

Patient empowerment as capabilities: the epilepsy patient's perspective at La Teppe

Highlights

- A new approach to patient empowerment with the capabilities approach
- Practices in epilepsy patient care that seek to empower patients
- Epistemic contributions of epilepsy patients to the empowerment discussion

Abstract

The purpose of the study was to work with a group of refractory epilepsy patients and residents at the socio-medical center of La Teppe (Tain l'Hermitage, France) to develop their definition of empowerment. A qualitative research methodology was used, consisting of focused ethnography and in-depth interviews. The study shows that they understood empowerment as the ability to develop and take advantage of opportunities in their overall lives. This perspective closely aligns with the capabilities approach, a theory of social justice which puts the priority on individual's opportunities to *be* and to *do*. Prioritizing the capabilities of being healthy, practical reason, and affiliation, patients and residents sought to become active in their life planning with and in spite of their disease. This article proposes a new definition of empowerment based upon these contributions. It also shows how the La Teppe, which works with patients and residents through the form of a personalized project, guides patients toward realistic opportunities in their overall lives.

Keywords

Empowerment, person-centered care, capabilities approach, La Teppe, European Association of Epilepsy Centers

1. Introduction

Patient empowerment is a hot topic in public health, medical education, and among healthcare institutions and patient associations. Because of competing priorities and uses, however, definitions continue to vary widely depending on the context and interest group for which it is used (see for example: Roberts 1999, Feste and Anderson 1995, European Patients Forum 2019, etc.). In addition, patient developed definitions are lacking. As healthcare organizations move toward person-centered care (Ekman et al., 2011), it will be necessary to solicit epistemic input from patients themselves into the design of programming on the ground. While medical schools and hospitals experiment with new ideas such as patient educators and/or patient expert programs (Donaghy et al., 2010), patient involvement in medical research (Young et al., 2019) and patient representation in ethical committees (Dekeuwer et al., 2009), those with more difficulties have often been left out of these programs. The research project specifically sought to solicit the contributions of a cohort of patients which face significant challenges to being empowered in order to understand their specific needs and priorities.

The participants in this study were refractory epilepsy patients and residents at La Teppe, the only center in France providing healthcare and medico-social activities for adult epilepsy patients. The center is specialized in complex refractory epilepsy cases and currently has capacities for outpatient and inpatient care (Omay et al., 2017). It is part of the European Association of Epilepsy Centers (Steinhoff et al., 2017) and works actively with several university hospitals centers (CHUs) in France. Patients and residents at La Teppe suffer from drug-resistant 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 medico-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, the activities organized for patients and residents are levers for these ambitions. Therapeutic workshops organized notably support persons to develop greater autonomy and social and professional skills allowing for increased capacities for reinsertion.

2. Methods

2.1. Study design and participants

In collaboration with the Healthcare Values Chair at the University of Lyon III (France), the study was designed as part of a research project on patient empowerment from a philosophical perspective. It was 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.

Research at La Teppe consisted of two fieldwork stages: 1) a focused ethnography stage; 2) an in-depth interview stage. A preliminary investigation of the topic was also conducted through review of international literature and informed by a one-year period of focused ethnography (as informed by Bikker et al., 2017 and Rashid et al., 2019) in two epilepsy patient associations in Lyon and in Grenoble, France, to better understand the difficulties of living with epilepsy from the patient's perspective.

The purpose of the focused ethnography research stage 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 questions asked in the next research stage.

In the second research stage, in-depth qualitative interviews were used to solicit the meanings and understandings of patients and residents of their life with epilepsy. Interviews with caregivers were also conducted to better understand La Teppe's approach to patient care. 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. Although questions are fairly open, the method combines structure with flexibility (Ritchie and Lewis, 2014) by allowing the researcher to probe answers given by participants in order to understand the reasons, motivations, opinions, etc. about the answers given.

Consent for patient and resident participation was obtained in a verbal matter and involved the active support of social workers who explained the uses and purposes of the research to potential participants, who then volunteered for participation in the in-depth interviews. A second verbal consent was solicited from the researcher directly prior to the interview. The interviews were recorded and transcribed if agreed by the participants. The retranscriptions were anonymised post-interview.

In the analysis stage, the data gathered in the two research stages was analyzed by an intuitive process of thematic analysis informed by Taylor and Bogdan (1998). This included looking for and investigating themes by examining the data in as many ways as possible, such as listening to the interviews, reading the interview transcriptions and field notes to spot correlations/differences, undertaking a conversational analysis to understand in what ways the themes were discussed, etc. The interviews between caregivers and patients were analyzed separately to avoid bias.

2.2. Measures

In the focused ethnography stage, the researcher spent several full days in three hospital services, as well as visited several of La Tepe's workshops and protected workplaces. The researcher also observed consultations with neurologists. In the interview stage, 19 refractory epilepsy patients and residents in three hospital services participated. They came from a diversity of educational, work, and age backgrounds and all had complex refractory epilepsy. The ten healthcare professionals interviewed included neurologists (3), psychiatrists (1), nurses (3), and social educators (3). Interviews lasted on average one hour.

3. Results

For patients and residents at La Tepe, empowerment means the ability to develop and take advantage of opportunities in their overall lives. It included but was wider than participation in healthcare decision making and involved developing and maintaining supportive relationships with families, friends and fellow patients, as well as finding ways to be active in the workplace. The multidisciplinary team at La Tepe played a facilitating role in helping them to elaborate and maintain these life choices.

The patient's perspective largely corresponds with the capabilities approach (CA). Originally developed by economist Amartya Sen (2001) and conceptualized in philosophy by Martha Nussbaum (2001), 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). In the approach, governments and their institutions cannot just create opportunities; they also need to create the means for citizens to use them in practice. Failure to secure this for persons is a question of injustice.

The approach provides a criticism to utilitarian approaches of well-being, which aggregates well-being on a large scale. The CA advocates instead that persons must be considered individually, because they are sources of agency and worth in their own right (Nussbaum 2011). 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. Because the approach focuses on stimulating the conditions for *individual choice*, it leaves open how people will choose to use them. Central to the approach is therefore a distinction between capabilities and functioning: that is, we will seek to create the conditions in our societies for people *to be* and *to do* on an individual level (their capabilities) but not their choice of what to do with them (functioning). The approach is therefore particularly relevant to a person-centered approach, in which active participation of the patient is solicited and their right to autonomy respected (Entwistle et al., 2013).

The CA also has the strength of including borderline or difficult cases in its conception of social justice (Nussbaum 2009), which has been largely absent from utilitarian and social contract theories (see for example, Rawls 1997). The approach seeks to nourish capabilities in *all persons*, no matter their threshold for completely autonomous choice. Some persons may never be able to break free from a surrogate. However even those with significant cognitive difficulties can be nurtured toward greater choice. This perspective was particularly relevant for patients and residents at La Tepe. Their priority was to develop a *capability set* (Venkatapuram 2009) that would enable them to the design and plan their lives; however they also needed considerable assistance to arrive at a threshold.

4. Discussion

During their time at La Tepe, patients and residents developed their capability sets with the help of a multidisciplinary team. These capabilities were focused on their overall life choices, with and toward others in society. They included 1) being healthy 2) developing their practical reason 3) affiliation.

4.1 Being Healthy

For patients at La Tepe, being healthy was the most important part of their care plan and their principal motivation to be at the institution. All of the persons interviewed understood being healthy as stabilizing their seizures. However as all of them had refractory epilepsy, their definitions of stabilization varied: it could include completely stopping the seizures, reducing them to the extent possible, and/or understanding when and in what circumstances they occurred. Because of this, the neurologist was a key actor in helping them to become and stay healthy. However, patients also sought to develop their own knowledge independent of the doctor's expertise. As Borkman (1976) has shown, experiential knowledge has several features: it is pragmatic, orientated to the present, and holistic. One of the means for them to actively work toward being healthy was to acquire experiential knowledge in order to find ways to better understand and/or reduce their seizures. While more studies are needed to confirm the efficacy of individual subjective strategies to control seizures (Kotwas et al., 2016), for interviewees, this experiential knowledge enabled them greater perceived self-control of their seizures. In turn this helped them develop and take advantage of opportunities in their overall lives.

However, when patients could not gain a certain amount of self-control of their seizures, this also affected their capabilities 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 does not mean that they were unable to form a conception of the good: on the contrary, they had very specific goals and dreams; however, without seizure stabilization, they often put their lives on hold. In order to plan their lives in spite of seizure recurrence, they needed to adapt their life projects to the constraints of their disease; this was possible for some thanks to the accompaniment offered by La Tepe, which allowed them to try out new projects, activities, and employment possibilities, in order to see what they could *be* and *do* in spite of the refractory nature of their epilepsy.

4.2 Practical Reason

Capability scholar Martha Nussbaum (2011, p. 34) 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.*" 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 the CA. It helps us to scrutinize our values and our judgements about which activities are important to us. It gives us the possibility to plan our lives, as well as to decide which activities should be prioritized among others (Nussbaum 2011).

Practical reason remains central to the patients' and residents' perspectives of empowerment at La Tepe. 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 what they wanted to do with their lives. These conceptions of the good took the form of working, sports, and/or hobbies, but it also involved nurturing their friend, family, and love relationships.

All of the participants interviewed had lived through multiple failures: in education, in professional or family life because of their epilepsy, psychological, and/or behavioral problems. Professionals at La Tepe stated that sometimes a patient's fear of failure was so severe that upon arrival, there was often considerable work to get them to take risks to envisage what was possible in their lives. To develop this capability of practical reason, they often needed the supportive environment offered by La Tepe's multidisciplinary team, as well as the work and

leisure possibilities offered by the institution to both develop the knowledge of what they were capable of doing, as well as the confidence to act on it. If failures made them think they were incapable of working, for example, social workers could encourage them to try again and help them find a new type of workplace in which they could succeed. Developing patients' and residents' practical reason helped them to critically reflect about what adaptation was needed to envisage their life — and future — in society in a realistic perspective, even when seizure stabilization was not fully possible.

4.3 Affiliation

The capabilities approach recognizes that we all live in a wide circle of social relationships and that these can either be facilitating or damaging to a person. 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 of social interaction; to be able to imagine the situation of another.*” (Nussbaum 2011). Our ability to show concern, to empathize, is essential to enable us to live together in society and to participate in valuable forms of social relationships. In the CA, all persons, even those with severe disabilities, 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 the approach not only because development of their *capability sets* allows them to *receive* care, but also because it enables them to *give* assistance, love, and friendship to others. From the patient and resident perspective at La Tepe, affiliation was a facilitating factor in developing and taking advantage of opportunities in their lives, and in enjoying positive relationships with healthcare providers, families, and other patients.

4.3.1 The Doctor-Patient Relationship

The healthcare alliance remained an important means for patients and residents at La Tepe to be empowered. They understood the healthcare decision making in relational terms, and sought to cooperate with their doctor and/or with family members in order to make decisions about their care. However, in order to be able to exercise their capabilities within the consultation, they also identified the need for a facilitating environment. This concretely meant that they wanted to be treated as a person by their doctor (as opposed to an object, or merely as a patient) with rights (but not duties) to decision making in the consultation. However, the ways to do so varied depending on their *capability set* as well as perception of their role in the consultation: 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 before making a decision. However, certain forms of experiential knowledge they developed to control their seizures (in particular leisure or sports activities) were not necessarily shared with their doctor, as it was believed to either be irrelevant to treatment planning or because it belonged to their private domain. As they believed this knowledge enabled self-control of their seizures, it was also a means of exerting their autonomy outside of the doctor's office.

4.3.1 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 both in their ideas of the good and in helping them develop their capabilities. However, these relationships were also 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 detrimental effect has not been extensively researched (Aydemir et al., 2016). However, from the patient's perspective at La Tepe, it remained necessary to limit or stop overprotection by family members in order to plan their lives and develop their capability set. Indeed one of the principal reasons they chose to come to the institution was to develop independence from their parents and/or other family members. They called it their “escape route” or the “place where they felt free” as it provided a means to develop their capability sets apart from overprotective family members.

4.3.2 Patient-to-Patient Affiliation

Being empowered also meant the *capability to assist other patients*. Their way to exert agency is not just as a passive receiver of assistance, should it be from the doctor or the family. It also means exerting agency through helping others. As the CA shows, their abilities to contribute to society are not just as *receivers* of care, but also as active *givers* of care for other patients in ways that *only they* are capable of doing because of the shared connection of their disease. Upon arrival at La Teppe, they often discovered persons like them for the first time. They found themselves in an environment in which epilepsy was the norm, a place where they did not have to fear their epilepsy or experience stigma due to their disease. This facilitating environment enabled them to become active carers for others: they brought expertise on disease and treatment to other patients; they participated in experimental research to help doctors; and they were a source of social support for other patients and residents. This patient-to-patient reciprocity was an important means for them to live well with their epilepsy.

4.4 Proposition of a new conceptual framework for patient empowerment

Based upon these contributions, we propose a flexible and multipurpose conceptual framework of empowerment, which we define as *the patient's capabilities to develop and make their life choices, with help as needed from their support network*. We retain the idea of *capability* in our approach for several reasons. In the first place, we are changing the starting point of our vision of patients: we see them as persons, with their own desires and priorities, and not just as waiting for assistance. Secondly, we have shown that they are striving toward development of their *capability sets*, which will enable them to plan their lives.

This framework will therefore help patients to be empowered in their overall lives, with the support of others as needed and desired by them. This assistance may include helping them find the right treatment for their condition, but also assisting 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 support the patient, etc. The strong call in the CA for a facilitating environment shows us how much we need others not only to acquire but also to mobilize our opportunities. This proposal is therefore a holistic concept of empowerment, involving a wider social responsibility in helping patients to live well with their disease. This also means that we will give a new task to healthcare institutions: to help nurture patients toward their capabilities.

5. Patient Empowerment at La Teppe

This section will elaborate on the methodology La Teppe uses to help patients and residents toward their capability sets. The care plan takes the form of a *personalized project*, which is developed with the patient or resident and the interdisciplinary care team. It has been informed by two laws regulating medico-social centers in France (Law n° 2002-2 and Law n° 2005-102), as well as the contribution of patients through social life councils and patient commissions, which ensures that the rights and needs of patients and residents are at the heart of the organization of the care and support process. It is orientated both toward stabilizing their epilepsy (when possible) as well as giving the resources to help them design and plan their life projects. The word “personalized” specifically means that 1) the patient is the center of the healthcare plan; 2) it is developed *with* them; 3) it integrates the contributions of multidisciplinary healthcare providers to ensure its success.

The contribution of a multidisciplinary team is key. A diverse range of professionals operate in coordination to help them toward their life objectives: between nurses, neurologists, generalists, psychologists, psychiatrists, social educators, and other professionals, the healthcare team practices a global approach to care, taking into

consideration their medical, psychological, and social needs. The interdisciplinary team in each service works together with specific roles and tasks. For instance, social workers are the main professionals tasked with the *life objectives* part of the personalized project, whereas nurses and doctors take the responsibility for the *medical objectives*, and psychologists and psychiatrists with the *psychosocial objectives*. This permits professionals to “be in their professional roles,” giving them the space for well-argued choices among each other based upon their separate areas of expertise. It also means that everyone knows who is responsible for what part of the project, avoiding the collusion of anonymity (Balint 1968). The patient’s responsibility in this process is also clear.

The personalized project is a compromise between the requests of the patient and the capacities for support by the institution, and it has been agreed, discussed, and negotiated before being put into place. Each actor knows the possibilities and the limitations of the support provided. The head of the project is also head of the service, who is usually a doctor in the service. As the success of the personalized project is always the end goal of the healthcare plan, medications and technical solutions are adjusted to prioritize the ability of the patient or resident to complete it. However, as it is not a perfect or failure-free methodology for working together, it also allows for evolution and modification in time and based upon patient experience. Patient and resident participation varies depending on their capability sets and desires to participate; however the maximum capacity for participation in elaboration and implementation is always sought in order to facilitate its success. This process specifically includes nurturing their capability of practical reason, in order to help patients and residents understand what they can realistically hope to plan and achieve with their epilepsy, in particular in the workplace.

The methodology used by La Teppe gives a realistic means for healthcare institutions to support patients toward their capabilities, in particular for those patients and residents with the most difficulties, in the ways and means appropriate to them.

Conclusion

The epilepsy patient’s perspective of empowerment at La Teppe is aligned with the goals of the capability approach. This new conceptualization has several advantages. In the first place, it reflects a person-centered perspective, as it aims to respect individual choices. While this emphasis may be an ideal for some patients, it also reminds us (as healthcare providers, as patients) that the choice which is to be advocated and defended is the patient’s. In the second place, it gives a new task to healthcare institutions: to help patients toward elaboration of their capabilities, and the example of La Teppe showed how an interdisciplinary care team can stimulate these opportunities. Finally, it advocates 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 thus widens our focus from seeing those patients as *receivers* of assistance, to those who are also capable of providing care *for* others. Is it not time to see them in this way?

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Declaration of competing interest

We have no competing interests to declare.

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