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Self-control of epileptic seizures by nonpharmacological strategies

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A B S T R A C T

Despite the unpredictability of epileptic seizures, many patients report that they can anticipate seizure occurrence. Using certain alert symptoms (i.e., auras, prodromes, precipitant factors), patients can adopt behaviors to avoid injury during and after the seizure or may implement spontaneous cognitive and emotional strategies to try to control the seizure itself. From the patient’s view point, potential means of enhancing seizure prediction and developing seizure control supports are seen as very important issues, especially when the epilepsy is drug-resistant. In this review, we first describe how some patients anticipate their seizures and whether this is effective in terms of seizure prediction. Secondly, we examine how these anticipatory elements might help patients to prevent or control their seizures and how the patient’s neuropsychological profile, specifically parameters of perceived self-control (PSC) and locus of control (LOC), might impact these strategies and quality of life (QOL). Thirdly, we review the external supports that can help patients to better predict seizures. Finally, we look at nonpharmacological means of increasing perceived self-control and achieving potential reduction of seizure frequency (i.e., stress-based and arousal-based strategies). In the past few years, various approaches for detection and control of seizures have gained greater interest, but more research is needed to confirm a positive effect on seizure frequency as well as on QOL.

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1. Introduction

Epilepsy is the most common neurological disease, affecting between 40 to 70 persons per 100,000 in the world [1] and between 55 and 60 per 100,000 in Europe [2]. The disease is defined by the chronic and spontaneous repetition of seizures. Among patients with epilepsy (PWE), seizures in 30% remain drug-resistant despite optimal administration of pharmacological treatments [3]. For these patients, curative or palliative intervention (i.e., gamma knife, radiosurgery, thermoagulation, radiofrequency ablation) can be proposed. However, these methods are not accessible for all patients, are not always completely effective, or may be refused by the patients. Interestingly, some patients describe employing certain cognitive, emotional, and behavioral strategies that, in their personal experience, can reduce seizure intensity or even prevent seizure occurrence [4–6]. In particular, clinical features that warn of an impending seizure are especially useful, in order for the patient to be able to use these strategies effectively [7,8]. This review will focus on nonpharmacological strategies developed by PWE that attempt to prevent the consequences of seizures or to control the seizure itself. Various alert symptoms (due to seizure aura, prodrome, or precipitant factors) that patients can use to anticipate seizures will be described. The relationship between anticipation of seizure and self-control of seizures will be examined. Therapeutic possibilities for enhancing anticipation and self-control of seizures in PWE will then be reviewed.

2. How do patients anticipate their seizures?

The unpredictability of seizures is one of the most disabling aspects of drug-resistant epilepsy. It is indeed the reason for elevated risks of major accident or death, feeling of loss of control, psychosocial handicap, and need for long-term antiepileptic treatment [9]. Predicting seizure occurrence could have a positive impact on quality of life (QOL) and could increase the efficacy of pharmacological and nonpharmacological treatments [9]. Many patients report experiencing subjective manifestations that may be used as alert symptoms to anticipate seizures. These can involve sensory, behavioral, cognitive, or emotional changes and are specific to each individual [10]. They include “auras” that precede...
seizures from a few seconds to a few minutes and “prodromes” that are temporally distinguished from auras, since they appear a few minutes to two days before the seizure and may last from 30 min to several hours. Patients also report identification of precipitant factors that appear to trigger their seizures [11] (Fig. 1).

2.1. Auras and prodromes

Auras, which are of course the first subjective semiological features of the seizure, may be experienced by between 45% and 65% of people with partial epilepsy [12]. These are related to objective EEG abnormalities and characterized by various symptoms that are produced according to the type of epileptic discharge and the anatomical localization of seizure onset. These include neurocognitive changes (such as déjà vu), emotional changes (anxiety, fear), sensory changes (somatosensory, olfactory, gustatory, auditory, or visual), or viscero-autonomic features (e.g., epigastric sensation, feeling of retrosternal oppression, and tachycardia).

Prodromes are recognized by between 6.9% and 39% of PWE [13–15]. These are heterogeneous between patients and are characterized by diverse clinical features including behavioral changes, cognitive disorders, mood changes, fatigue, sleep disorders, headaches, gastrointestinal symptoms, changes in appetite, and altered voice [14,15].

While auras are part of the ictal event and participate in the detection of the onset of the seizure, prodromes are preictal, unaccompanied by objective EEG changes, but could also be used as alert symptoms by the patients [16].

2.2. Precipitant factors

Subjective identification of at least one potential triggering factor affecting the likelihood of seizure onset has been reported by 60 to 70% of patients [17,18]. For example, 28% of patients (from a cohort of 104) reported that 100% of their seizures were linked to a precipitant factor. In addition, 33% reported that the majority (75 to 99%) of their seizures were triggered by a precipitant factor [11]. Stress [19], stressful events [20], sleep deprivation [21], symptoms of depression, symptoms of anxiety, and fatigue [22–24] are the most frequently reported precipitant factors. Stress is the most frequently reported by PWE in general [25] and, more particularly, those with temporal lobe epilepsy (TLE) [11,17]. Lanteaume et al. [26] use the term “emotional vulnerability” to define this particular sensitivity to stress as a seizure precipitant in PWE. It appears that patients who report high levels of stress are more likely to be able to predict their seizures than patients with lower stress levels [27]. However, the existence of specific neurobiological factors underpinning emotional vulnerability remains uncertain. Positron emission tomography (PET) data obtained in patients with TLE with emotional vulnerability in comparison with patients not reporting sensitivity to stressful events depicted more marked changes in amygdala-related networks [28]. Moreover, patients who reported seizure precipitants tended to have higher levels of anxiety than those who did not report any [29]. A high level of anxiety could itself act as a precipitant factor through neurophysiological and hormonal alterations related to the impact of stress hormones on neuronal excitability and thus seizure susceptibility [30]. On the other hand, patients with
high anxiety levels could also be more likely to seek explanations for the onset of their seizures. Moreover, it is difficult to determine whether experiencing stress or anxiety is the seizure precursor or whether it is rather the feeling of an impending seizure that increases the level of stress and anxiety; indeed, both mechanisms could coexist.

2.3. Alert symptoms and seizure prediction

Predicting a seizure through identification of a prodrome remains rather poorly characterized despite good sensitivity for positive prediction in one study, which found specificity of 31.9% and sensitivity of 83.2% [22]. The marked interindividual variability of prodromal expressions makes them too poorly specific for clinical use of seizure prediction [7]. Furthermore, studies assessing the predictive value of prodromes are usually based on paper-based diaries in which the precursors can be identified retrospectively. Patients who experience prodromes may more often tend to retrospectively interpret certain subjective manifestations as having been symptoms of an impending seizure. To overcome this bias and ensure the prospective nature of prodrome prediction, Maiwald et al. [31] used personal digital assistant electronic devices (PDA) in which time of entry for each event (ictal and preictal) could be controlled. This allows more precise evaluation than paper-based diaries despite the fact that seizures were not objectively confirmed by EEG recording. This in fact showed no relation between prodrome and seizure, with predictive values that did not exceed chance. Patients therefore reported the existence of predator symptoms of epileptic seizures but were not necessarily able to use these to detect seizures prospectively. However, in an e-diary study, Haut et al. [32] noted a sensitivity of about 50% and specificity of about 95% for subjective prediction in patients reporting self-prediction ability. Interestingly, they reported an interindividual variability in self-prediction accuracy associated with levels of self-awareness of mood and premonitory features.

Despite mixed results on the effectiveness of self-prediction, the data remain generally encouraging. However, no study to date has established a link between prodromes and precipitant factors and seizures with EEG evaluation. The predictive value of these subjective alert symptoms has thus never been objectively demonstrated [7]. This lack of objective effectiveness should not, however, diminish the value attributed to the subjective point of view of the patient, since this remains very pertinent from a clinical point of view. Indeed, this subjective perspective is important given the role of perceived self-control in the improvement of quality of life for PWE [33]. In addition, nearly 90% of patients believe that it is important to find ways to predict seizures [34]. Prediction ability might therefore be trained in some patients in order to increase its specificity, in order to implement effective prevention strategies within an adequate time window.

3. Does anticipation help to control seizures or to prevent their consequences?

The clinical relevance of anticipation is for the patient to be able to use this prospectively to control the seizure. The time window in which anticipation is possible is therefore crucial, in order to have sufficient time to take effective measures. Therefore, considering the delay between the different alert symptoms and seizure onset, patients use preventive or control strategies in order to decrease the risk of potentially adverse consequences of the seizure (e.g., a fall) or to implement strategies in order to abort the seizure itself. The precipitant factor is often temporally too distant from seizure onset to allow implementation of a control strategy of seizures; on the other hand, auras are generally too close, and by the time the patient recognizes the aura, it is too late to implement any strategy. Although prodromes may not apply to large numbers of patients, this timeframe seems to be adequate to implement control strategies in the most efficient way possible. In fact, the type of strategies used by patients appears to depend on the type of alert symptoms they recognize.

3.1. Behavioral, emotional, and cognitive strategies

Despite the low specificity of the predictive value of alert symptoms, it appears that patients use these as alert symptoms to anticipate their seizures and spontaneously develop preventive or control strategies [4,5,10,24,35]. Nearly 80% of patients with prodromes, who attempted to prevent or stop their seizures using personal strategies, relate doing it successfully [10]. The various spontaneous strategies used by patients can be classified as behavioral, cognitive, or emotional.

Behavioral strategies tend to be prevention strategies. They mainly consist of preparing for the consequences of the seizure (sitting or lying down, alerting someone). They also concern adopting a lifestyle supposed to prevent the occurrence of seizures (no smoking or drinking alcohol, regular sleep). Finally, they sometimes consist of trying to stop the seizure itself or its precipitant (drinking, breathing fresh air, breasting deeply). Indeed, regardless of attempts to control the seizure, the experience of an aura has the advantage of alerting the patient to an impending seizure and promoting the adoption of safe behavior, producing a significant reduction in accident risk [36].

Cognitive strategies tend to be control strategies. They mainly consist of concentrating intensely or focusing attention on something else and thus concern mainly the control of the seizure itself. Between 20% and 56% of patients who experience auras or prodromes use these symptoms to try to control their seizures [35,37]. Of these patients, 70% believe that their strategies are effective [35]. Finally, emotional strategies consist of relaxing, thinking positively, or adopting a neutral emotional state. Emotional strategies tend to be more often used when patients have a general sense of awareness of a seizure risk (e.g., stressful events) than with immediate sense of awareness (e.g., auras) [5]. Patients with self-reported stress-triggered seizures frequently report (57%) attempts to relax to prevent or stop the seizures triggered by stress, and 88% of them believe that this method can reduce the frequency of seizures [27]. Those who did not report stress as a seizure trigger are less likely to try these methods (25%) [27]. The use of seizure control strategies is connected to the degree of seizure susceptibility awareness: the more that patients are aware of a risk of seizure, the more they tend to use strategies to try to control the seizure [5]. Thus, experiencing alert symptoms prior to a seizure is connected to the idea that a seizure could be voluntarily controlled.

3.2. Perceived self-control (PSC) and locus of control (LOC)

The ability to voluntarily control seizures is linked to the concept of perceived self-control (PSC). Perceived self-control is a psychological construct defined as the belief that one’s own capacities and actions can influence one’s environment, situation, or a desired result [38]. The PSC is constructed from the concepts of self-efficacy and locus of control (LOC). Self-efficacy refers to the perception of the subject’s own capacities to perform an action or achieve a goal [39]. The LOC is an a priori assessment of what determines the success or failure of an action based on self (internal LOC) or external factors (external LOC). External LOC includes two kinds of determinants of what happens to us: chance (external chance LOC) or other people (external powerful others LOC). The LOC impacts upon our PSC over what happens to us. When the LOC concerns the success or failure of an action on health, the usual term is health locus of control (HLC). This is a determinant of the behaviors that a person will adopt about his or her health and of the degree of PSC over this. While the LOC and HLC correspond to a stable personality trait, PSC is defined as a flexible element, concerning a specific situation, depending on the interaction between the LOC (and HLC) and the individual’s environment at a given time in a given context [40]. Perceived self-control is constructed by experience and facilitated
by learning [41]. In epilepsy, high internal HLC is associated with greater PSC over seizures [42].

The recognition of alert symptoms increases awareness of seizure risk for patients and can augment the PSC of seizures. The relationship between awareness and seizure self-control has been investigated for auras and precipitant factors but not yet for prodromes. Since auras are ictal events, the time between them and the full-blown seizure is generally very short (seconds rather than minutes). It might therefore be difficult for the patient to use aura symptoms to sufficiently anticipate and control the seizure onset. More frequently, auras are used to prepare for the seizures and to employ prevention strategies (i.e., warning family members, lying down to prevent a fall). However, in previous research, the experience of auras has been associated with two different HLC profiles in drug-resistant epilepsy. It has been reported that patients who have auras tend to have a more internal HLC and suffer less from depression than those who do not experience auras [43]. It seems logical that having an aura could not itself be the direct determinant of the HLC. Lohse et al. [12] hypothesized that it is not the aura that determines the feeling of control but the ability to use it as an alert signal to prepare for the seizure. Although these authors did not observe any differences in terms of HLC between people with and without auras, they showed that, within the group with auras, those who claim to be able to act on their seizures by identifying an aura have an internal HLC that is significantly higher than those who cannot (p = 0.006). Interestingly, no difference was observed in anxiety and depression, either between the groups with and without auras or between those who respond to auras and those who do not react. The group who reacted to auras only used behaviors that prepared for the seizure, not strategies to control the seizure onset.

Identification of precipitant factors is associated with a higher perception of seizure control. All patients with a high score on PSC scales identify at least one precipitant factor, and about 80% can identify more than one factor. Thus, they can identify seizure trigger situations in daily life so as to avoid them and seek lower-risk situations of seizure onset. In contrast, less than 40% of patients with low scores can identify several precipitant factors, and 33.3% cannot identify any [42].

Velissaris et al. [44] identified two categories associated with PSC over seizures: limited loss of control and pervasive loss. Patients affected by a pervasive loss of control appear more likely to develop cognitive and behavioral coping strategies than those with a limited loss of control. This might be explained by a greater need for regaining a feeling of control in patients with a pervasive loss. However, patients with high internal HLC frequently have well-controlled seizures, whereas patients whose HLC is external, and who score highly on the Powerful Others subscale, tend to have poorer seizure control [44].

3.3. Perceived self-control of seizure, anxiety, depression, and quality of life (QOL)

Many epidemiological and clinical studies have shown a high rate of PWE suffering from psychosocial problems directly related to emotional and cognitive deficits [45]. Kanner et al. [46] estimate a lifetime prevalence of depression of between 30% and 35% in PWE. Depression is one of the principal predictors of poorer QOL [47]. The link between depression and QOL is mediated by negative illness perceptions [48]. Beliefs held by patients about their disease determine their sensitivity to depression and its impact on QOL. Seizure frequency is another important factor of decreased QOL in epilepsy [49,50]. Moreover, anxiety is also a significant factor in decreased QOL [51], and the severity of anxiety is related to a decrease in QOL [52]. Anxiety in epilepsy can be produced by neurobiological mechanisms [30,53], pharmacological factors, and psychosocial issues including seizure worry [51,52,54]. In particular, seizure worry has been found to be the most important factor affecting QOL, apart from depression [47].

Patients with higher scores on Powerful Others external HLC have higher anxiety scores, which is not the case for internal and Chance external HLC [55]. The HLC is also likely to be crucial in depression levels in epilepsy since low scores on depression scales are associated with higher internal HLC scores and lower external Powerful Others HLC scores. In addition, patients who have a high PSC could be less subject to anxiety and depression [42]. The PSC over illness is a good predictor of patients’ resilience. Low perception of control over seizures is associated with vulnerability in PWE. Those who demonstrate greater control also show more resilience and report a higher QOL than those with low PSC [33]. The way in which PWE perceive they are able to control their seizures and health seems to strongly affect their well-being and QOL (Fig. 2). In conclusion, people with high PSC report being able to abort only some of their seizures [24], but this feeling of control seems to contribute greatly to QOL. Therefore, PSC might be a pertinent aspect to enhance in PWE, independently of objective seizure control.

4. How can seizure prediction be improved with external supports?

Identification of prodromes would appear to be the best option for anticipating seizures. As preictal events, they also represent a possible source for identifying precursor physiological signs [56]. Although alert symptoms could potentially help to anticipate the onset of seizures, it appears that they are not necessarily reliable because of lack of sensitivity, in that not all patients experience auras. There is increasing interest in research into external supports for patients to detect or predict seizures such as Seizure-Alert Dogs (SADs) [57], seizure detection systems by biosensors [58], and e-diaries [59] in order to enhance patients’ own perceived detection or prediction strategies. These external supports may help to enhance the detection or the prediction of seizures. Detecting seizures concerns the detection of ongoing seizures, whereas predicting seizures concerns the identification of preictal or prodromal changes that occur minutes, hours, or days prior to seizures [58].

4.1. Seizure-Alert Dogs (SADs)

Based on reports of pet dogs that could spontaneously alert their human caregivers to an oncoming seizure, SADs have been trained to give warnings to PWE. However, SADs essentially detect tonic–clonic seizures, and exactly what changes SADs detect is unknown. It is speculated that SADs might detect changes in human behavior, changes in heart rate, or olfactory cues, but they might also detect nonepileptic seizures [57]. No study has been designed to objectively measure the effectiveness of SADs on seizure detection or prediction by EEG evaluation. It is therefore difficult to determine if SADs are detectors or predictors of seizures. Unexpectedly, a reduction of seizure frequency has been observed in patients assisted by SADs [60]. This effect could be indirect, via reassurance and stress reduction. It is also possible that once alerted, patients then implement control strategies, thus reducing seizure occurrence. On the other hand, given the positive impact of pets on physical and psychological health [61], the benefit in terms of seizures could be related to the mere presence of a dog in the patient’s everyday life. No study to date has yet compared the effect of SADs versus untrained dogs on seizure frequency to clarify this point.

4.2. Biosensor detection systems

In addition to the subjective experiences of patients, many clinical and physiological data highlight the existence of objective preictal physiological changes. Through analysis of scalp and intracranial EEG, accelerometry, electrodermal activity, functional imaging, electrocardiography, and motion sensors, many teams are trying to develop seizure detection and prediction systems [58]. The best performances have been shown by scalp and intracranial EEG and by accelerometer. In self-reported opinions, 90% of PWE state that the development of detection devices is an important goal, with a preference for high sensitivity rather than specificity [34]. With devices based on EEG features,
sensitivity is between 65% and 100% for predicting a seizure from a few seconds to 10 min before its onset [58]. The most practical device in everyday life for the patients is presented in the form of a wrist-worn biosensor bracelet measuring electrodermal activity and accelerometry. It shows a sensitivity of 94% in seizure detection [59]. The use of predictive EEG systems is not well-suited to outpatient use [58], so currently, the effective biosensors for patients are mainly detection methods. Biosensors are potentially useful devices for some patients who do not experience alert symptoms. Biosensors could also be useful in patients with aura or prodrome, to better recognize their own alert symptoms. Finally, biosensors present the main advantage of anticipation so that patients can adopt prevention or control strategies. These assumptions need to be further investigated to confirm the possible efficiency of biosensors in identifying alert symptoms and adopting prevention or control strategies.

4.3. E-diaries

E-diaries are another external support that can increase anticipation of seizures and possibly help with seizure control. Many patients note their seizures on paper-based diaries, but this method presents several disadvantages: patients do not necessarily have them at hand after every seizure, they do not always adhere to them for long-term evaluation, and they may not be encouraged to notice additional details (i.e., duration or severity of seizures, menstrual cycle, missed or extra medication, precipitant factors, and mood). To overcome these disadvantages, various purpose-made electronic seizure diaries have been developed in which precise entries can be made by the patients [59]. Such electronic versions are associated with better compliance and graphs are easily generated from the data, which more readily allow comparison of seizure occurrence with other events, thus facilitating recognition of precipitant factors and increasing patients’ sense of control and self-efficacy. E-diaries can be used as a seizure prediction method since patients who use them might be able to develop their self-prediction capacities. Despite the fact that these studies are not founded on EEG confirmation of seizures, they remain more objective than paper-based diary studies, since they collect data prospectively.

5. How might patients better control their seizures?

In cases of drug-resistant epilepsy, patients can develop spontaneous strategies to control their seizures. Various methods have been investigated to help patients to develop effective strategies including behavioral, cognitive, or emotional approaches [6]. These can target stress management, when stress and emotional distress are precipitant factors, or aim to control the seizure onset itself. The various methods appear to have an effect on both patient well-being and seizure control. Stress and emotional distress management are mainly targeted by cognitive–behavioral therapy (CBT) potentially associated with “mind–body” approaches, while control of seizure onset is rather targeted by behavioral approaches and cognitive methods based on arousal changes [64,65]. Among the latter approaches, a group of methods based on biological retro-control, collectively referred to as biofeedback or neurofeedback, represent a noninvasive biobehavioral intervention with therapeutic potential [66].

5.1. Stress-based approaches

Cognitive–behavioral therapies (CBT) involve the examination of the relationship between thoughts and emotions and aim to provide strategies for changing maladaptive thoughts. In epilepsy, they focus on perception of HLC and aim to increase the feeling of PSC of seizures. While a certain efficacy of CBT has been shown on well-being, its effect on seizure control is less clear [65]. Cognitive–behavioral therapies can be associated with the so-called “mind–body” approaches. These mainly concern mindfulness, relaxation therapies, meditation, and yoga [67]. All these methods are based on the observation of one’s own mental state and physical activities, using attention training and process-oriented awareness. They are known to reduce perceived stress. In the management of refractory epilepsy, mindfulness [68] and yoga showed an effect on well-being and seizure frequency [69]. The mechanisms underlying the decrease in seizure frequency are not yet known; this might be explained to some extent by a greater awareness of bodily sensations and thoughts associated with epileptic seizures, thus allowing optimal anticipation. The effect on well-being and stress management
might also be an explanation resulting in a reduction of precipitant factors.

5.2. Arousal-based approaches

Operant conditioning, aura interruption, and systematic desensitization are methods especially focused on seizure control. Control methods based on operant conditioning trace back to the 1970s and rely on the principle of reward/punishment in response to absence/occurrence of seizures [70]. The two other methods intervene in preictal and ictal periods. They are based on shifting attention when alert symptoms are recognized [71]. Their efficacy on seizure control is not well-established [65].

Derived from an operant conditioning approach using positive physiologic reinforcement, biofeedback (BFK) provides effective control strategies to regulate physiological activity. This is a method to enhance self-regulation, which renders physiological information visible. This is based on monitoring a patient’s bodily responses using heart rate, electrodermal activity, or brain waves; in the latter case, biofeedback using recorded EEG activity is called neurofeedback. Through visual and auditory feedback, patients learn how to voluntarily modulate their physiological responses in real time [72]. In this sense, BFK shares some similarities with psychological, behavioral, and CBT approaches. Protocols using EEG [73,74] and electrodermal activity (EDA) [75] have been investigated and have shown efficacy in terms of seizure reduction, even years later [76,77]. The aim of these methods is to teach patients how to voluntarily reduce cortical excitation (in neurofeedback) or increase peripheral sympathetic arousal (in EDA BFK) to decrease the seizure threshold [78,82]. As evidence of clinical efficacy of EDA BFK in the management of epileptic seizures, Nagai et al. [75] reported a mean reduction of seizures of about 50% in the BFK group, whereas no difference was observed in a control group. Moreover, there was a positive correlation between reduction in seizure frequency and degree of patients’ improvement in EDA over BFK sessions. Similar results, associated with a positive effect on psychometric evaluation of depression and negative affects, have been reported in patients with stress-triggered seizures (the “emotional vulnerability” group of patients with TLE identified by Lanteaume et al.) [79], suggesting an additional positive effect of this method on well-being. This improvement in well-being could be explained by an effect of increased self-efficacy and PSC since patients could learn to inhibit their seizures to some degree using their own strategies.

5.3. Optimization of seizure self-control by using a combination of techniques

Perceived self-control is an important element for patients with refractory epilepsy, especially in terms of seizure control. Different strategies to control seizures and prevent seizure consequences may potentially be used alone or in combination. Some approaches are more likely to be effective in interictal periods, targeting the seizure precipitant factors, especially stress (i.e., CBT, associated with “mind–body” approaches), whereas others focus on preictal and ictal periods (auras and prodromes) targeting direct seizure onset control (i.e., arousal-based approaches) or attempting to prevent consequences of the seizure (i.e., therapeutic education focused on behavioral strategies, such as lying down to protect themselves [6]).

Using different methods within an adequate time window may be very helpful for patients in the management of their disease. For example, strategies learned in biofeedback sessions seem to be effective for seizure onset control [75,79]. These strategies could be particularly effective when applied during preictal periods. Better anticipation of seizures could optimize the effectiveness of these strategies. However, for optimal efficacy, seizure prediction methods would need to be improved in sensitivity because self-prediction by alert symptoms is clearly unable to effectively anticipate all seizures for all patients. Indeed, patients are not always aware of their seizures, and some are never aware of them [80]. It might also be difficult to judge the efficacy of the methods learned for controlling seizures. Associating e-diaries with a biosensor represents an interesting perspective for detecting and recording seizures [59]. In addition, patients could compare the biosensor alerts with their perception of their subjective manifestations prior to a seizure and thus eventually increase self-efficacy in seizure detection. Adopting this kind of device might be useful to measure the effectiveness of countermeasures developed by patients, via the different psychobehavioral approaches in addition to drug treatments for the management of refractory epilepsy. Patients could objectively evaluate their seizure occurrence and obtain feedback that reinforces their self-efficacy and their PSC of seizures and improve well-being.

Fig. 3. From anticipation to prevention and control by personal and supported methods.
6. Conclusion

Many patients report developing individual subjective strategies to control their seizures, but more studies are needed to confirm the efficacy of these. Moreover, objective (e-diaries or even EEG recording) and subjective (psychometric evaluations of QOL and QOL) efficacy might be investigated. Further studies are needed to analyze and compare subjective perception and objective evaluation on EEG, in order to better investigate the link between phenomenological data and neurological data. Nevertheless, nonpharmacological supports have shown interesting results on QOL. Given the relationship between QOL and PSC in patients with refractory epilepsy, these methods aimed at optimizing the self-management of seizures could be useful as adjunctive treatment. Future studies investigating nonpharmacological approaches for these patients should focus on psychological parameters at the individual patient level, such as PCS, and in terms of outcome, should assess effect not only on seizure frequency but also on QOL.

Conflict of interest

The authors report no conflicts of interest.

References


