

Strengths and limitations of considering patients as ethics 'actors' equal to doctors: reflections on the patients' position in a French clinical ethics consultation setting

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Abstract

The Clinical ethics centre in Paris offers its services equally to doctors and patients/proxies. Its primary goal is to re-equilibrate doctor–patient roles through giving greater voice to patients individually in medical decisions. Patients are present at virtually all levels, initiating consults, providing their point of view and receiving feedback. The implications of patients' involvement are threefold. At an operational level, decision-making is facilitated by repositioning the debate on ethical grounds and introducing a dynamic of decisional partnership, although contact with patients can make it difficult to deny their demands and set the limits of our role. Ethically, it reinforces patients' autonomy and grants them a place of veritable ethics 'actors', with the danger that this may become excessively autonomy oriented. Finally, at a collective level, the programme fulfils its political purpose in promoting patients' rights and the ideal of *démocratie sanitaire*, but complicates balancing individual demands with collective values.

Introduction

The question of how and to what extent patients and their representatives or proxies (hereinafter 'patients') should be integrated into clinical ethics consultation is currently the subject of deliberation and debate, evidenced at least in part by the collection of papers in this issue of *Clinical Ethics*.

The Clinical ethics centre (Cec) at Cochin Hospital in Paris was established in 2002, following the law on patients' rights of 4 March 2002.¹ This law transformed the traditional vision of medicine through emphasizing the patient's role as an actor of her own health and by promoting co-decision in medical issues. In line with this view, the Cec offers clinical ethics consultation services to doctors as well as to patients and/or their proxies, being equally accessible to all. This choice of operational model was both deliberate and political, and raised big controversies in the local medical community. However,

our hypothesis was that patients, being the primary concern when difficult decisions need to be made, have to be considered as actors in ethics deliberation. Our starting point was to accord a different status to patients than in the traditional vision of medical ethics and to consider them *a priori* just as relevant an ethics 'actor' as doctors when facing ethical decisions.

Having worked with this model for six years, the purpose of this article is to critically examine the role of patients in our setting. In the first section, we provide an overview of the Cec's experience. We then examine the strengths and limitations of providing such a role to patients, through operational, ethical and political lenses.

Role of patients at the various stages of clinical ethics consultation

The Cec's primary goal is to offer an aid to medical decisions in clinical situations that are considered ethically problematic or 'grey'. To achieve this, the Cec gives greater voice to patients at the individual level of singular medical decisions and introduces a multidisciplinary approach including the presence of lay members. Working this way, it helps all different actors to clarify the grounds of possible ethical conflicts, it re-equilibrates doctor–patient roles and favours co-decision-making.

The patient's place at the various stages of clinical ethics consultation described below is a direct consequence of the Cec's starting point and objectives as described above.²

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Calls for consults

The Cec is equally accessible to all agents concerned with the medical decision: health-care professionals, patients and their proxies. Any one of these agents who faces an ethical dilemma in a specific clinical situation can call for an ethics consult. Patients' (or proxies') calls for consult represent one-third of the cases.

When the Cec's assistance is solicited, it is essential that all parties involved in the decision are informed about the consult and provide consent to it. In situations where the patient or doctor refuses to participate, the process cannot proceed since we consider that the only way to help in dealing with ethical dilemmas addressed to the Cec is by listening equally to both positions. Sometimes questions that concern only a specific doctor (e.g. 'Should I inform the patient of a specific diagnosis?') or a specific patient (e.g. 'Would I obtain help if I want to have access to active euthanasia?') are addressed to the structure and treated by meeting only the doctor or the patient, although this is rarely the case.

The consult

The process of the clinical ethics consult begins with the consultant team having a meeting with the doctor (or other health professional) and a separate meeting with the patient. Meeting 'the doctor' involves discussions not only with the physician in charge, but also if possible with different members of the health-care team involved in the decision, as the views even among the health-care team may differ. On the other hand, if the patient so desires (or in cases where she cannot express herself³ due to her medical condition), her proxies are consulted so as to provide an idea of the patient's point of view before the incapacitating event, as well as their own. When interviewing each participant, the Cec team works towards an in-depth understanding of each position and the ethical grounds that support it.

The consult is always conducted by a multidisciplinary team – an approach maintained throughout the consultation process. The consult team is composed, at minimum, of a doctor and a non-doctor, both of whom are members of the ethics group. Half of the members of the ethics group are doctors or nurses and half are non-clinicians, such as social scientists and researchers (philosophers, jurists and sociologists), psychologists or social workers, or lay members (journalists, patients' representatives), all previously trained in clinical ethics.⁴ Underlying the composition of the consultants' team is the idea of different and complementary perspectives of listening, so that if the doctor can identify with the clinician member of the team and feel that his ethical point of view and dilemmas are better understood by this consultant, the patient may be better able to identify with the non-medical member, feeling that he could better advocate for him. Thus, the ethics consult assures due consideration of the perspectives and positions of all stakeholders in as balanced a way as possible.

Ethics case conference

Once the elements relative to the case and the views of all relevant stakeholders have been gathered, the next step is

to plan an *ethics case conference*. The deliberating group is the multidisciplinary ethics team described above. Information relative to the case is presented by the consult team who have met and discussed the problem with both sides. Our goal is neither to deliberate on what is *right* or *wrong*, or *good* or *bad* from a moral perspective, nor is it to decide on the course of action to be taken in the actors' place. Rather, our concern is to present both sides' arguments in an equal way, to identify the conflict of values at stake, and to help clarify and prioritize the ethical challenges embedded in the decision at hand.

The members of the treating medical team are usually invited to participate in the case conference. They are not asked to provide their point of view (as this has already been collected by the consultants), but their presence is useful since they can provide additional medical information about the case if required. Moreover, it can be interesting and useful for them to familiarize themselves with the Cec's methodology for dealing with ethical dilemmas. Involving the treating team also reinforces procedural transparency and respects the consultative – and not decisional – role of the case conference. However patients, although informed of the collective deliberation process, are generally not invited to participate. The reasons for this choice and its implications are discussed below.

Output and feedback

The output of the deliberation process consists in providing all the interested parties a clear, calm and full understanding of the other possible positions. This is done by conveying the content of the ethics discussion as well as the course of the thought process that took place during the conference (the different ethical arguments put forward, their respective weight, the position(s) that seemed to prevail). The consult is successful if it leads the doctor as well as the patient to re-discuss and 'ethically' find the best or more acceptable resolution to the situation together.

The output is communicated by the consult team to all the actors not present at the case conference, in a way that is appropriate to each stakeholder (medical team, patient or proxy), but is as detailed and equivalent in terms of meaning as possible. It is stressed to all parties that the Cec's conclusions are purely consultative and have no decisional status.

Follow-up

After a certain period of time, which varies from case to case, follow-up data concerning the 'evolution' of the case are gathered from both doctors and patients.

Discussion

In this section, we will address the strengths and limitations of having such a central position for patients in the ethics consultation process. Our analysis will proceed through three successive dimensions: an operational, ethical and political one, even though such a distinction is somewhat artificial.

Operational implications

At a practical level, our experience is that re-equilibrating doctors' and patients' positions by according them a place as equal as possible actually facilitates decision-making in ethically conflicting situations.

Several factors may explain this. First, meeting the patient usually provides new facts to those given by her doctor. Patients often feel free to engage with the consult team regarding different issues apart from their medical condition. Indeed, patients often do not feel comfortable expressing their doubts or conflicting thoughts to their health-care providers, fearing the impact it will have on their medical treatment.

Moreover, systematically meeting everybody equally introduces a framework that redefines the relations of power and allows for a shift in each stakeholder's perspective. There is also the possibility to 'take a step back' and gain a certain distance from the situation causing the ethical conflict.

For patients, feeling that their position is understood, welcomed and respected and that the arguments and values they put forward are equally legitimate to those of the doctors often de-emphasizes the conflicting aspects of the situation. Besides, the fact that their physician is sensitive enough to the ethical dilemmas arising in their care to call or accept an ethics consult attenuates the tensions and reinforces trust.

In this manner of operating and by introducing the patient as an ethics 'actor' and equal partner in medical decision-making, the consult process allows for a repositioning of the debate on ethical grounds; helping 'to develop the shared view that everybody has good "ethical" arguments',⁵ as Reiter-Theil suggests, enables a new dialogue and dynamic in the carer-patient relationship.

However, giving such a prominent place to the patient in the ethics consult process also poses some questions regarding the Cec's positioning and limits of action. Although we agree with Reiter-Theil that 'the patient's wishes should never be taken as an imperative, but should be included in real counselling and reasoning on the basis of respect and care',⁵ giving a voice to patients and welcoming them as ethics 'actors' can cause them to feel that if their demands are *a priori* receivable on an ethical basis, then they are automatically acceptable at an operational level as well. This could make it more difficult to deny them their requests. Moreover, meeting with the patient is very often an intense experience, given that it involves intervening at a crucial moment of the patient's life. After this meeting members of the consult team may feel personally engaged towards her, which could undermine or be suspected as undermining their judgement and the way they will advocate for her during the case conference. Because of these two considerations, it is sometimes difficult for the Cec to remain outside the operational dimension of the outcome. This difficulty is even more salient when the medical team insists on its original position, while the ethics group is inclined to be more convinced by the patient's arguments. In such cases, what should the limits of the Cec's role be? To ameliorate

this possible problem, constant and careful revisiting of our role and its limits is crucial.

Ethical implications

At the theoretical ethical level, it is clear that the decision to actively involve patients better respects their autonomy and re-equilibrates the place occupied by autonomy arguments in balancing the decision. This particular way of functioning aims not only at reinforcing patients' autonomy but, furthermore, at introducing patients as genuinely legitimate *co-actors* in medical decision-making and not as simple vectors of preferences, as the traditional medical ethics approach would suggest.

Nevertheless, some questions remain. First, it is not really the case that patients' and doctors' roles are 'equal' in the ethics consult process. Patients still remain 'patients' – a status illustrated by the fact that they are usually not invited to participate in the case conference. The reasons evoked for this are that it could be harmful to them and because participants in the conference say they will feel uneasy speaking freely in the presence of patients. This position, already explored in the literature,⁶ is subject to a counterargument that we are being over-protective of our patients and over-emphasizing the role of the health professional, in contrast to the objectives of the programme. However, not including patients in the ethics conference helps us achieve a sound and clear articulation between the ethical and operational aspects of the situation.

In addition, our position is that in letting patients attend the case conference, there is a risk of 'going to the other side', thus creating a different imbalance, this time too much in favour of the patient. As we have stated above, the consult process itself already emphasizes the patient's autonomy and urges the consultant team to advocate for the patient, given that she represents the most vulnerable party (up to the point where it becomes difficult to deny her demand). Will it not be even more difficult to contest this in her presence? In light of this observation, one could argue that the decision not to include the patient in the ethics case conference functions as a guard against being excessively autonomy oriented.

Political implications

As mentioned above, the Cec was created in a specific political context and to pursue specific societal objectives, to promote what is called in France the ideal of '*démocratie sanitaire*'. This means to put forward patients' rights at the individual as well as the collective level. At the individual level, this consists of recognizing patients' rights of shared decision-making in the clinical decisions that concern them. Therefore, the emphasis given to patients' autonomy was clearly a political choice. At the collective level, the objective is to acknowledge citizens' rights to actively participate in the choices to be made regarding medical or bioethical issues that may have societal implications. This is the significance of the important place

accorded to lay members in discussing each ethically problematic decision within the Cec. As it has been pointed out elsewhere, the success of this model suggests that 'the consultation service is perceived as a relevant answer to a larger move toward more patient representation in decision-making and more collegial reflection on the ethical dimensions of medicine',⁷ a trend that is today even more in keeping with society's continuing demand.

The appreciated presence of lay members in the Cec as well as the topics of the cases for which it is solicited, i.e. on new, innovative and often unexplored fields where medicine meets or contrasts social values, attest to the fact that the Cec actually occupies a position at the interface between medicine and society. In fact, this is the way medical teams often perceive the structure. To answer to their demands, an important portion of the Cec activity is now dedicated to research, on ethical recurrent dilemmas that they meet in their daily clinical practices, when being related to some ethically problematic fields such as assisted reproduction, living organ donation or sex-reassignment surgery. Yet, the research consists in studying the ethical issue at stake through our clinical ethics approach, meaning on a case-to-case basis and on a successive patient cohort.^{8,9} Collaborating with medical teams in such a way allows for a more comprehensive and detailed understanding of the ethical issues raised by today's medical practice. It also constitutes a way of contributing to the national reflection by nourishing the public debate with real-life elements, coming from the interaction between doctors and patients at the everyday clinical level, in the sense of a bottom-up approach.

On the other hand, the Cec's positioning also entails political risks. As can be expected, some individual demands that are addressed to the Cec, although ethically relevant, are bound to be 'off-limits', whether legislative or societal. Facing such demands, the question is: if giving such an emphasis to patients' choices logically leads to viewing them as potentially acceptable, could it not be at the expense of collective best interest? Judging an individual demand that goes against society's choices at a particular moment to be ethically relevant runs the risk of rendering the collective consensus established up to that point more vulnerable.

The second risk of such a choice is to make it difficult to clearly separate ethics from politics. In our context, supporting either the patient's or doctor's point of view could be interpreted as taking a political stand. It is therefore important when choosing a specific position to clearly distinguish whether our choice is really a translation of ethical and not political considerations.

Conclusion

The Cec programme described above is quite an innovative model in clinical ethics. Its design is intrinsically related to the historical, social and cultural context of its creation. Its starting point is to consider patients as equally legitimate ethics 'actors' as doctors are. The law that willed such a rebalancing and led to the programme's creation was inspired by a strong political as well as ethical

mandate, namely the reinforcement of patients' autonomy. In this context, the central place accorded to patients at all levels of the clinical ethics consultation is directly aligned with the Cec's purposes.

In light of its six-year experience, this model appears to be efficient in pursuing its objective and responds to an authentic demand. However, such a particular way of 'doing' clinical ethics gives rise to a range of new questions, both ethical and political, and critically interrogates the relation and the margins between these two levels. Where ethical conflicts cannot be resolved, existing tensions between patients and doctors perhaps reflect societal tensions (as illustrated, for example, by the debate on withdrawing alimentation-hydration in terminally ill patients) that deserve to be submitted to public debate. The Cec programme is heading in that direction by not only pleading for a more active role for the patient in the decisions that concern her, but also by its active engagement to submit medical and bioethical issues that are met in everyday practice for public discussion with civilian society.

At present, and given the success of this model, it seems unthinkable to take a step back and not consider the patient as a veritable ethics 'actor'. On the contrary, we believe that patients are still far from being considered enough as such. However, in order to achieve an optimal integration of the patient's perspective, the remaining questions we raised need to be addressed in an efficient way.

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