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# Patient empowerment as capabilities: The perspective of patients with epilepsy at a medical-social center in France

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## **TITLE PAGE**

**Proposed Title:** Patient empowerment as capabilities: the epilepsy patient's perspective at a medical-social center in France

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## **Patient empowerment as capabilities: the epilepsy patient's perspective at a medical-social center in France**

### **Abstract**

The aim of the study was to develop a new conceptual framework of empowerment based upon the refractory epilepsy patient's perspective at the medical-social center of La Teppe (France). A qualitative research methodology was used, which consisted of focused ethnography and in-depth interviews. The 19 patients interviewed came from three hospital services and were in the age range of 20-60. 10 interviews were also conducted with healthcare providers, which included neurologists, psychiatrists, nurses, and social educators. Results were analyzed via an intuitive process of thematic analysis. The researcher also constructed narrative cases of the patient interview to better understand patient responses in context. The results show that patients understood empowerment as the ability to develop and take advantage of opportunities in their overall lives. This included searching to be healthy by reducing their seizures, developing their practical reason in order to be able to make more autonomous life choices, and living with and toward others in positive social relationships. The patient's perspective on empowerment encompasses but also goes beyond their medical care. We therefore propose a novel conceptual framework for empowerment as the patient's capabilities to develop and make their life choices, with help as needed from their support network. In order to help patients toward empowerment, clinical care can include discussions and dedicate resources that help patients work toward their overall life projects. Several methodologies, including the use of a personalized project and therapeutic patient education, are elaborated to give ideas for empowerment programming in epilepsy care.

### **Keywords**

Patient empowerment; person-centered care; capabilities approach; La Teppe; European Association of Epilepsy Centers

### **1. Introduction**

At the current time, there are no patient developed definitions of empowerment [1] and current definitions remain inadequate for epilepsy patient care. Because of competing priorities and uses, definitions of empowerment continue to vary widely depending on the context and interest group. Current definitions of patient empowerment include: *an educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions* [2]; *a redistribution of power between patients and physicians. Empowered patients attempt to take charge of their health and their interactions with healthcare professionals* [3]; and *a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important* [4].

The two main limitations with using these current empowerment definitions in the context of epilepsy patient care is their focus on individual autonomy and lack of clarity on the role of others (families, doctor, etc.). For instance, Roberts [2] sees empowerment as an educational process that will enable the patient to take responsibility for healthcare decision making. Similarly, Feste and Anderson's definition [3] seeks to reverse doctor-patient asymmetry so that patients can "take charge" of their health. In these definitions, the role of the healthcare provider remains unclear. We have also presumed for the patient responsibilities for healthcare decisions they may not be capable or desire to take. The third definition of empowerment, proposed by a patient's group [4], reflects a global view of the patient and as a person in society. Unlike in the previous definitions, the patient's role is clear (to define what is of importance to them): however, it again leaves out the critical role of the healthcare provider (as well as others) which may help the patient to become empowered. What we can see from these three definitions that patient empowerment has been over-associated with individual autonomy. In the overall empowerment movement, feminist scholars [5] have criticized those empowerment definitions which have minimized the role of contextual and structural factors.

From the standpoint of treatment outcomes as well as quality of life, empowerment is a beneficial goal from both the patient's and the healthcare provider's perspectives. This is particularly the case for with refractory epilepsy and psychiatric comorbidities, including psychogenic non-epileptic seizures, which is one of the most frequent psychiatric associated comorbidities in epilepsy. These patients have had long healthcare journeys across specialties and have to deal with multiple constraints related to their condition. The complexity of their epilepsies and associated comorbidities also makes them particularly vulnerable to being "talked for" by their families or by their healthcare providers. For these reasons, however, they are also those patients who can benefit the most from patient empowerment programming. First of all, empowerment can be a means for them to

develop greater capacity for choice and to overcome the burden of overprotection. Secondly, it can give them confidence in overcoming past failures and help them to plan their lives. Finally, it can help them to better understand their epilepsy, the treatment, and to find individual ways to manage it. For instance, in the case of comorbidities and in particular psychogenic non-epileptic seizures, empowerment programming may be able to help patients to better regulate their emotions by developing knowledge about their epilepsy.

This study is focused on clarifying the concept of empowerment from the patient's perspective to better understand what they need and want from empowerment, as well as to help design realistic empowerment programming. It therefore sought to fill a research and clinical gap. The first aim of the study was to develop a new conceptual framework of patient empowerment based upon the epilepsy patient's perspective. The second was to source these perspectives among those with more difficulties, notably refractory epilepsy patients, as these patients are often left out of the empowerment discussion.

## **2. Material and Methods**

### **2.1 Study design and location**

In collaboration with the Healthcare Values Chair at the University of Lyon III (France), the study was designed as part of a philosophical research project on patient empowerment and led by a researcher with a dual background in philosophy and sociology. A convention of research collaboration was signed between the university and La Teppe and the necessary declarations to the National Commission for Informatics and Liberty (Commission Nationale de l'Informatique et des Libertés or CNIL) were made prior to the start of the research.

The participants in this study were refractory epilepsy patients and residents at La Teppe, the only center in France providing healthcare and medical-social activities for adult epilepsy patients. Drug resistant (or refractory) epilepsy is currently 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.*"[6] La Teppe is specialized in complex refractory epilepsy cases and currently has capacities for outpatient and inpatient care [7]. It is part of the European Association of Epilepsy Centers [8] and works actively with several university hospitals centers (CHUs) in France. Patients and residents at La Teppe suffer from refractory epilepsy with associated comorbidities including psychiatric disorders.

As a site with fully shared medical-social and healthcare reception structures, La Teppe employs about 500 people including nurses, specialized care workers, psychologists, speech therapists, and social workers, working toward a global approach to epilepsy care. The uniqueness of the site and its combination of health and medical-social services make it possible to develop care pathways and diverse psychosocial rehabilitating programs in a stimulating and inclusive environment. La Teppe aims at inclusion and self-determination of the persons welcomed and accompanied with the proper articulation between highly technical care, whilst also seeking to maintain and develop autonomy, freedom, and protection. It also responds to the growing demand of vulnerable persons to benefit from access to the city, to citizenship, and greater participation in the expression of their life choices. By promoting culture, sport, and eco-responsibility, activities organized for patients and residents are levers for these ambitions. Therapeutic workshops support persons to develop greater autonomy and social and professional skills allowing for increased capacities for reinsertion.

### **2.2 Participants**

As there are currently no definitions of empowerment coming upon the epilepsy patient perspective, a wide spectrum of patients was chosen for this study. Two hospital services and one medical care home at La Teppe participated. This broad selection of services and patient profiles was intentional in order to understand the shared experiences among patients at La Teppe in spite of age or background. It also informed the diverse healthcare journey for patients at La Teppe, as many passed through several services before leaving the hospital or deciding to live full-time in a medical care home. For instance, the first hospital service was geared toward younger patients who had often left home for the first time and were trying to find ways to work in spite of the severity of their epilepsy. The second service took those who were soon ready to leave La Teppe to rejoin family members or to work in a protected work environment. The third site was a medical care home on site, where residents often stayed long-term after completing their personalized project in one of the hospital services.

19 refractory epilepsy patients and residents in the three hospital services participated in the interviews. 13/19 of the research participants was in the age range of 20-25 and came from the two hospital services geared toward this age group. This selection was a reflection of the specific healthcare plan of the establishment, which takes young adults in order to help them develop a personalized project, which often involves working in a protected work environment. However, in order to have a more holistic understanding of empowerment at La Teppe, 6

patients were also sourced from the medical care home on site. These persons were slightly older than the other patients, with two in the age range of 30-45 and four in the age range of 45-60. Because they were in a medical home, their project was no longer focused on working; however, most stayed active by participating in therapeutic workshops offered by La Teppe.

Ten healthcare professionals were also interviewed to better understand La Teppe's approach to epilepsy patient care and included neurologists (3), psychiatrists (1), nurses (3), and social educators (3). They were principally sourced from the three services of the patient interviews, although one came from the neurological observation site and one person worked in a third service. These two additional healthcare providers were included in order to have a more holistic understanding of epilepsy patient care at the establishment.

At la Teppe, it was necessary to consider how to establish real consent of the participants, as most patients or residents had some difficulties with reading and writing. In this situation, it did not make any sense to have the patients sign a consent form. Verbal consent for patient and resident participation therefore involved the active support of social workers who explained the uses and purposes of the research to participants, who then volunteered to participate in the in-depth interviews. A second verbal consent was solicited from the researcher prior to the interview in order to explain the purposes and uses of the study. All of the interviews were recorded and transcribed. In addition, several persons with severe intellectual disabilities were included in this research project, one in the hospital service for those who had often left home for the first time, and two in the medical-care home. In the case of the persons with severe intellectual abilities, the same process was followed, although the researcher spent considerable time before the interview in order to explain clearly the uses and purposes of the research and the recording of the interviews and the retranscriptions to ensure that they fully understood and agreed to the interview process and its analysis.

### **2.3 Methods of Recruitment and Data Collection**

Participants were sourced among severe refractory epilepsy patients who lived full-time at the care institution. They were chosen based upon their willingness and capability to participate rather than age, seizure type and/or psychiatric comorbidity. This was for two reasons. Firstly, because this study used qualitative methodologies, it would have made it challenging to make meaningful conclusions based upon this type of criteria due to the relatively small selection of patients. The second reason was because of the focus of the research, which sought to better understand refractory epilepsy patient conceptions of their empowerment. It was thus preferable to gather a diversity of patient profiles and to analyze these contributions together to find common themes. These patients did however share however many common points: they had severe refractory epilepsy, they lived full-time at La Teppe due to the severity of their epilepsy, and they all had difficulties with finding appropriate employment due to the severity and unpredictability of their condition. It may be helpful in future research to distinguish among seizure types and/or other factors to understand if there are differences among different profiles of patients.

The patients and healthcare providers interviewed were sourced both directly and indirectly (using a snowball methodology [9]) by healthcare providers or the researcher. For instance, after introduction to patients in the hospital services during the focused ethnography stage of the research, several participants directly expressed their willingness to participate in the interview stage to the researcher or to a healthcare provider in the service. Other patients were sourced by healthcare providers who recommended certain patients to be interviewed based upon being able to adequately communicate with the researcher and/or being well enough (psychologically and physically) to participate. They were not necessarily those who agreed with their treatment plan or had a positive experience at La Teppe. Several patients also told other patients about the research and were recruited to participate in the interviews in this manner. Participants were free to leave the interviews at any time: for example, due to conflicting activities, two participants who had initially volunteered dropped out of the interview phase.

The healthcare providers were recruited in the same manner: they either directly volunteered for participation during the focused ethnography stage of the research, depending on their availability to participate and their specific roles in the service, or were recommended by other healthcare providers due to their specific roles or functions in the service or at La Teppe as a whole.

Interviews of both patients and healthcare providers lasted on average one hour. Interviews were recorded and retranscriptions were anonymized post-interview. In parallel to the recordings, the researcher also kept a field notebook during the interviews and the focused ethnography stage to record key words, surprises, and non-verbal expressions in order to better inform the analysis.

## **2.4 Interview Methods**

A preliminary investigation of the notion of patient empowerment was conducted through review of international literature, as well as informed by a one-year period of focused ethnography in two epilepsy patient associations in Lyon and in Grenoble, France, to better understand the specific difficulties of epilepsy from the patient's perspective. The interview guide was first tested with these patients, which enabled the interview grid at this stage to be narrowed from 7 to the 2 principal questions. It was found in the pilot testing phase that the two in-depth interview questions was broad enough to solicit the patient's views on their empowerment and had the added advantage of enabling the participant to lead the discussion on the issues that interested them. In-depth qualitative interview methodologies are particularly suited to solicit patient contributions as they allow participants to articulate their illness experience in their own words. In addition the methodology allows the discussion to flow from participants' responses, reducing the influence of the researcher in the themes that emerge.

Field research was conducted at La Teppe from February – May 2018 and consisted of two stages: 1) a focused ethnography stage; and 2) an in-depth interview stage. In the focused ethnography stage, the researcher spent several full days in the three services in which interviews were conducted, as well as visited several of La Teppe's workshops and protected workplaces and observed consultations with neurologists. The purpose of the focused ethnography research stage (as informed by Bikker et al.[10] and Rashid et al.[11]) was to better understand the environment of the institution and as well as to witness how actors (healthcare providers and patients) lived and worked in the service. It also helped inform the discussion with the patients as it gave the researcher the context of the healthcare plan at La Teppe, the specific needs of their patients, and the specialties and roles of the healthcare providers in each service.

The two questions asked to patients were:

- 1) Please tell me about your epilepsy?
- 2) What do you understand by patient empowerment?

Follow-up probes [12] were used depending on participant responses, including asking about their opinions and feelings about their medical care, their family environment, and what patients wanted to achieve in their lives despite their epilepsy.

The healthcare provider interviews had the same format and questions, although the questions were slightly changed as the interviewee was a healthcare provider rather than a patient. The main purpose of the healthcare provider interviews was to better understand the specific healthcare plan at la Teppe, as well as to understand the differences between their ideas on empowerment and those of their patients. The two questions asked to healthcare providers were:

- 1) Please tell me about your work at La Teppe?
- 2) What do you understand by patient empowerment?

As with patient interviews, follow-up probes were used at various times of the interview process to help understand the motivations, feelings, and opinions of the interviewees.

## **2.5 Thematic Analysis**

The analysis relied on both primary (the fieldwork) and secondary material (literature review). The primary material consisted in the notes taken during the focused ethnography and interview stages and the recordings and the transcriptions of the interviews.

The data was analyzed by an intuitive process of thematic analysis [13]. This included looking for and investigating themes by examining the data in as many ways as possible, which included reading and rereading the interviews/field notes, relistening to the interview transcriptions, looking for emerging themes, reading international literature on the topic to spot correlations/variations, etc. The thematic analysis also took into consideration how and in what way the theme was discussed. Once identified, certain phrases were regrouped and compared to better understand the phenomena, but also to compare contradictory or complementary themes. Particular attention was paid to what sprang to mind first when the patient answered the two in-depth questions. Healthcare providers and patient contributions were analyzed separately in order to avoid bias.

As a last step in the analysis, the researcher constructed a certain number of narrative cases out of the patient interviews to better understand the patient's responses. Having read the interviews a number of times, it was

obvious that these interviews were “filled with stories” as Byron Good has described in his own research on epilepsy [14]. These stories were often the best means of analyzing the patient contributions, because they were situated in their environment, their temporalities, and in their relationships with others. They also allowed the researcher to analyze what was important to patients in these stories through their narrative emphasis.

Age and gender differences were taken into account in the analysis; however, this was not found to be the main criteria affecting patient responses. It was also not relevant to distinguish in these interviews according to the education level/profession, as most of these patients were unable to work due to the refractory nature of their epilepsy or their inability to find an employer that would accept them. Most had also experienced difficulties in finishing secondary school and/or vocational training due to the severity of their epilepsy.

### 3. Results

19 refractory epilepsy patients and residents (8 males and 11 females) in the three hospital services participated in the interviews. 13/19 of the research participants was in the age range of 20-25 and came from the two hospital services geared toward young persons. This selection was a reflection of the specific healthcare plan of the establishment, which takes young adults in order to help them develop a personalized project, which often involves working in a protected work environment. However, in order to have a more holistic understanding of empowerment at La Teppe, 6 patients were also sourced from the medical care home on site. These persons were slightly older than the other patients, with two in the age range of 30-45 and four in the age range of 45-60. Because they were in a medical home, their project was no longer focused on working; however, most stayed active by participating in therapeutic workshops offered by La Teppe.

The thematic analysis revealed three main themes in patient conceptions of empowerment: being healthy, practical reason, and affiliation. The main factors affecting these perspectives was whether or not their epilepsy was stabilized, how autonomous they could be in planning their lives due to their condition, and whether their relationships with others (healthcare providers, families, friends, other patients) were conflicting or supportive.

<b>Table 1: Themes of Patient Definitions of Empowerment</b>		
	<i>Patient Definition</i>	<i>Persons Involved</i>
<b>1. Becoming Healthy</b>	Stabilizing seizures	Patient, doctor
<b>2. Practical Reason</b>	Adaptation needed for an active life in society	Patient, social educators, doctor, family
<b>3. Affiliation</b>	Facilitating relationships with healthcare providers, families, and other patients	Doctor, family, other patients

#### 3.1 Becoming Healthy

For refractory epilepsy patients in this study, being or becoming healthy was defined as the possibility to stabilize seizures. As all participants interviewed had refractory epilepsy, however, their definitions of stabilization varied: it could include completely stopping their seizures, reducing them to the extent possible, and/or understanding when and in what circumstances they occurred.

Patients who were not able to find a satisfactory means of either stabilizing or limiting their seizures spent more time developing experiential knowledge independent of the doctor’s expertise. Their means to do so included acquiring knowledge of their bodies and finding individual ways to limit seizures, such as reducing stress, practicing sports or art. Some even considered it akin to their treatment regimes. As one patient expressed it, “*sport is a good thing...I consider it a good medicine.*” These forms of experiential knowledge were not necessarily shared with their doctor as some patients believed it to either be irrelevant to treatment planning or because it belonged to their private domain. In addition, as it enabled self-control of their seizures, it was also a means of exerting their autonomy outside of the doctor’s office.

#### 3.2 Practical Reason

Practical reason remains central to patient perspectives of empowerment at La Teppe. Despite complex forms of epilepsy, coupled with behavioral, psychological, and sometimes even learning development problems that have prevented them from attending regular schooling and integrating non-protected workspaces, most were capable of thinking critically about and planning what they wanted in their lives. According to one patient, empowerment means that, “*I’m going to envisage my life. I am going to make my own choices.*” This notably involved thinking critically about what adaptation they needed to envisage their life — and future — in society in a realistic

perspective, even when seizure stabilization was not fully possible. Developing and using their practical reason notably centered on thinking about what kind of profession they could integrate, but it also involved actively planning their private lives, including love, friendship, and family relationships, as well as hobbies and sports activities.

However, when patients could not gain a certain amount of self-control of their seizures, this also affected their abilities to plan their lives. For instance, several persons interviewed said they were waiting to stabilize their epilepsy to be able to plan what they considered “real” projects, such as working. This meant that without seizure stabilization, they often put their lives on hold. However some also maintained that they could be healthy – in spite of seizure reoccurrence – if they could adapt their life projects to the constraints of their epilepsy. Therefore empowerment for these patients was also a question of adaptation.

### **3.3 Affiliation**

From the patient and resident perspective at La Teppe, affiliation was central to their idea of empowerment: being able to enjoy positive relationships with healthcare providers, families, and other patients was an important factor in planning and taking advantage of opportunities in their lives.

#### **3.3.1 The Doctor-Patient Relationship**

The healthcare alliance remained an important means for patients to be empowered. They understood healthcare decision making in relational terms and sought to cooperate with their doctor and/or with family members to make decisions about their care. As one patient expressed it, *“we speak together. We speak together before taking a decision.”* However, the ways to participate in the consultation varied for patients both depending on their individual capabilities as well as their perceptions of their role: this could mean proposing a treatment to their neurologist, sharing experiential knowledge (side effects of treatment, a record of seizure activities, knowledge of their medication), and/or discussing the proposed treatment plan with their families and/or other patients. For instance, one patient defined empowerment as joint decision making with her doctor and family: *“for me it’s when they (doctors) make me proposals...and either I tell them for instance that I would like to eliminate a medication or I let them or my parents decide.”*

In all patient descriptions of their healthcare, a supportive relationship with their doctor was sought. None described making decisions independently of the doctor’s expertise, nor a desire to do so. Those who had more conflictual relationships said they had sometimes to “insist” to have their voices heard; however, their goal was still to work with the healthcare provider toward a successful treatment plan. In addition, not all patients wished to be active decision makers in the consultation, and those with the most difficulties often regulated this role to their doctor or family; however, even these patients stressed the need for open dialogue with their healthcare provider. They notably expressed the need to have information about their treatment explained to them in an accessible manner so that they could better understand and be willing to adhere to the treatment plan.

#### **3.3.2 The Role of the Family**

Another important relationship for patients and residents to cultivate was with their family members, as these persons played a pivotal role in their life projects. However, these relationships were often conflictual due to overprotection. Most persons interviewed said that overprotection often led to an *in-capability* to plan their lives but also to relational problems with their family members who had to deal with the burden of dependence. Although overprotection is common in persons with epilepsy, its potentially detrimental effect has not been extensively researched [15]. However, from the patient’s perspective at La Teppe, empowerment encompassed a way to limit overprotection by family members. 13/19 patients interviewed specifically cited this as an important factor in their empowerment. Indeed one of the reasons they chose to come to the institution was to develop independence from their parents and/or other family members. They called La Teppe their “escape route” or the “place where they felt free” as it provided a means to develop their capabilities without the intervention of family members.

#### **3.3.3 Patient-to-Patient Affiliation**

Being empowered was also described by patients as the *capability to assist other patients and doctors*. This included both through social support and help with clinical research. Patients who had the most difficulties in achieving stabilization in particular emphasized their role as “helpers.” One of these patients for instance defined empowerment as, *“advancing for myself, but also advancing for others later on...you’re moving forward the future of epilepsy...for yourself, but for others firstly.”* Another patient described the importance of social relationships in living well with her epilepsy at La Teppe and claimed that it was a facilitating factor in reducing her seizures. What this result suggests is that patients do not only understand empowerment as a means to help



themselves (in order to achieve greater autonomy, as some definitions currently propose), but also see it as a way to contribute to society by helping others.

#### 4. Discussion

The current study aimed to develop a new framework of patient empowerment based upon the refractory epilepsy patient's perspective. Patient responses from the medical-social center in which this research took place focused on the themes of being healthy, developing their practical reason, as well as developing facilitating relationships with others (family members, healthcare providers, and other patients). These results can be explained by the setting in which this research took place, as all patients had severe refractory epilepsy, which meant that they had to rely on considerable assistance from others. They therefore viewed healthcare decision making mostly in relational terms, which involved the active support and guidance of healthcare providers, families, and other patients. In addition, due to recurrent problems of developing autonomy in planning their life projects due to the complexity of their epilepsies, their ideas on empowerment also went beyond their medical care and were focused on gaining capabilities to be active in their overall life projects and to build supportive relationships with others.

##### 4.1 Patient Empowerment and the Capabilities Approach

The patients interviewed in this study, who were in the age range of 20-60 and interviewed in a medical-social center in France, have perspectives that align with the capabilities approach (CA). Originally developed by economist Amartya Sen [16] and conceptualized in philosophy by Martha Nussbaum [17], the CA is a goods based approach to social justice, which seeks to inquire into the real opportunities individuals have in their lives. The CA is interested in what the individual person can *be* and *do* (their capabilities). The approach provides a criticism to utilitarian approaches of well-being, which aggregates well-being on a large scale. It advocates instead that persons must be considered individually because they are sources of agency and worth in their own right. Theorists advocate it as a liberal approach to justice, because it recognizes significant differences among peoples and their right to decide what is the good life. The approach is therefore particularly relevant to a person-centered approach to healthcare, in which active participation of the patient is solicited but their right to autonomy respected [18]. The approach however recognizes the need for a facilitating environment to enable persons to exercise their choices, by which they mean the persons and resources needed to help persons develop their capabilities. Therefore while the approach recognizes the right for persons to decide what is the good life for them, it also invests in considerable assistance (a facilitating environment) to enable them to arrive at a certain threshold of choice.

This need for a facilitating environment is the main distinction from current approaches to empowerment described in the introduction. What patient contributions showed is that they actively needed and sought the assistance of healthcare providers, their families, and other patients, to be empowered, which is a reflection of a relational autonomy approach. The term relational autonomy recognizes that persons are socially embedded and that we act within the context of social relationships [19]. For instance, in order to be able to participate actively in the consultation, patients identified the need for a supportive relationship with their doctor. Similarly, patients who were able to overcome overprotection of their family members were more capable of planning their lives by trying out new activities, employment, or hobbies. Thus building their capabilities was a facilitating factor in developing healthy relationships and relieving the burden of dependence.

The CA seeks to respect the individual's autonomy and right to choose what they consider the good life. Developing this capability was also the priority of patients interviewed in this study. For instance, patients sought to increase their experiential knowledge as a way to better control their seizures. While more studies are needed to confirm the efficacy of individual subjective strategies to control seizures [20], from the patient's perspective, this knowledge enabled them greater perceived self-control. In turn, this helped them be able to envisage a life and future in society.

They also sought to develop and use their practical reason, which in particular involved critical thinking about the adaptation they needed to envisage their life — and future — in society in a realistic perspective due to the complexities of their condition. Capabilities philosopher Martha Nussbaum defines practical reason as, "*being able to form a conception of the good and to engage in critical reflection about the planning of one's life.*" [21] Practical reason permits a person to live dignity, to have a life that is "truly human." The capability to search for, and pursue, our version of the good is central to our self-worth. It helps us to scrutinize our values and our judgements about which activities are important to us, giving us the possibility and confidence to plan our lives. In the current study, the patient's priority in empowerment was to develop a *capability set* [22] that would enable them to the design and plan their lives; however they again needed considerable assistance to arrive at a threshold for choice. This was because of all of the participants interviewed had lived through multiple failures:

in education, in professional or family lives, and there was often considerable work to get them to regain confidence to take risks and to envisage what was possible in spite of past failures. This was made possible by the facilitating environment offered by La Teppe's multidisciplinary team and the diverse educational and work activities offered by the establishment, which helped them see what they were able *to be* and *to do* in spite of past failures.

Finally, patients in this study emphasized that empowerment included being able to participate in valuable forms of social relationships, should it be in the doctor-patient relationship, with their families, or with other patients. When these relationships were empowering, they helped patients to live better with their epilepsy and to be more autonomous in planning their lives, as these persons helped them work toward greater capabilities for choice. Martha Nussbaum defines affiliation as, "*being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms social interaction; to be able to imagine the situation of another.*"[21] Our ability to show concern and to empathize is essential to enable us to live together in society, and as the patients in this study have shown, is crucial to their empowerment.

#### **4.1.1 The Capabilities Approach and Disability**

A final distinction in the patient's approach which has not been mentioned in current patient empowerment definitions is the patient's focus on helping others. This idea is however emphasized in the capabilities approach and in the current study. The CA includes persons with cognitive difficulties in its conception of social justice [23] because it believes that stimulating the capabilities of persons with disabilities enables them to be not only *receivers* of care, but also active *givers* of care to others. It therefore defends nourishing capabilities in *all persons*, no matter their threshold for completely autonomous choice. This idea was important in patients' conceptions of empowerment. They notably used their capabilities to bring expertise on disease and treatment to other patients, to participate in experimental research to help doctors, or to be a source of social support for other patients. They thus offered a social contribution through their unique experiences as patients.

#### **4.2 Novel Conceptual Framework for Patient Empowerment**

The patient's perspective of empowerment in this study aligns with the capabilities approach in recognizing the significant role of a facilitating environment and was understood in terms of developing capabilities to make life choices. We therefore define a new framework for patient empowerment as *the patient's capabilities to develop and make their life choices, with help as needed from their support network*. This conception of empowerment is wider than just healthcare and/or treatment adherence. It seeks to help patients to be empowered in their overall lives and includes an active role for others in helping them to achieve a threshold. Assistance may include helping them find the right treatment for their condition, working with them adapt their life projects due to the limitations that their disease imposes, providing adapted education facilities and workplaces, programming which helps family members to overcome overprotection, etc. This proposal is therefore a more holistic concept of empowerment, involving a wider social responsibility in helping patients to live well with their disease. Under this framework, a new task will be given to healthcare institutions: to help nurture patients toward their capabilities *to be* and *to do*.

This conceptual framework, in alignment with the CA and the patient's perspective, has a specific advantage in clinical care: it seeks to promote capabilities in all persons, even those with severe disabilities. As the patients at the Teppe have shown, they are capable of both receiving assistance (*being cared for*) but also of giving assistance (*caring for*). Thus the capabilities of persons with severe disabilities are cultivated in our framework not only because helping them allows them to *receive* care, but also because it enables them to *give* assistance, love, and friendship to others, therefore helping them become active contributors to society. In order to realistically implement this new conceptual framework in the context of epilepsy patient care, it will be necessary to design an integrated system allowing the patient to be at the center of a care and support network. For instance, in the context of clinical care in France, one example is the national resource center for rare disabilities with a severe epilepsy component (FAHRES), which targets patients with severe epilepsy and disabilities. Its mission is to improve the quality of life of these patients and their caregivers and to promote their autonomy and protection. This support requires a particular expertise, knowledge of existing networks and care structures to integrate the patient empowerment approach.

#### **4.3 Methodologies to Incorporate Patient Empowerment in Epilepsy Patient Care**

To ensure the realization of empowerment as capabilities in the context of epilepsy patient care, this section will propose several methodologies to work with the patient. The first methodology is to center the healthcare plan on a personalized project. La Teppe utilizes this methodology in their approach to epilepsy patient care. The advantage of this methodology is that it can incorporate both medical and patient-centered goals, permitting the doctor to have a global view of the patient and for medications and technical solutions to be adjusted to prioritize

the ability of the patient to succeed in their personalized project. Because of the global nature of the project, a diverse range of professionals will be needed to ensure its success (nurses, neurologists, generalists, psychologists, psychiatrists, social educators, and other professionals). In terms of interprofessional coordination, it is advisable to designate both a reference person as the privileged interlocutor between the healthcare team and the patient, as well as to give professionals specific tasks relative to the project and their expertise. The personalized project is not a perfect or failure-free methodology; therefore it should allow for evolution and modification. Patient participation will vary depending on their capability sets and desires to participate; however the maximum capacity for participation in elaboration and implementation should be sought in order to facilitate its success.

Therapeutic patient education (TPE) is another methodology which can be used to facilitate empowerment in complement to the personalized project. It can help the team address *with* and *for* the patient how to achieve their ideas of empowerment through greater knowledge of their illness and of their capabilities. In France, therapeutic patient education programs are proposed by the National Health Authorities and authorized by the Regional Health Agencies. However a national framework [24] has been developed to standardize practices specifically for epilepsy care, which has been supported by the French League Against Epilepsy (FLAE). The framework is focused around five “life periods” which serves as a reference tool for professionals and takes into account various handicaps. As a flexible tool which allows professionals to create and adapt their own programs, patients, family and healthcare providers are actively involved in both its design and implementation. At La Teppe, the methodology has been designed in a person-centered perspective and includes individual and/or group sessions and regular or ad hoc participation of specific professionals depending on the issues identified. It therefore encompasses not only the needs of patients in terms of their medical care, but also facilitation of their personalized project. In the case of psychogenic non-epileptic seizures for instance, specific work on emotions are included into therapeutic patient education programmes to enable psychologists to work with patients to better regulate their emotions [25].

#### **4.4 Limitations**

The current study used a qualitative methodology with a relatively small participant size. This allowed an in-depth study of empowerment from the epilepsy patient’s perspective to emerge; however, for future research it would be relevant to expand this study to a greater number of participants in order to be able to make distinctions between factors such as types and severity of epilepsy, age, education, etc.

#### **Conclusion**

Despite limitations, the current study has helped conceptualize a new framework of patient empowerment as the individual’s capabilities to develop and make their life choices, with help as needed from their support network. Our framework aims to respect the individual patient’s choices about what they want to achieve in their lives despite their illness. However, it has also widened the empowerment discussion on autonomy in order to better understand the ways, means, and persons needed to help the patient achieve it. Clinical care for epilepsy which uses this framework will therefore seek to both improve the quality of life of patients and their caregivers while also promoting their autonomy and protection. Our approach advocates for helping those with the most difficulties to a threshold level of empowerment due to the valuable social contribution they offer to us all. The approach widens our focus from seeing those patients with the most difficulties not only as *receivers* of assistance, to those who will also be empowered in providing care *for* others. Is it not time to see them in this way?

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#### **Declarations of competing interest**

None

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