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The value of ethical principles to reflect on emerging issues in epilepsy care and research

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ABSTRACT

In the age of patient participation, ethics are more important than ever to help guide clinicians in situations of uncertainty. *Principles of Biomedical Ethics* by James F. Childress and Thomas L. Beauchamp remains the most important reference in medical ethics. In their work, they conceptualize four principles designed to help guide clinicians in decision making, notably beneficence, non-maleficence, autonomy, and justice. While using ethical principles dates back to at least Hippocrates, the introduction by Beauchamp and Childress of the principles of autonomy and justice have helped to deal with new challenges. This contribution will discuss how the principles can help elucidate issues of patient participation in epilepsy care and research using two case studies.

Methods. – In this paper, we will discuss the equilibrium to be found between two principles (beneficence and autonomy) in the context of emerging debates in epilepsy care and research. The methods section details the specificities of each principle and their relevance to epilepsy care and research.

Results and discussion. – Using two case studies, we will explore the potential and limits of patient participation and how the ethical principles may help to provide nuance and reflection in this emerging debate. First of all, we will explore a clinical case which involves a conflictual situation with the patient and family about psychogenic nonepileptic seizures. We will then discuss an emerging issue in epilepsy research, namely the integration of persons with severe refractory epilepsy as patient research partners.

1. Introduction

Thomas Beauchamp and James Childress' *Principles of biomedical ethics* [1] remains the most widely used guide of clinical ethics. First published in 1979 and now in its 8th edition, it is based upon four ethical principles (non-maleficence, beneficence, autonomy, and justice), which aim to guide clinicians in situations of complexity and uncertainty. While using ethical principles in medicine dates back to at least Hippo-

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Table 1 – Biomedical principles and their main points.

Principle	Definition	Clinical implications
Non-malfaisance	Responsibility to minimize pain and suffering	This principle gives the healthcare provider responsibilities not to inflict undue harm and to minimize pain and suffering. It also clarifies when a healthcare provider can be held responsible for actions that cause non-intentional harm. For instance, in the case of misdiagnosis due to a rare condition, we cannot reasonably hold the doctor responsible if they use all training and resources available and still fail to diagnose the patient correctly. However, we can hold them responsible for negligence or lack of attention, such as if a doctor takes the patient's history and forgets to ask about medication allergies
Beneficence	Responsibility to promote the well-being and the interest of patients	This principle helps examine how far to go to ensure the well-being of patients without paternalism and to reflect on how to promote well-being at what scale (including whether we should consider the beneficence to the individual patient or to society). It is more constraining than the principle of non-maleficence (a negative principle)
Justice	Emphasizes fairness and equality among individuals	This principle asks us not to discriminate between patients (the treatment cannot vary from one patient to another for arbitrary reasons), but also to consider the effects of clinical decisions on the allocation of healthcare resources and what makes a system just
Autonomy	Right to self-determination, including making decisions without interference	This principle focuses on the patient's right to make life choices without interference from others. This includes responsibilities of healthcare providers to help their patients toward greater capacity for choice. It also emphasizes the right of patients to decide whether or not to exercise their autonomy, as well as recognizing that autonomy can be exercised in various degrees and temporalities

crates (the principle of *prinum non nocere*, or ''do no harm''), Beauchamp and Childress' innovation is to integrate the principles of autonomy and justice into the debate for the first time. In their proposal, Beauchamp and Childress made the choice to focus on (only) four principles. While this makes it a restrictive list, these four principles have shown their value in interdisciplinary discussions, as they are both easily understandable and mobilized. We have chosen to use Beauchamp and Childress' principles – and in particular their conceptualizations of beneficence and autonomy – due to their value to elucidate the debate on patient participation to an interdisciplinary audience.

While underutilized at the current time in epilepsy, the principles have already been used in certain clinical contexts, including to guide conversations with patients and families about sudden unexpected death in epilepsy (SUDEP) [2] and to counsel on epilepsy surgery [3]. As a general, flexible guide, we can expect that the decisions taken will be contextual, depending on the culture, the regulatory framework, as well as individual relationships with the healthcare team, patients, and families. Concretely, this means that the relative importance of each principle will be defined and debated in each situation, as we will see with the discussion of two case studies. Table 1 summarizes the principles and their main points.

2. Methods

In the results/discussion section, we will work with two of the principles (beneficence and autonomy) to discuss case studies from emerging issues in epilepsy care and research. In this section, we will elaborate the two principles in more detail so that it can serve as the basis of the discussion.

2.1. *Principle of autonomy*

Beauchamp and Childress' conception of autonomy recognizes that patients have a right to self-determination and to make decisions without inference from others. It involves giving the patient all the necessary information to make an informed decision, making sure this information has been fully understood, and recognizing that the patient is capable of making the (final) decision. However, this principle goes beyond just information giving. It also makes healthcare providers responsible to support patients in their capacity for choice. In their formulation, it is up to the patient to decide how to exercise their autonomy as they wish and are capable (it is the patient's *right* to decide). However, it is up to the clinician to create the possibility for choice (it is the clinician's *responsibility* to help cultivate and guarantee the patient's capacity for choice). It is for this reason that the principle should not be (only) understood as encouraging the patient's individual autonomy, but rather been seen as a responsibility for healthcare providers to create an environment in which the patient can realistically act. In this formulation, patients are not alone. We will *respect their autonomy* by giving them information, but also access to other resources (other healthcare providers, patients) to help them toward greater capacity for choice.

Beauchamp and Childress also recognize that autonomy can be exercised to various degrees and temporalities. This definition is both relevant and realistic in the context of epilepsy, where patients may choose not to play an active role in their healthcare and relegate this role to their healthcare provider and/or to their family. Indeed, patients may also be able to exercise choice in some aspects of their life choices whilst relying on their supporting network to play a more active role in others. For instance, some persons with epilepsy

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are active by identifying trigger factors for their seizures but rely on their neurologist and/or family to make decisions on their medication. Others, in particular those who have had epilepsy since childhood, may be ''experts'' of their individual epilepsy and want to play an active role in deciding medication. Patient participation also evolves in time, with some patients becoming more or less active depending on what degree of engagement they wish to and are capable of having.

While autonomy is often considered the most important principle of Beauchamp and Childress' proposal, it is important to note that the authors do not make this claim. For them, autonomy must be weighed up against the other principles to determine the most important to the subject and context. It therefore may be coherent with (or conflictual with) the other principles, depending on the subject at hand.

2.2. *Principle of beneficence*

Having discussed the principle of autonomy, we will now detail the principle of beneficence. This principle can be defined as promoting the well-being and the best interests of patients. Doing good for another is more restrictive/demanding than doing harm (non-maleficence) and implies responsibilities at both the individual and collective level. This principle brings considerable complexity to healthcare, notably by considering how far the clinician can/should go. It notably asks ''what are the contours (and limits) of a beneficial action?'' For instance, is it sufficient to promote the physical health of patients, or are we are also responsible for promoting their emotional, social, and spiritual well-being? Another challenge in specifying the principle of beneficence is how far we should go to promote the well-being of patients and when this represents a type of paternalism. The principle of beneficence also considers whether we should look at well-being at the individual or at the collective level (whether healthcare providers are responsible for promoting the well-being of their individual patients or whether they should put the needs of public health first).

In the context of epilepsy care, beneficence is not easy to determine because the healthcare team is tasked with missions that go beyond treatment. This includes making decisions that will affect the patient's quality of life (driving, the ability to exercise certain professions, etc.). In addition, given the stigma experienced by patients with epilepsy and their families [4], it is important for the healthcare team to help patients toward greater autonomy and social integration. The difficulty today is that some of these ways to promote patient well-being may also lead to accusations of paternalism, in particular when it interferes with the person's autonomy. This means that in some circumstances the principles of autonomy and beneficence may conflict, or more likely involve a balancing act between ensuring that clinicians are ''doing their best for their patients'' while also trying to respect their autonomy.

When considering the principle of beneficence, there is also a balance to be found between the interests of the individual patient and limited healthcare resources. This makes it particularly challenging for healthcare providers in public welfare states such as France to find a balance between promoting beneficence for individual patients, finding ways to respect their autonomy, but also their statutory obligations in the just allocation of healthcare resources. We will explore one of these situations in our first case study.

3. Results and discussion

We will now debate two case studies in epilepsy care and research. We will first of all discuss a conflictual clinical situation with a patient and the family concerning diagnosis of psychogenic nonepileptic seizures. We will then turn to an emerging issue, namely the integration of particularly vulnerable individuals (refractory epilepsy patients) in research. The two case studies we will discuss have been chosen for their importance to the debate on patient participation. The subject has evolved in the last few decades to involve not only patient participation at the clinical level (as the first case study will show), but also patient involvement in strategic committees, as patient experts in hospitals, and as patient partners in research (as the second case study will show). Both are forms of patient participation, although they bring forth different ethical questions given their levels of analysis. In both discussions, we will mobilize the two principles of beneficence and autonomy to reflect on patient participation, although in different ways given these different levels. To make the link between these two case studies, however, at the end of the discussion, we will elucidate the common issues and solutions that the principles have helped bring to the issue of patient participation.

3.1. *Acceptance of the diagnosis of psychogenic nonepileptic seizures*

In this first case study, we will discuss the balance to be found between the principles of autonomy and beneficence in dialogues with patients and families about psychogenic nonepileptic seizures. According to the International League Against Epilepsy (ILAE), psychogenic nonepileptic seizures (PNES) present paroxysmal time-limited alternations in motor, sensory, autonomic, and/or cognitive signs and symptoms; however, they are not caused by ictal epileptiform activity [5]. Unlike epileptic seizures, which are related to excessive discharges in the brain, PNES has psychologic underpinnings and causes. They are involuntary and can involve at least a partial alternation of consciousness.

The diagnosis of PNES can take years and sometimes even decades. Misdiagnosis is common due to overlapping clinical features with epilepsy and low awareness of PNES by clinicians. In addition, epilepsy is a risk factor for the development of PNES and some patients may experience both [6], while patients with (only) PNES are often initially misdiagnosed as suffering from intractable epilepsy. Misdiagnosis of PNES leads to unnecessary prescriptions of anti-epilepsy medications, increased iatrogenic injury, morbidity, social stigma from epilepsy, and significant costs to the healthcare system [7].

However, once clinicians are able to establish a diagnosis, another challenge awaits them, namely how to communicate with the patient and the family to help them accept the

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diagnosis and the need for psychological treatment [8]. As the initial cause of PNES may be trauma experienced in childhood, this often complicates the dialogue. However, patient acceptance of the diagnosis of PNES is vital and has been correlated with better healthcare outcomes. Caregivers have also been shown to play an important role in acceptance [9].

In the case study, we will discuss a common situation in which the patient/family may not accept the PNES diagnosis and request additional tests. We will then mobilize the principles of beneficence and autonomy to elaborate the necessary balance to be found and to find potential solutions to this dilemma. In this discussion, we will rely upon a case described in the New Atlantis [10]:

> A patient in his 30s came to the hospital overnight after falling and the team suspect epilepsy. They conduct an EEG, a CT scan, and labs, all of which were negative. During the night, although the patient and his mother claim that the patient had seizures, there are no abnormal electrical discharges on the EEG. The clinical history suggests emotional trauma in childhood. The team concurs that the patient is suffering from PNES and spends considerable time explaining the situation to the patient and his mother. They are angry and do not accept the diagnosis. They do not understand why the physician does not accept to prescribe anti-epileptic medications and demand an MRI to find the ''real diagnosis.'' While the neurologist initially refuses, the patient complains to hospital management and finally gets what he wanted: an expensive MRI, which shows nothing abnormal.

This case study shows the challenges facing healthcare providers in the age in which patient participation is advocated. For the clinician, the test is unnecessary and incurs costs to the healthcare system (principle of beneficence). However, from the patient's perspective, it is possible that the healthcare team made a wrong diagnosis and the patient asks for more tests (principle of autonomy).

If we take the patient's perspective, we can see that the patient and his mother are having a hard time accepting the diagnosis. While we do not know the end of the story, we can expect that the expensive MRI, which showed nothing abnormal, may be a facilitating factor in accepting the diagnosis, as ''all the tests have been done.'' From this perspective, the decision made by the hospital administrator may have been a good one in the long run, even if it incurred additional expenses. However, if we take into consideration the physician's fiduciary responsibility to the state and the need to make sure that resources are allocated fairly, we may not come to the same conclusion. Indeed, an MRI is an expensive procedure and the healthcare team has no reason to believe it is necessary. By agreeing to the procedure, resources are being directed away from needy patients. The principle of beneficence asks us to decide whether the individual patient or the needs of public health be prioritized; here, no easy solution can be found.

Given the patient's insistence, it is also likely that if the hospital had not agreed to perform the test, the patient and/or family would have found another hospital/healthcare provider willing to do so. There is also no guarantee that the second hospital/healthcare provider will diagnose the patient correctly given the difficulties of diagnosing PNES. Therefore, the decision to incur a costly test may be the right one, if we take this long-term view. However, it also sets up a dangerous precedent by ceding to the patient's demand in the name of autonomy. Indeed, although this principle emphasizes the right to self-determination, in some cases it might lead the clinician to cede to the patient's and family's desires, even if the clinician believes this is harmful (principle of non-maleficence) or at the very least, unnecessary or wasteful of healthcare resources. In this case study, we can see the difficulty of prioritizing one principle (autonomy) over another (non-maleficence).

Given that there is no ideal solution to be found to this dilemma, we suggest taking a wider view by focusing on how to accompany the patient and family in the transition to home care. Here, Beauchamp and Childress' principle of autonomy can help. The principle emphasizes the healthcare provider's responsibility to support the patient's capacity for choice. If we think of autonomy in this way, the healthcare team will consider how to support him both during his hospital stay, but also in a long-term perspective for when he leaves the hospital and what resources he may need.

In the context of PNES, interdisciplinary coordination is necessary to consider the complex psychological factors that result in the condition. A psychologist or psychiatrist may help the patient to better understand the condition and possible treatments. In addition, the patient can be referred to a specialty epilepsy nurse, providing an alternative resource to discuss treatment options and a different resource person who was not involved in the conflictual situation in the emergency room. Another important resource may be a patient expert/mediator in the hospital or referral to an epilepsy patient association. This will help the patient to discuss with persons in similar situations, helping reduce stigma and to realize that he is not alone. Given the importance of the family member in these situations, the mother may also be directed to family support groups at this time.

In conclusion, as this example shows, today's healthcare is rife with situations requiring a difficult balance to be found between the principles of autonomy and beneficence. By mobilizing the principles of Beauchamp and Childress, we were necessarily led not to cede to the patient's demands, but rather to reflect on how to best support the patient and their family, even in (or especially in) conflictual situations. We notably find a path forward by considering the responsibility of healthcare providers to help patients toward a greater capacity for choice. This helps us to consider the temporalities of acceptance and to find ways to realistically support the patient and his family. In these situations, an interdisciplinary healthcare team and the involvement of patient associations become particularly valuable to accompany the patient long-term.

3.2. *Integration of severe refractory epilepsy patients in research*

In this second case study, we look at an emerging issue in patient participation, namely the involvement of patient partners in clinical research, frequently known as patient and public involvement in research (PPI). This case study

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brings forth different issues than that of the previous discussion, as it is focused not on the micro level (the individual patient–healthcare team interaction) but on the macro level (how a patient may be able to benefit a research project). However, both cases are important to the evolving debate on patient participation and raise similar issues of how to best support patients in the new roles expected of them. It is important to note however that the focus in this case study is wider, as we are interested not only in the benefit to the individual patient, but also that of the research team.

To start with, PPI is promoted based upon the idea that people affected by an illness have the right to have a say in research, which concerns them (principle of autonomy) but also that they can help improve research through their experiential knowledge (principle of beneficence). In health projects, PPI has been shown beneficial, in particular to help the team identify research priorities and new research topics [11–13]; to develop methodology appropriate to the group being studied [14]; and/or contribute to the analysis by providing new perspectives [15,16]. Patient research partner integrations in health projects has been practiced for several decades in the United States, United Kingdom, and Canada, although the subject is only beginning to reach France (and other European countries). Patient partner integration in epilepsy research is worth considering not only because of the ethical and political goal of greater patient participation, but also for its potential benefit for epilepsy research. While we will argue here that PPI may be desirable, in this section we explore what needs to be taken into consideration before envisaging collaboration by using the principles of autonomy and beneficence.

Our case study focuses on integration of severe refractory epilepsy patients to research projects, as to our knowledge these persons have thus far not been significantly integrated into clinical or social science research, even in countries with well-developed PPI programs. Refractory epilepsy represents approximately one-third of epilepsy patients. The condition is defined as, ''*the failure of adequate trials of two tolerated and appropriately chosen and used AED schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom*'' [17]. In the case of severe refractory epilepsy, the neurological condition may be complicated by a variety of factors influencing the quality of life of the person, including psychological, behavioral, and/or cognitive problems, restrictions in education, work and leisure, and social isolation. Because of these difficulties, some severe refractory epilepsy patients may live full-time in medical-social institutions.

At first glance, these persons may not seem the ideal candidates to participate in a research project. They may seem a ''borderline case,'' those who may not be appropriate for such kinds of participation due to their disability. On the other hand, severe refractory epilepsy patients are often those persons who, by nature of the severity of their illness and the limitations of modern medicine to treat it, have developed experiential knowledge to live with their epilepsy. They also are in many cases associated with emerging research and often the first persons to try out new solutions/treatments. They are therefore a group likely to be interested in participating in research, as well as potentially able to bring value to the research team through their experiential knowledge.

If we take into account the principle of beneficence for the research team in this discussion, we suggest that this knowledge will benefit the research team if it is harnessed in realistic and appropriate ways. For instance, if the team is researching the efficacity of a new medication, while the team may be focused on statistical, biomedical indicators of effectiveness, a patient may be able to help identify indicators relevant from the patient perspective, enabling a more global view. Patient input can also be used to help develop project materials at the design phase – such as the consent form – so that the language is accessible and understandable from the patient perspective. Patients may also play an important role in the restitution phase of the research, raising awareness on the research results, in particular among other patients. These are just a few ways in which the research team may benefit from the experiential knowledge of these patients.

Another reason to consider collaboration is the benefit to individual patients. As these persons often suffer from social isolation and limitations on work and social opportunities, they are often seen by society and unfortunately by themselves and their families as ''dependents.'' However, as Bogaert and Petit [18] have shown, advancing research in epilepsy may be empowering for the patient by helping them play an active part in society. It may also be a positive factor in their social integration and build their confidence. Therefore, from the standpoint of beneficence to individual patients, participating in research seems a promising way to promote their quality of life as well as facilitating their social inclusion.

Therefore, both from the standpoint of beneficence to the research team and patients themselves, this kind of collaboration appears desirable. However, the next question becomes how to make it successful. PPI research has shown that in many cases, the involvement of patient research partners is superficial and initiated largely based upon obligations to funders. This leads to frustrations for the research team and for patient research partners, particularly when their roles are unclear. In the case of integration of persons with severe refractory epilepsy, there are additional issues to consider. As these persons already face limitations due to their illness, if there is a pressure to ''perform'' (for instance by contributing significantly to all aspects of the research process, of giving a certain number of hours/days of engagement, etc.), this may increase their stress and/or set them up to failure if they are unable to contribute as planned.

Here, the principle of autonomy can help the team reflect on how to promote a beneficial research environment for both the patient and the research team. First of all, given that the principle emphasizes self-determination, this means that the patient research partner will necessarily play an active role in determining the scope and extent of their cooperation. This means personalizing the partnership for each research project and putting into place a flexible approach that can be revisited if needed. This also means communicating their right to withdraw from the project if participation is not beneficial, causes stress or other issues. If a patient is living in a medical-social institution, it may also be worth considering integrating such cooperation into the personalized project to enable follow-up by the health and social care team. Such a realistic plan of cooperation, one in which the person with epilepsy feels both comfortable and capable of participating, will also

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be the best means to ensure participation is not symbolic. Finally, as participating in research could potentially bring back traumatic experiences, it will also be important to consider if psychological support will be needed to support integration and well-being.

Furthermore, investing in collaborative methodologies to enable patient's contribution to be valued remains essential for PPI to work. For instance, if these persons are invited to a discussion with doctors/researchers in which they feel inhibited to speak, this likely will both have a negative impact on the person as well as inhibit contribution to the research project (principle of non-maleficence). It may also remind them of conflictual situations they have lived in the past in their healthcare. To prevent this from happening, in practical terms, this may mean investing in separate discussion groups or the use of an outside facilitator to facilitate exchange. It will likely also involve investing in trainings for patients so that they can learn the basics of how research is conducted, including research ethics, as well as information, vocabularies, and methodologies specific to the project. Putting these measures into place will both increase their capacity to contribute, help avoid conflict, but also build their confidence.

Therefore, while the integration of patient research partners is a promising new way of making epilepsy research pertinent from the patient perspective, and in particular of including those most vulnerable into the discussion, their integration needs to be carefully planned and negotiated with the research team and an honest and open discussion initiated with patients. In addition, to ensure that patients are welcomed in the research team, it will also be necessary to raise awareness among the researchers of the roles and benefits of their participation.

In summary, we have seen that the principle of beneficence has helped to reflect on how to ''do good'' both for patient research partner and for the research team, while the principle of autonomy has helped identify the supporting tools and environment needed to ensure successful cooperation. By considering the patient's right to self-determination, we also envisaged a co-construction process in which patient research partners can be actively involved in determining the nature and extent of their cooperation to make it realistic and beneficial to them.

To conclude this discussion, if we return now to the previous case study, in which beneficence and autonomy somewhat conflicted, in this second case study we can see how these principles can also mutually reinforce each other. The principles' strong point is to help elucidate dilemmas in this flexible manner and to be able to consider a subject from different perspectives. The ability to hierarchize the most important principle in the discussion or to find ways to articulate two or more in the context therefore makes it a dynamic guide for reflection and to help find practical solutions.

4. Conclusion

In this paper, Beauchamp and Childress' principles of autonomy and beneficence have helped navigate the muddy waters between patients' rights and healthcare provider's responsibilities in two case studies related to epilepsy care and research. While the two cases we have discussed have brought forth different issues, the principles of beneficence and autonomy have shown their value to reflect on and find practical solutions to both situations of patient participation. They have notably enabled us to think of the patient's well-being in the long-term, whether in healthcare or in research. They have also helped to take the perspective of the patient, healthcare provider, and the researcher to determine the important issues to consider in each debate. Most importantly, perhaps, they have helped us think about the resources and support patients need to play an active role in care or in research, and therefore to work toward a realistic means of respecting their autonomy.

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