners, set up several support groups for the hospital’s teams since the first cases of SARS-CoV-2. Epidemic constraints led to a mix of face-to-face meetings and audio and video conference communication. In addition to the units in which collegial support meetings were already in place, daily multidisciplinary meetings involving medical and paramedical professionals were organised in all services receiving patients with COVID-19; two members of the committee strengthened the discussion circle, in addition to the palliative care practitioner, the psychiatrist and the intensivists already present. The same was true for the daily COVID-19 meetings, where discussions of therapeutic choices raised ethical dilemmas around therapeutic engagement and limitations. In addition to these structured and regular proceedings, the emergency referral procedure of the ethics committee, already in place, was deployed on the basis of 24/7 shifts, via a dedicated email address and above all a duty call known to all stakeholders. Each referral (usually concerning a decision to transfer a patient or not to the ICU) was the subject of the relocation of two to three members of the committee and/or the organisation in real time (especially overnight) of a conference call to guarantee collegiality. Overall, up to 10 cases per day were discussed with the ethics committee, either in plenary sessions or during a referral; at the peak of the crisis, up to four referrals were organised in emergency in a day. The structure of our ethics unit permitted us to immediately propose three members, whatever the time of day and the type of dilemma. We considered that 12 members was the adequate size for a 427-bed hospital (of which about 50 were dedicated to patients with COVID-19) and an ICU of up to 28 beds. Finally, the ethics committee held specific thought-searching biweekly sessions among members to share medical situations, discuss the broad ethical principles involved in the dilemmas debated and propose solutions to further assist patients and practitioners.

The philosophy of this ethical unit was to offer a reflective support to the teams, but at the same time not to replace the decision-making processes already
in place, especially in the ICU. It remained a guiding light offered at the request of practitioners, and not a moral injunction on what should be done or not.

Access to critical care
Two vital threats of a different and competing type
The issue of transfer to the ICU of severely ill patients with COVID-19 took a rapidly increasing importance from China to Europe: all French north-east regions had to adapt to the outbreak of the epidemic wave and with it to a possible limit in the number of beds, ventilators, equipment, drugs and above all caregivers. Thus, as well as for other chronic diseases, the management of patients with cancer faced a double challenge: at the individual level, the perspective of the prognosis of neoplasia, fatal in a large number of cases when MV was required, and subsequently with the addition of a neoplastic disease—ethical principles of beneficence, non-maleficence and autonomy appeared here in the foreground
and on a collective scale, the equitable distribution of access to care in the context of strained medical supplies, taking into account factors such as age or, here in particular, an underlying pathology such as cancer—for this second point, the principle of justice becomes the cornerstone.

Thus, cancer management in times of pandemic emphasises a more general problem: the conflict between the outbreak of an acute and often lethal pathology, and the presence of a chronic disease, which requires the maintenance of an appropriate offer of care but which, in itself, exposes the patient to a vital risk. How can we approach the ridged narrow path between two threats of a different type and temporality, whose combination requires the weight of two ‘competing’ pathologies, both at the individual and collective levels?

Reconciling two requirements: prioritising the individualisation of decisions by resisting utilitarian choices is a constant tension and a luxury. Very quickly, recommendations were made on the main ethical issues related to the COVID-19 epidemic, in the general population or for specific situations such as critical care or oncology. The National Advisory Council of Ethics, regional ethical structures, academic societies and health agencies recalled the main ethical principles applied to the pandemic context. Their common feature was the emphasis on the principle of justice and equity, in the face of a situation where the means available proved to be limited. Until then, this principle was cited only last, as the allocation of resources could appear, in the Western world, a bit constrained. The COVID-19 pandemic turned the tables: the issue of equity in access to care came suddenly to the forefront.

However, even in a situation of collective demand for solidarity, each stakeholder always considered that the ethical pillars of respect for dignity, autonomy and non-maleficence remained central and applied to each person. This is not a simple statement of well-meaning intentions: even at the height of the epidemic wave within the hospital, where the ICU beds were under maximum tension despite deployment from 12 to 28 places, each case of each individual patient was examined in a multidisciplinary committee, in the light of the individual benefit (or lack thereof). The requirement for justice was seen as ‘an inspiration to the other three principles, [not] as an additional and external principle [...] isolated from respect for autonomy, beneficence and non-maleficence’. But is it not a luxury that only a specialised centre could afford?

No doubt yes: the sanctification, even temporary, of a cancer centre has made it possible to absorb the influx of infected patients with more essential preparation. Furthermore, it is also the collective measures implemented, the collegial and early reflection, and the constant ethical monitoring that have guaranteed respect for the fundamental principles of care, even at the cost of sometimes considerable tensions.

Defining a ‘decision framework’ outside of algorithms and simplified choices
The decision-making process until the implementation (or continuation) of ICU invasive therapies always involved, in this order, the following elements: (1) collection of patients’ wishes (anticipated directives, identification of proxy and so on); (2) prior general condition and comorbidities (predominant overall prognostic factor); (3) assumed reversibility of acute failure (number and type of organ failures: short-term prognostic impact); and (4) finally cancer prognosis (in the medium to long term).

The first available data quickly showed that SARS-CoV-2 pneumonia was of greater severity than other causes, with a mortality exceeding 50%; its duration was extended, and evolution was often erratic; respiratory sequelae were frequent; and rehabilitation time proportional, in fact, to the duration of invasive support. The surviving patients were, in the majority, young patients, without comorbidity, in good general condition.

Based on these findings, and as an extension of our historical decision-making path, we defined a large decision-making framework for SARS-CoV-2 pneumonia in patients with cancer. Patients’ wishes, expressed either in the context of the oncology course or in the context of the epidemic rise, remained the first cornerstone of the medical and ethical approach: any expression of refusal of treatment or unreasonable obstinacy was carefully sought. The performance status was then predominant in defining the level of therapeutic engagement. Finally, the characteristics of neoplasia were put into perspective with acute severity, predictable ICU and rehabilitation durations: the indication for ICU admission for COVID-19 pneumonia was based on the preservation of a satisfactory general condition, absent or mild comorbidities, and an...
The role of an ethical watch

In the midst of tension associated with the influx of patients with COVID-19 into conventional units and ICUs, the violence inherent in any decision whether to transfer or not to the ICU, the frequent immediacy of the decision to be taken, and finally the spectrum of the shortage of beds, drugs or caregivers, an external and supposedly neutral reflexive contribution, as defined in the French law of 2005, was indispensable. The multi-daily interventions of the ethical unit in multidisciplinary meetings attempted to bring the necessary collegiality in times of crisis. Whatever the degree of urgency, this deliberative collegiality allowed to recall, beyond the more or less explicit and pervasive constraints of equitable access to care, the necessary respect, for each patient, of their wishes and decision-making autonomy, the indestructible principles of dignity of the person, beneficence and non-maleficence, and the duty of information and communication with patients and proxies.

However, the repetition of requests for debates as well as the sometimes extreme urgency of the situations presented did not always allow the necessary temporality for a peaceful, cool-headed reflection. To compensate for this deleterious compression of time, we strengthened our perseverance both on collegiality, as previously mentioned, and on the primacy of anticipation of possible clinical aggravation, in order to define reasoned and shared care goals (‘advance care planning’, ‘goals of care’). Although genuine advance care planning, as such, is still too rarely described in the medical records, one available tool provided a useful support in formalising the level of therapeutic engagement, particularly in case of worsening: indeed, the Aid to Decision-Making Form (previously in place for 4 years at our institution and now available in each computerised chart) was updated daily, thanks to the efforts of both the ethics committee and the supportive care department to extend the culture of anticipation. Thus, most practitioners now agree that the crisis period was an ‘accelerator of acculturation’ towards more anticipation and a clearer definition of the oncological project: each physician had to ‘revisit’ the benefit:risk ratio of cancer treatments and to identify more lucidly (and collegially) those with little expected benefit. This more stringent assessment led structurally to a better involvement of the palliative care practitioners as regards patients with cancer. We certainly hope that this evolvement will continue until after the pandemic.

Dealing with an additional vulnerability: isolation

Beyond the dramatic issue of equity and eventual sorting out between patients, the conflict between collective health demands and individual humanity embodied also in the isolation imposed on patients and their loved ones, including in cases of critical state, palliative situation and death. Oncology patients, with or without virus contamination, had their visiting conditions drastically restricted. Those infected with COVID-19 were further affected due to the reinforced barrier measures in routine daily care. The imperative rule to protect the families from risk of contamination in the hospital, and themselves from transmission from outside, was accepted by the vast majority of patients, enduring the decision with courage and resilience and the loneliness imposed by the pandemic.

The pandemic led the caregivers to compete with imagination and initiatives to reduce as much as possible the consequences of isolation. In our oncology hospital, the caregivers, used but never accustomed to the vulnerability of patients with cancer, shared in their own heart the frustration of not being able to ‘be in the care’, an entire part of the care. Thus, the teams organised themselves to facilitate visual exchanges between patients and loved ones, thanks to the digital tablets present in the rooms, the setting up of audio or video appointments using the phones of patients or those of the caregivers themselves, and responding
as much as needed to the phone calls of relatives. The psycho-oncology unit strengthened its presence in the units, either for patients, relatives (including video consultations) and teams. Finally, the patient committee, in conjunction with the ethics committee and the supportive care department, was mobilised to be a source of proposals.

For patients in serious or even terminal condition, visiting restrictions were eased, with permission to have at least one relative, without compromising the barrier measures necessary for the safety of each person. In case of death, visits were organised before the patient was placed in protective cover, under regulated conditions. The inhumanity of the situation, constantly outcropping despite all the attention paid to diminish it, required acceptance of a compromise in constant tension between health requirements and humanity of care. Throughout the epidemic period, the ethics committee and the palliative care team intervened daily in the services, both to help with reflection on derogatory conditions and to offer a listening ear to caregivers affected by complex and painful situations, sometimes themselves self-isolated to protect their dear ones at home.

Reflection on issues of access to oncology care and treatment in a ‘prioritised’ COVID-19 health context

As with all patients with chronic disease, patients with cancer were exposed to the risk of interruption or delay in treatment. The urgent reorganisation of care facing the pandemic affected all care systems, and our cancer hospital faced similar challenges. Since the beginning of the epidemic, a double constraint was imposed, not only to protect immunosuppressed and vulnerable oncology patients from the risk of infection while taking care of patients with COVID-19, but also to reorganise the offer of cancer care in order to limit as greatly as possible the postponement of care. Each organ committee proposed a prioritisation for each type of cancer, according to treatment emergencies, retaining some of them, organising surgical procedures in partner centres or offering therapeutic alternatives to avoid coming to the hospital, when possible. At the height of influx of patients, increased video consultations and phone calls permitted maintenance of a minimum level of care activity and link with patients.

However, there is no denying the strain on a non-infinitely stretchable healthcare system as yet unsuitable for a long-reported and feared epidemic risk, and this will have to be further analysed. Not only the measures taken to best preserve the fairness of access to care but also their transparency will need to be carefully considered. In France, some patient associations have already referred the case to the highest legal authorities for ‘inequality of access to hospital care’, believing that transparent criteria should be applied in the choice of whether to hospitalise, or not, patients with COVID-19, but also regarding access to hospital or management of end-of-life and palliative care.

While patients such as those in a comprehensive cancer centre were partly protected from the consequences of such tension, patients with cancer have been necessarily impacted, like others, by the epidemic. In many hospitals, the presence of cancer was considered one of the causes of non-admission to ICUs, ignoring the individualisation of the criteria mentioned above. The prioritisations in oncology management may have led to postponement of some treatments or to proposal of suboptimal options. Like other pathologies such as vascular or neurological diseases, coming to the hospital was reduced by the patients themselves, anxious to the risk of contamination and subjected to the double injunction to continue to treat them while respecting confinement; in many cases, the fear of COVID-19 surpassed irrationally that of cancer itself. The fear of a rebound in the health crisis, in another form, after the decrease in the epidemic wave, is therefore real.

‘Health democracy’

The issue of the permanence of democratic exercise in the context of a health catastrophe arose from the beginning of the epidemic, through the questions of freedom to travel and to work, but also of the strategy to allocate and prioritise medical resources. We introduce here the concept of ‘Health democracy’, well known (but poorly involved) in France as ‘Démocratie sanitaire’, meaning that patients in health issues have the same rights as citizens in societal issues, both at the collective and individual levels.

Our ethics committee quickly recognised the difficulty in sharing transparently the issues and complexity of the crisis between either professionals, mobilised and attentive to do the best in a disaster setting, or patients and users, who do not doubt the efforts made, but may feel and suffer from unilaterally and sometimes opaque decisions. From this incomunicability emerged societal concerns on the criteria of choice and the equity in care access (old age, cancer, dialysis and so on). Patient associations criticised the lack of transparency of choices rather than the choices themselves. If the use of admission criteria according to patient life expectancy and their chance of survival was already practised within a fixed and accepted framework, the situation is very different with a submerged hospital system. In several North American states, considering that no single criterion captured all morally relevant values, a ‘multi-principle allocation framework’ was built in order to prioritise which patients should benefit of scarce critical care resources. Without prejudging the validity or not of these criteria, we would like to stress here that this allocation framework was ‘based on intensive engagement with diverse citizens’ groups, ethicists, and disaster medicine experts’; in France,
The decisional processes were: carried out in an opacity that can cast doubt on [their] fairness. However, the choice made must not only be fair, but also be perceived as such by the patients and their families. They must be assured that a disabled person is treated as a valid person and that the social level will not be included in the choice.

Thus, if sharing is tricky, not to do anything is an obvious source of misunderstanding. Clarity and transparency on the issues, their causes and their impacts, are therefore necessary, but the ridged path is narrow. In our country, neither the medical caregivers nor the patients’ world is used to this dialogue. Our patients committee, consulted as tactfully as possible on the question of decision-making strategies, confessed its reluctance to enter this extreme and painful area of democratic exercise. However, even in extreme circumstances, physicians cannot avoid a fair transparency on the criteria for their choices, and on the means used to limit subjectivity and exclude arbitrariness. In our institution, the ethics committee and the patients committee communicated regularly on the main issues of the crisis, but we would be also convinced that, at a broader level, the views of patients and citizens were actually included in policy responses to COVID-19.

How can we imagine the ‘world after’?

At the end of April, we asked hospital residents, young oncologists in training assigned to the ‘COVID-19 sector’, how they had experienced scientific uncertainty during these atypical months, if they had not been too baffled. All replied that the lack of reliable data on the virus and the evolution of the disease, constantly changing, had not saddened them. In fact the opposite occurred; this academic blur had allowed them to return to the fundamentals of care, to the data of clinical examination, to an empathetic relationship with the patient and the encounter of a face. Beyond deontologism or consequentialism, the ethics of the Other, using Levinas’s terms, appears here central.

Is that to be the ‘world after’? Let us hope so. Apart from the great unknown of the spread and clinical manifestations of SARS-CoV-2, the pandemic has brought little unexpected revelation. It rather emphasised the characters of individuals, and the qualities and flaws of systems and organisations. At least we can draw some lessons and perspectives from this period. Perhaps we could make a hypothesis in the form of hope for the near future.

First, the clash between an acute illness and an underlying disease both compromising the life-threatening condition provoked a necessary dialogue between ICU physicians and specialists of a chronic disease. This dialogue, as we have seen, often occurred under very stressful conditions, but the meeting was inevitable, and it took place! The frequency and intensity of these meetings will now encourage oncologists and intensivists to better anticipate and get to know each other better.

The pandemic also prompted a deeper reflection on the goals of cancer care. A careful and early shared definition of advance care planning is the cornerstone of the relevance of care. The critical importance of early supportive care is emphasised in oncology during the past decade. Also, the pandemic not only underlined the importance of anticipating a possible worsening of the patient, but also strengthened the role of supportive and palliative care. Critical care and supportive care are two sides of the same coin, that of a holistic approach in medicine.

The numerous reorganisations needed in facing the pandemic demonstrated the flexibility of medical skills. The anaesthesiologists became resuscitators, oncologists became physicians in infectious diseases, and internal medicine and surgeons left the operating theatres to come help in ICUs. As pointed out by our residents, adaptation was made possible by a return to the basic fundamental principles of care. This contrasts with the steady evolution towards a hyperspecialisation of medicine: neither molecular medicine nor artificial intelligence will replace the flexibility of the caregiver’s brain, nor the eminently human and humanistic foundation of medicine.

Physicians also recognised uncertainty in medicine as a permissible and not dishonourable element. Although ever present in medicine, uncertainty is largely ignored in practice, and medical studies do not form this dimension that affects both knowledge and the relationship between the physician and the patient. The outbreak of the pandemic highlighted the possibility of not knowing, without failing to continue to care. This was one of the recurring messages of our ethical cell during the COVID-19 pandemic, but the caregivers had already accomplished most of the way on their own.

The importance of ethical support is not limited to times of a health crisis: ethical thinking should be everywhere in medicine, and the constant questioning of the meaning of care is a necessary condition for respecting the fundamental principles of medicine. An ethical watchdog is only there to remind us of these basic pillars and help with decision-making; it is not a substitute for the thinking (or decision) of each professional. When temporality is compressed by urgency and the multiplication of ethical dilemmas, or when collegiality proves insufficient, each caregiver can find in themselves the moral resources for the resolution...
of ethical conflicts. One of our colleagues in charge of the palliative care unit, facing end-of-life conditions degraded by the extreme isolation of patients, authorised exceptional visits by relatives while strictly respecting health rules. Beyond the sanction of isolation to prevent the spread of the virus, the ethical imperative of respect for the dignity of individuals enabled an entire team to resolve the moral conflict imposed by organisations in times of crisis.

Finally, the pandemic taught us that, even in the worst conditions of tension, the deontological principles permitted us to respect the individual and their dignity, resisting the pressure of utilitarianism. It is not a moral judgement on what is right or wrong; it is a societal choice of values (still) privileged in our country. Other countries have been forced to assimilate other principles, in this case distributive justice, for various reasons: a different epidemiological impact of the pandemic, and/or a different culture and relationship to moral philosophy. For example, Italy and the USA have reported the need for a more clear ‘sorting’ procedure faced with the influx of patients needing critical care.11 12 Has France escaped such pressure? Certainly not: in the north-east and the region around Paris, similar questions have arisen. And when they were not specifically referred to the ICU physicians, it is likely that some form of ‘sorting’, whether explicitly or not, occurred as regards access to the emergency room or emergency transportation. At the very least, ethical thinking has ensured, at our hospital as elsewhere, to limit the utilitarian dimension induced by the pandemic.

CONCLUSION

It is undoubtedly the role of an ethics committee embodied in the real life of the hospital (and above all during a major sanitary crisis) to be involved in many aspects of patient care. This includes reflexive monitoring in respect of fundamental ethical principles, but also providing help to enlighten and resolve ethical dilemmas in clinical complex situations, support caregivers in their daily practice and sometimes listen to their own suffering, and recall general democratic principles in health decisions. Ethical monitoring assists physicians in decision-making, promoting the supportive and palliative dimension of care in a holistic approach. Finally, the principles of deontological ethics, centred on the respect for dignity of each suffering person, including during the context of sanitary tension, may counterbalance, at least in part, the collective injunction of a strictly utilitarian approach.

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