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Seizures as a Struggle between Life and Death: An Existential Approach to the Psychosocial Impact of Seizures in Candidates for Epilepsy Surgery

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Abstract

Introduction: Mental health comorbidities such as depression and anxiety are common in epilepsy, especially among people with pharmacoresistant epilepsy who are candidates for epilepsy surgery. The Psychology Task Force of the International League Against Epilepsy advised that psychological interventions should be integrated into comprehensive epilepsy care. ***Methods:*** To better understand the psychological impact of epilepsy and epileptic seizures in epilepsy surgery candidates, we analysed interviews with this subgroup of patients using Karl Jaspers' concept of limit situations, which are characterised by a confrontation with the limits and challenges of life. These are especially chance, randomness, and unpredictability, death and finitude of life, struggle and self-assertion, guilt, failure, and falling short of one's aspirations. ***Results:*** In 43 interviews conducted with 15 people with drug-resistant epilepsy who were candidates for epilepsy surgery, we found that these themes are recurrent and have a large psychosocial impact, which can result in depression and anxiety. For some people, epileptic seizures appear to meet the criteria for traumatic events. ***Conclusion:*** Understanding epilepsy and seizures as existential challenges complements the neurobiological explanations for psychological comorbidities and can help tailor psychological interventions to the specific needs of people with epilepsy, especially those who are candidates for surgical treatment.

Introduction

Epilepsy is a common neurological condition affecting over 50M people worldwide. It is characterised by recurring, unprovoked seizures [1]. Between 25% [2] to 40% [3] of people with epilepsy suffer from drug-resistant epilepsies. Drug resistance is defined as the failure of two anti-seizure medications to control seizures [4]. Surgical resection of the epileptic focus is an

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option for up to half of these patients [3]. Comorbidities like depression and anxiety are common in people with epilepsy, with prevalence rates of 35% and 26%, respectively [5]. In candidates for epilepsy surgery, psychiatric comorbidities seem more prevalent still. One study in epilepsy surgery candidates showed that 78% of patients had psychiatric abnormalities, and 60% met criteria for an ICD-10 or epilepsy-specific psychiatric diagnosis [6]. In another study, 46% had "abnormal anxiety" on the Self-Rating Anxiety Scale prior to the surgery [7], while a further study found that 47% reported minimal anxiety, 37% mild anxiety, 12% moderate anxiety, and 4% severe anxiety according to the Beck Anxiety Inventory [8].

In recent years, there is increasing attention to psychological trauma in epilepsy. Half of patients with epilepsy report symptoms of post-traumatic stress disorder (PTSD) [9], and anxiety and depression significantly correlate with PTSD symptoms in epilepsy populations [10]. It was suggested that epileptic seizures themselves may be experienced as traumatic and may sometimes lead to "post-epileptic PTSD," occurring in up to 51% [9]. In a study of 107 people with drug-resistant focal epilepsy, 45% reported at least one traumatic experienced seizure, one-third of whom met the criteria for PTSD (15% of the total sample) [11]. Another study among 120 people with difficult-to-treat epilepsy found that although fifty reported a traumatic seizure, only six fulfilled the diagnostic criteria of PTSD [12].

There are plausible biopsychosocial mechanisms that can explain symptoms of depression and anxiety in epilepsy [13, 14]. Much research has been done into the subjective experience of epilepsy that may be involved in such processes. One qualitative study in newly diagnosed epilepsy found a pervasive feeling of loss in psychological domains (such as loss of confidence, sense of control, enjoyment, and independence), as well as feelings of anger/frustration, distress, fear, anxiety, embarrassment, depression, and stigma. Losses also loom in social domains, including loss of employment or driver's licence, and overall day-to-day social activities [15]. Another study in people with newly diagnosed epilepsy highlighted the loss of control, such as grappling with uncertainty, vulnerability, increased awareness of mortality, diminished sense of self, and restrictions in social domains (driving, family, work, and leisure activities) [16]. A longitudinal qualitative study among eighty epilepsy surgery candidates found that they were especially hoping for a "normal" life which would include less seizures, no more medication, a richer social life, and more self-confidence which included independence and autonomy. At the same time, they were fearing the operation, continuing seizures and potential long-term adverse effects [17].

These works highlight the need for adequate psychosocial support in all phases of the disease, from newly diagnosed to drug-resistant candidates for epilepsy surgery. In recent years, the Psychology Task Force of the International League Against Epilepsy (ILAE) recommended the integration of psychological interventions in comprehensive epilepsy care to improve quality of life and decrease symptoms of anxiety and depression [18]. There is evidence supporting the positive effect of cognitive-behavioural, systemic, mindfulness, and psychoeducative approaches on the burden of epilepsy [18]. Other forms of psychotherapy include psychodynamic and existential-humanistic approaches, which have been investigated less in the context of epilepsy.

In this study, we seek to better understand the psychosocial impact of seizures in surgical candidates with drug-resistant epilepsy by taking an existential perspective. This is guided by the concept of "limit situations" (*Grenzsituationen*) introduced by the German psychiatrist and philosopher Karl Jaspers. Our study may contribute to better tailor psychotherapeutic approaches to the specific needs of people with drug-resistant focal epilepsy who are candidates for epilepsy surgery.

Jaspers' Concept of Limit Situations

The term "limit situations" has entered everyday language in the sense of an extraordinary or extreme situation: one reaches a limit of one's own abilities and resources; the situation can no longer be mastered with familiar means, and all attempts at a solution fail. But this does not exhaust the existential depth of the concept of a limit situation. According to Jaspers [19, 20], in genuine limit situations the basic conditions of existence, the *conditio humana*, come to light: for example, the inevitability of *having to die*, of *having to suffer*, of *having to assert oneself and struggle*, of *being at the mercy of chance*, and finally of *being guilty*. Thus, in limit situations the contradictions of life are revealed, which cannot be overcome, but have to be endured. While, for example, the awareness of mortality usually remains something general ("we all have to die"), in a limit situation the threat of death suddenly emerges as something that directly affects me: "I am indeed going to die!" Suddenly, the person becomes aware of this situation as inevitable, as their fate, which they cannot escape. These are shattering experiences after which life cannot go on as usual. A traumatic event, for example, is a limit situation.

"In every limit situation," Jaspers writes, "the ground is pulled out from under my feet" [20]. Something is broken; what Jaspers calls the *"housing" (Gehäuse).* These are fixed basic attitudes, general assumptions, thought structures, and ideologies that shield people from the bare realities of life and the abysses of existence. Limit situations are revelations: the conditions of existence, which were previously shielded and hidden by the housing, suddenly become visible and shatter taken-for-granted assumptions. The basic characteristic of limit situations is thus *failure*: they are experienced when the housing breaks, i.e., when a life plan or a fixed framework of basic convictions fails. Limit situations are therefore, according to Jaspers, *"… not overseeable; in our existence we see nothing else behind them. They are like a wall against which we bump, against which we fail. They cannot be changed by us, but only brought to clarity…"* [19]. Since limit situations question the hitherto valid framework of interpretation, the fundamental order of one's own life, they elude all foresight and predictability. The continuity of the previous life concept is interrupted.

Limit situations, however, also carry within them the potential of *freedom*, namely, to enter into the limit situation, to come to terms with it, and thus to gain a more fundamental understanding of one's own existence. As Jaspers writes, *"We become ourselves by entering into the limit situations with our eyes open"* [19]. A person is thus faced with the choice to accept the limit situation, to face it, and thus to find themselves in a new way; or to avoid it, be it through denial, rationalisation, or repression. Thus, the limit situation offers the chance of an existential reorientation. On the other hand, if a person is not able to cope with the situation, this can shake his or her mental structure to such an extent that mental illnesses, such as depression or PTSD, may arise [21]. Jaspers' description of limit situations can be summarised using the following themes that may play a role in drug-resistant epilepsy, the run-up to epilepsy surgery, and certain types of epileptic seizures:

- Chance, randomness, and unpredictability.
- Death and finitude of life.
- Struggle and self-assertion.
- Guilt, failure, and falling short of one's aspirations.

We examined these themes of limit situations highlighted by Jaspers in interviews with people with epilepsy under the assumption that they have an influence on psychiatric symptomatology. We also investigated whether these experiences can be opportunities for an existential reorientation in Jaspers' sense. We will discuss to what extent drug-resistant epilepsy with ongoing seizures can be meaningfully described with the concept of limit situations and how this understanding may help support people with epilepsy.

Material and Methods

Participants

Participants were recruited through the Epilepsy Center of the University Hospital in Freiburg, Germany, for a study that aimed at identifying the neurophenomenological correlates of seizure warning signs (auras and prodromes) using a combination of (micro-)phenomenological interviews and electro-encephalography (EEG). The study included adults with drug-resistant epilepsy who were scheduled for video-EEG monitoring in the context of presurgical evaluation and who had at least one epileptic seizure in the past year with suspected temporal, parietal, or insular epileptic seizures as well as an IQ estimated over 80 by the attending physician or neuropsychologist. For inclusion in the study, the IQ was not estimated using formal objective tests.

We followed a purposive sampling procedure for the neurophenomenological study and selected people in whom the clinical files mentioned possible auras or prodromes. About one in three people invited to participate declined, most commonly because they felt that the study interviews would add too much time on top of the clinical investigations already scheduled. None of the participants included ended their participation during the study. People with addictions or severe psychiatric comorbidities that could impede communication, such as psychosis or mutism due to severe depression or autism, were excluded, as were people with primarily frontal seizures as they frequently occur during sleep. Comorbidities were assessed by the attending physician who also thoroughly reviewed the entire medical files. The study protocol was approved by the Ethics Committee of the University of Freiburg, Germany (Protocol number 578/19), and registered in the German register for clinical trials (Deutsches Register Klinische Studien number DRKS00021409). All participants provided written informed consent prior to study participation.

Procedure

Participants scheduled for a multiple-day hospital admission were recruited by PRB and DMA. Interviews were conducted by PRB, a physician, and psychotherapist with a PhD on neurophysiology of epilepsy and training in the microphenomenological interview method (see below). She was not involved in clinical care of the participants and informed participants of this before participation. Participants were told that the aim of the study was to better understand their personal experience with epilepsy in general and to explore seizure experiences more specifically. Participants were not informed about the concept of limit situations. A first interview was conducted prior to or upon admission, and follow-up interviews were conducted during the hospital stay. The number of follow-up interviews was dependent on the number of seizures that occurred during the hospital stay, data saturation in the interviews, or the clinical condition of the participants. For instance, tiredness caused by seizures, sleep deprivation as a part of the seizure evaluation, or changes in medication led to restrictions in the number of follow-up interviews. Study participation ended upon discharge from the hospital. A debriefing interview was offered.

Interviews

The first interview was a semi-structured interview with non-inductive, open questions covering the participants' general experiences with epilepsy, the impact of the condition on their daily life, and their coping strategies (questions included "Can you tell me about your experience with epilepsy?", "How does epilepsy influence your life?", "Do you encounter difficulties because of your seizures/epilepsy and if so, what helps you?"). In the same interview or in a follow-up interview, participants were also asked to describe a typical seizure in detail ("Please describe your first seizure," "How many types of seizures do you have, and how often do they occur?", "Please describe your habitual seizures," "Have you identified triggers?"). The hypothesis that epilepsy and epileptic seizures may be experienced as limit situations emerged during the analysis (see below in section 2.4 and the section on study limitations in the discussion), and the interviews did therefore not contain explicit questions related to the concept of limit situations. The interviews that were conducted during the in-patient phase were based on the microphenomenological interview method, which has an open format and is designed to obtain a very detailed reconstruction of a brief event and the associated feelings, thoughts, and sensations [22, 23]. Interviews were completed when no new information emerged. Participants were also offered basic drawing material if they wished to visually express their seizure experiences.

Analysis

The interviews were audio-recorded and transcribed verbatim by a researcher who was not involved in the clinical care or interviewing of the participants (MLAB). Then, following an exploratory data-driven approach, all transcripts were read in their entirety by MLAB and PRB, enabling the identification of commonalities. It was at this stage that the hypothesis emerged that epilepsy and epileptic seizures could represent limit situations. We then conducted a theory-driven phenomenological analysis in which we assessed the appearance of the main themes of a limit situation in the interviews. A data-driven thematic analysis on the metaphors and figurative language that people in this sample use in seizure descriptions was recently published [24], and a micro-phenomenological analysis detailing the experiential structure of the seizures described by our participants will be published in future elsewhere. These analyses are based on the micro-phenomenological seizure descriptions, whereas the current work is mostly based on the first interviews about the impact of epilepsy on the life of the person, with additional information drawn from the seizure descriptions. ATLAS.ti (V8) was used to support the analysis, which was conducted in German and discussed and reviewed by PRB, MLAB, and TF in a peer-debriefing process. The quotes presented in this article were translated into English and then proofread and compared to the German originals by a native English speaker proficient in German.

Throughout the interview, analysis, and interpretation processes, we tried to minimise potential biases in the following ways: the researcher interviewing the participants was not involved in their clinical care, so that she could keep an independent position and not be involved in clinical decision-making. The person transcribing the interviews and leading the analysis was also independent from the clinical team, and was not involved in conducting the interviews. This way, she could assess the quality of the interviews. She was also the one who selected the quotes presented here. Regular debriefing sessions with the entire team were held to reduce the risk of overinterpretation. The theme of limit situations emerged during the analysis process and was not "front-loaded" into the design of the study either explicitly (through direct questions relating to limit situations) or implicitly (through expectations from the researchers).

Results

The entire corpus consisted of 43 interviews, with a total duration of 29 h, conducted with 15 participants (8 men, 7 women, average age of 31 years; see Tables 1 and 2) recruited between May 2020 and April 2022. In total, 21 patients were contacted to participate, of which 6 declined. The reasons for declining included no interest (1x) and worry that participation would cost too much time (3x) or energy (2x). Two patients had both epileptic and non-epileptic seizures during the monitoring. It was possible to retrospectively disentangle the different types of seizures, based on EEG and linguistic characteristics. The non-epileptic seizures are not included in the present data analysis. Single interviews had an average duration of 43.5 min (range 10–90 min). The interviews were conducted in German in fourteen participants who were German native speakers and in English in one participant who was an English native speaker. No adverse effects were reported in relation to the interviews. At least one theme related to limit situations was present in each interview from the 15 participants. We therefore consider data saturation to be achieved. Three participants used the proposed drawing material, shedding additional light on the phenomenology and exact sequence of the seizures, but this did not provide information that is relevant for the current analysis on limit situations, so that it will be presented elsewhere.

(1) Chance, Randomness, Unpredictability

One of the most recurrent themes in the interviews is the randomness and unpredictability of epilepsy and seizures. They confront people with the randomness of life in several ways. Firstly, the diagnosis of epilepsy often comes out of the blue. Secondly, seizures are unpredictable, leading to a feeling of being at the mercy of the disease. Thirdly, people who are conscious or partially conscious during seizures report how they cannot control or predict their behaviour during the event.

All participants clearly remembered their first seizure and described how this event completely changed their

Table 1. Patient characteristics

Number	M (1)/ F (0)	Age, years	Age at onset of epilepsy, years	Type, lateralisation of epilepsy	Lesion(s), localisation	Type of seizures	Psychogenic seizures (y/n)	Relevant psychiatric diagnosis (ICD-10)	Number of interviews	Total interview duration, min
1	0	45	11	Parietal lobe epilepsy, R	Lesion of unknown aetiology, parietal operculum R	Focal aware sensory and tonic seizures	n	F33.0, suspected F45.40	7	468
2	1	21	19	Temporal lobe epilepsy, L and R	Meningoencephaloceles, temporo-polar L and R	Focal aware sensory and cognitive seizures, focal aware and focal impaired awareness motor seizures, focal to bilateral tonic-clonic seizures	n	None	6	217
3	0	39	38	Temporal lobe epilepsy, L	Postoperative gliosis, temporo-lateral posterior L	Focal aware sensory seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	F32.0	4	149
4	1	32	28	Frontal lobe epilepsy, L	3 focal cortical dysplasias, frontal L	Focal aware sensory and cognitive seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	F06.3, F41	1	36
5	0	28	<1	Genetic epilepsy (Dravet syndrome)	No	Focal aware sensory seizures, focal to bilateral tonic-clonic seizures	y	F44.5, F33.4	3	103
6	1	32	20	Posterior cortex epilepsy, L	Defect of unknown aetiology, temporal posterior-parieto-occipital L	Focal aware sensory seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	None	3	101
7	1	36	31	Temporal lobe epilepsy, R	Dysembryoplastic neuroepithelial tumour, temporo-polar and temporo-mesial R	Focal aware sensory seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	None	3	88

Table 1 (continued)

Number	M (1)/F (0)	Age, years	Age at onset of epilepsy, years	Type, lateralisation of epilepsy	Lesion(s), localisation	Type of seizures	Psychogenic seizures (y/n)	Relevant psychiatric diagnosis (ICD-10)	Number of interviews	Total interview duration, min
8	1	48	39	Temporal lobe epilepsy, R	No	Focal aware sensory and cognitive seizures, focal impaired awareness seizures	n	None	2	76
9	0	29	26	Undefined, presumably L	Hemiatrophia cranii et cerebri, hemispheric L; gliosis, temporo-polar L	Focal to bilateral tonic-clonic seizures	y*	F43.1, F44.6, F32.2	1	51
10	0	20	18	Insular epilepsy, L	Postencephalitic atrophia and gliosis, insular L	Focal aware sensory and cognitive seizures, focal aware motor status epilepticus	n	F33.0	2	80
11	1	21	15	Temporal lobe epilepsy, L	Volume increase of unclear significance, amygdala L	Focal aware sensory seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	None	2	73
12	0	25	20	Temporal lobe epilepsy, L	Ganglioglioma WHO I, temporal anterior L	Focal aware cognitive seizures, focal impaired awareness seizures	n	None	2	38
13	1	38	6	Temporal lobe or insular epilepsy, L	Blurring of grey-white matter junction, posterior parahippocampal gyrus L	Focal aware sensory seizures, focal impaired awareness seizures, focal to bilateral tonic-clonic seizures	n	F06.3	1	52
14	0	21	9	Perisylvian epilepsy, L	Polymicrogyria, perisylvian L and R	Focal aware sensory and cognitive seizures, focal atonic seizures, focal to bilateral tonic-clonic seizures	n	F43.2 in history	3	81
15	1	32	2 (12)	Temporal lobe or parietal lobe epilepsy, L	Blurring of grey-white matter junction, parahippocampal gyrus L	Focal aware cognitive seizures, focal impaired awareness seizures	n	F33.4	3	128

The interviews included in this analysis described epileptic seizures. L, left; R, right; M, male; F, female; y, yes; n, no; WHO, World Health Organization. *The seizures that were recorded during the hospital stay were not epileptic, and the patient also had epileptic seizures in the past.

Table 2. Sample characterisation

Age, mean (std), years	31.3 (8.85)
M:F, *n* (%)	8(53): 7 (46)
Age at onset, mean (std), years	21.53 (11.95)
Disease duration, mean (std), years	12.27 (12.07)
Epileptic focus	
Temporal/parietal/insular	10
Perisylvian	1
Frontal	1
Posterior	1
Undefined	2
Focus side L:R:B	10:4:1
Concomitant non-psychiatric diagnosis, *n*	2
Concomitant psychiatric diagnosis, *n*	9

Y, year; std, standard deviation; M, male; F, female; *n*, number; L, left; R, right; B, bilateral.

lives. Perhaps this is where seizures most clearly resemble limit situations: their occurrence pulls the ground out from under a person's feet, suddenly thwarting their previous expectations of life. From that moment, any given situation may be brutally disrupted by a seizure. In general, seizures were described as surprising, startling events, even if in the course of their often chronic disease people have learnt to expect them to happen *at some point*.

> I get jarred, startled in the moment, even though I had an expectation that it might happen, not that severe but that it would happen. (participant 1)

This unpredictability of the seizures frequently leads to anxious hyperawareness in our sample. The possibility that a seizure might occur is described by participants as a constant threat, contributing to avoidant behaviour and isolation. In an attempt to regain a sense of safety, people often try to withdraw from situations in which a seizure could be particularly harmful. This has consequences in all areas of life: previous roles may be fundamentally altered. Family members are now worried that the patients may suffer a seizure and may become overprotective. Professionally, many participants reported that they lost their jobs or were unable to complete a chosen training as a result of the disease. They felt that there was no safe place to protect themselves from the threat of seizures. Thus, the conviction that life can be planned and controlled is lost. Many participants also reported feeling an utter loss of control over the body and behaviour during seizures, leading to feelings of profound helplessness.

> . . . [having] no control over your own body and just being at the mercy and this, that you can't communicate, you can't say what you would like, yes. And where you are aware of it all and that it then always just gets worse. (participant 5)

One of the participants reported that he preferred having generalised tonic-clonic seizures, as they caused him to lose consciousness and he did not have to bear the feeling of helplessness and loss of control that he experienced during focal seizures.

(2) Death and Finitude: Seizures as an Existential Threat

Epilepsy is associated with excess mortality due to Sudden Unexpected Death in Epilepsy (SUDEP) [25]. What is reported much less is the subjectively experienced fear of death around seizures [26], which is rarely routinely screened for in clinical practice [27]. Almost all people in our sample reported intense fear and anxiety before, during, or after the seizures. The raw existential character of this fear is striking. Even though people had experienced many seizures before, some or even all of them were able to arouse a fundamental fear of death. This is possibly linked to the felt loss of self in a seizure.

> It is as if you had to die and you resist and resist and then all of a sudden you give in and say okay now. And then, death does not come and get you, so the epileptic seizure releases you. (participant 3)

Seizures are thus a confrontation with a loss of self and with the finitude of life. People did not immediately disclose that by "anxiety" they meant "existential fear." It took several longer interviews before they described this, possibly reflecting its intensely threatening nature. Its occurrence may therefore be largely underestimated. When accompanied by such extreme fear, seizures correspond to the DSM-5 criteria of traumatic events: they are experienced as life-threatening and lead to helplessness and loss of control.

(3) Struggle

People in our samples reported that they fight against the seizures. The language they used indicates externalisation and even personification of the seizure; descriptions are metaphorical and highly symbolic. One participant described her seizures as a bull, which she has to fight:

> In principle, the whole body fights, so like when this bull in principle is in the middle and then scratches its hoofs like "open the gate now," that's how I [imagined it]. Yes. That now explains it best for me. (participant 3)

When directly asked, she said she purposely chose the image of a bull, as it represented a violent and destructive power to her that cannot be tamed, capturing the violence of the seizures. She described herself as the torero in the arena fighting the bull. Another participant drew a direct comparison with a war, and the seizure trying to pull her down:

> I really experience this like a war. [. . .] Well. . . well going against each other. Pulling a rope one way and the other one pulling the rope the other way, and you don't want this this thing to pull you down off the rope. (participant 1)

Others describe seizures as an "evil" or "toxic" entity against which they are fighting. One participant describes wrestling and struggling against the seizure, and trying to resist a physical pressure that he described as closing in on him. Overall, the experience of seizures can thus be described as an existential cleavage that opens up within the person, in a sense "a struggle with oneself."

Our participants did not only fight against their seizures. For many, everyday life with the disease and the ever-present threat of seizures was a constant challenge. In some instances, every activity was influenced by the threat and the confrontation with the limits of existence. A major limitation in everyday life was not being allowed to drive and being dependent on public transport or other people to go to work or participate in leisure activities. Taking the public transport was described as challenging because many are afraid of having a seizure in public.

Seizures lead people in our sample to make lifestyle adjustments, as, for example, a regular sleep pattern, and limiting alcohol consumption can reduce the occurrence of seizures. For some, it involved more radical changes, such as changing jobs. Some saw this as a benefit, but others felt that they were missing out. Some consciously took the risk and interrupted their lifestyle temporarily to be able to participate in social events, always with the threat of a seizure on the horizon. Many said they could not make long-term plans, but have to take each day as it comes as it can bring new and unexpected challenges.

> I really just have to plan day by day. I can't say, "Yes, we'll go there in a week", but I have to say, "Let's see how I'm doing."
>
> I always have to fight, fight, fight. I don't have anything where I can say, "Yes, I'll just get it." (participant 9)

The limits the disease imposes on the life of the participants hamper their full participation in society. For one of the participants, this was linked to suicidal thoughts.

> Yes, sometimes I also have [. . .] suicidal thoughts. And I don't want to have the thoughts, but then they just come because I'm just sitting around at home and I don't have anything to do. (participant 5)

Overall, the disease thus led to a profound sense of otherness, of losing the self-evidence of life, making one's existence a constant struggle for balance and self-determination.

(4) Guilt

Guilt as a basic existential condition showed up in different ways: first, as guilt towards oneself, accompanied by self-hate and self-stigmatisation, and second, as guilt towards loved ones. We will explore both of these in more detail.

Several people mentioned that they have a low self-esteem because of the condition, and are disappointed, sad, or angry that they cannot live the life they wish for. This participant describes it as follows:

> That so very very bad, sad, angry, disappointed, feeling all these words together and then I hate myself - sorry for saying that so, but I have to say that so radically because it is so real. I hate myself for having that, for not being able to live like I, like I could maybe. (participant 9)

This quote also reveals the sense of guilt towards oneself, of not being able to live up to one's potential and aspirations. For this participant, this meant that although they had a professional education, they were not able to work in this chosen field. This is a recurrent theme. Although those affected struggle to maintain a normal daily life, they have had to make adjustments to cope with the condition. Some relinquished professional goals, while others gave up on personal dreams and ideals, such as relationships or a family. Being dependent on family members or friends to go to places was linked to feelings of guilt (not wanting to bother others), or feelings of not being autonomous. A large and recurrent theme, present in almost all the interviews, is the guilt towards others, especially loved ones, as these two quotes show:

> Because I always have the feeling that I'm a burden on my parents or something [. . .] I always apologise to my mother for the fact that she had to see another seizure, that she's already had to see her child in this condition and simply can't help. (participant 5)
>
> . . . because you always blame yourself. And you don't necessarily want to mess up someone else's birthday. You can't help it, but it's unpleasant for oneself. (participant 11)

People do not want their loved ones to see them having seizures, and many reported that, like the person quoted above, they apologise when loved ones see their seizures. What seems to be especially difficult to bear for the participants is that in addition to their own helplessness, loss of control and fear, they see the helplessness of their witnesses.

> . . . it's the fear of the observer stressing out, 'cause there's absolutely no control and the observer feels helpless, and then

> the fear and anxiety of the person really in the unknown trying to process it as well. (participant 1)

There was a double sense of guilt: first, towards oneself for having the seizures, and second, towards others for randomly putting them in a situation in which they also feel helpless and out of control. Some participants described that in such situations, they feel like they have to take care not only of themselves but also of the witness. Some have agreed with their relatives on a procedure in case a seizure occurs. To decrease guilt and anxiety, this can involve the relatives carrying on with what they are doing while pretending nothing is happening. Yet, even if such agreements can be put in place, several people said they have had phases in which they thought it would be better if they were dead.

(5) Dealing with Seizures

We have now seen that epilepsy and epileptic seizures can be regarded as existential limit situations in various respects. As Jaspers described (see above), there are two basic possibilities for reactions to limit situations. The first is a pattern of avoidance, hiding, and denial; the second, much rarer, seems to be a kind of radical acceptance and transcendence. We previously described a similar distinction in coping with seizures [28]. Regarding avoidance patterns, the attempt to hide seizures is a common theme also in this sample, which is often linked to the feelings of shame and guilt.

> you feel ashamed and you think oh shit ey you had something like this in front of your parents again and you couldn't hide somewhere and now they saw it again. (participant 6)

People reported they did not tell loved ones that seizures might have occurred, and do not talk about their condition openly. They also described avoiding situations in which seizures might be witnessed by people they do not know well, for example, at work or at sports clubs.

Despite the suffering and limitations that epilepsy has imposed on their lives, some people in our sample expressed gratitude for the fact that their condition was not as bad as some other conditions. A comparison to cancer was often made. A small minority in our sample (3 participants) explicitly said that they were grateful for the disease as it was, and that they had learned to see it as a possibility for personal growth and development that they would otherwise not have had.

> At the beginning, it was a bit difficult to cope with, [. . .it] can change your whole life, so it won't be the same as before, and you think to yourself, well, maybe it would have been better if I had stayed down that day. So the thought comes up because at this age you don't necessarily want to be restricted in many things, you have to have your own experiences. So at the beginning it was a bit difficult to deal with it, I have to say openly and honestly, but at some point you learn from it. You always grow with every situation. (participant 11)

Despite the fear that still accompanies the seizures, over the years these people have learnt a different way of dealing with them, which does not involve fighting:

> I've learnt this through fighting it, which, yeah, [is] another paradox: fighting is not gonna help, because I've tried that for a very very long time, and then I tried, "just ride this wave, just let it happen," and um, and that's my biggest weapon. (participant 1)

This attitude towards seizures can best be described as "radical acceptance." It does not take away the fear, but appears to give people a position in which they feel less helpless. They can weather the storm. This can give them a constructive and positive outlook on their life and their condition, without which they would not be who they are. These two examples can be considered as steps towards an existential reorientation in Jaspers' sense.

Discussion

We have shown that people with drug-resistant epilepsy who are potential candidates for epilepsy surgery experience their illness as repeated limit situations. The interviews and subsequent analysis reveal that symptoms of anxiety and depression may occur when seizures are experienced as traumatising events with an immediate threat to the person's physical and/or psychological integrity. Such events can be seen as limit situations, which confront the person with the fundamental vulnerability of life that is usually concealed, including its unpredictability, its finitude, the fragility of the body, and the unavoidability of guilt. Repeated exposition to such distressing situations may overburden the person's capacities of coping and have lasting psychological effects, such as PTSD, anxiety, and depression. In people who experience seizures as traumata, they can thus mean a confrontation with the abysses of existence and in this way cause or exacerbate existing mental health symptoms [29].

This existential analysis complements the current understanding from learning theoretical and neurobiological perspectives on the occurrence of depression and anxiety in people with seizures. Thus, the concept of "learned helplessness" denoting the inability to escape uncontrollable aversive events was linked to psychopathology in general [30] and more specifically to depression associated with epilepsy [31, 32]. Furthermore, a recent study showed that anticipatory anxiety is more frequent when the seizure onset zone involves the amygdala [33], a brain structure involved in fear, reward conditioning, and valence encoding [34]. While such approaches allow for important pathogenetic insights, they remain rather external to the individuals involved and do not easily connect with their personal experiences. Since epilepsy remains a permanent condition of life, it requires forms of coping that start from the subjective experiences of suffering and place them in an existential context. Therefore, our analysis complements the behavioural and neurobiological perspectives with the dimensions of *meaning* and *existence*, and addresses the question of *what it is like* to live with epilepsy. All these different facets contribute to the burden of epilepsy, but only on the basis of an in-depth understanding of the subjective experiences of illness can psychotherapeutic interventions support existential coping [31].

Psychotherapeutic approaches can broadly be divided into four schools: psychodynamic, cognitive-behavioural, systemic, and existential-humanistic [35]. Although Jaspers did not practice or teach "existential psychotherapy," his concepts of "limit situation" and "housing" are helpful for psychotherapeutic practice [36]. They require a change of attitude, a distancing from and questioning of the habitual worldviews and cognitive-behavioural patterns to understand how one is in relation to the world. Jaspers' claim (and that of other existentialist philosophers such as Jean Paul Sartre or Viktor Frankl) is that a person always searches for freedom regardless of their condition. Freedom, according to Jaspers, can only be achieved by becoming aware of and stepping out of the "housing." This requires that the person becomes aware of their wish for freedom and tries to follow it. This can happen in psychotherapy, if patient and therapist meet as fellow humans [36]. In the context of epilepsy, this means that beyond psychoeducation, learning new behaviour to deal with seizures and regulating emotions an additional question can be asked: "How can I become free as a human being, despite not being free of seizures"?

All schools of psychotherapy agree on the fact that change is possible and that trauma, although being a burden, can become an opportunity for growth. The potential for post-traumatic growth is increasingly well documented [37, 38]. There are also anecdotal reports about such trajectories in people with epilepsy [39]. Our analysis underlines the need for psychotherapeutic support to cope with epilepsy and seizures, as recommended by the ILAE Psychology Task Force [18]. Aside from the focus on the diagnosis of depression, anxiety, potential traumatisation due to the seizures, and maladaptive (neurotic) coping, the focus of psychotherapy should aim to help (1) support the transformation of the person's inner attitude towards the seizures; (2) restore the felt self-efficacy to counter helplessness; and (3) facilitate growth, development, and thriving in spite of, or maybe because of, the seizures. For personal growth to occur, it is of course not a pre-requisite that seizures are experienced as traumatic events.

Depending on the psychological burden, the three aims cited above may require extensive professional support from therapists or counsellors, which may not be readily available. There are several manualised or self-help programs available [40–42], which may help people cope with their seizures. Group-based approaches, such as self-help groups and mindfulness-based programs, were also shown to be beneficial for people with epilepsy [28, 43–45]. Based on the existentialist perspective we analysed here, we can hypothesise that the human encounter with other people who face similar challenges is powerful in transforming inner attitudes and showing ways towards growth and development. In sum, we suggest that the existential perspective may also be integrated in the understanding of psychological comorbidities in epilepsy and can contribute to integrative care for people with seizures.

The main limitation is our study sample, which consisted of people with drug-resistant epilepsy who were admitted in hospital for video-EEG monitoring in the context of presurgical evaluation. This is a highly selected population, i.e., those with drug-resistant epilepsy, in whom surgical resection of the epileptic focus is an option, representing probably less than 15% of the overall population of people with epilepsy [3]. These are likely people who suffer much from the disease and from the impending surgical procedure. Our sample is diverse in terms of age and disease duration, and our findings suggest that the experience of epilepsy as a limit situation is not dependent on these factors. Yet our findings may not be generalisable to all people with epilepsy. For instance, people who experience intense fear linked to their seizures may be more likely to accept surgical treatment. We did not include people in our study who mainly had seizures during sleep, as data were primarily collected for a neurophenomenological study for which it was essential that people could report about potential prodromes or auras. People with seizures during sleep may have different experiences although objectively they are those with the highest risk to die from SUDEP [25].

People with suspected generalised or multifocal epilepsies are not usually candidates for epilepsy surgery and were therefore not represented in our sample, but may also have different perceptions and experiences. People with reflex seizures, or those who exactly know their seizure triggers and how to avoid them, may experience seizures as less random and unpredictable. The experience of loss of control may then be less pervasive. Some people are able to control their behaviour during a seizure, and there is evidence that at least some people with epilepsy can acquire skills to interrupt seizures [46–48], although it is unclear how many people can learn this. Lifestyle adjustments too can lead to substantial seizure reduction, with some even obtaining full seizure control by lifestyle hygiene [49]. These subgroups are unlikely to become surgical candidates and are thus not included in our sample.

Not all people with epilepsy may experience their seizures as traumatising or as limit situations. The findings of qualitative studies in newly diagnosed epilepsy, however, highlight several themes that could be related to limit situations [15, 16]. For example, in the study of Velissaris et al., the theme "grappling with uncertainty" may be similar to what we have identified as "chance, randomness, and unpredictability," while the theme "increased awareness of mortality" seems directly related to Jaspers' "awareness of death and finitude of life" [16]. Velissaris et al. [16] identified limitations in the social domain, including frustration over driving restrictions and limitations in leisure activities, which mirror difficulties which we have highlighted under the theme "struggle and self-assertion." Jaspers' theme of "guilt, failure and falling short of one's aspirations" seems to appear in their study under "diminished sense of self," which included feelings of being "flawed" in some way, and in the domain of family, where people reported concern over the effect of the seizures on family members and their inability to fulfil their role in their family [16].

The study of Jacoby et al. [15] highlights the themes of "falling short of one's expectations" in even more detail. They analysed the sense of loss in psychological and social domains following new-onset epilepsy and convincingly linked this core experience of loss to seizures and reduced quality of life using social production function theory [15]. This theory links psychological well-being to the fulfilment of an individual's physical and social needs in light of their own goals [50]. Their account shows how seizures disrupt the attainment of such fulfilment, in line with our findings. Based on the results from these previous studies [15, 16], we hypothesise that also newly diagnosed epilepsy may be experienced as a limit situation. Further research is needed to verify this hypothesis.

Beyond epilepsy, other health conditions may be experienced as limit situations. This was previously described for mental health conditions such as trauma, depression, or hypochondria [21]. We also hypothesise that any sudden diagnosis of a potentially serious physical condition such as cancer, multiple sclerosis, or a heart attack may be experienced as a limit situation. Psychosocial burdens and symptoms such as depression and anxiety play an important role in these conditions, and the concept of limit situation may help to understand the origin of such symptoms.

Other limitations include our study design, in which the interviews were not specifically tailored to investigate limit situations. This can also be seen as a strength as there were no inductive questions or hypotheses in the data collection phase. A limitation of this is that we did not explicitly address these themes in the interviews and had to rely on spontaneous reports for this analysis. Although at least one of the themes linked to limit situations can be found in all interviews across all participants, we noticed that certain themes only seemed to emerge in the follow-up interviews, notably the existential nature of the fear and the themes of struggle and guilt, possibly reflecting the stronger interviewer-interviewee alliance which made it possible to address more intimate topics. Our study design did not impose a fixed number of interviews per participant, and some participants in our sample were only interviewed once because of their clinical condition. It is possible that more themes would have come up in these participants if follow-up interviews had been possible. Our approach and study set-up do not allow a meaningful quantitative analysis of the themes under study. Evaluating the frequency of the themes related to limit situations in future studies may help assess which aspects are most relevant in clinical contexts. Although two participants in our sample also had non-epileptic seizures, these types of seizures were rare and, therefore, no hypotheses about differences between epileptic and non-epileptic seizures could be derived.

Despite these limitations, we deem our findings relevant, as the psychosocial burden of drug-resistant epilepsy, especially among surgical candidates is extremely high. This subgroup of people is most at risk of psychopathological comorbidities, and the needs for complementary approaches to support quality of life are high. Our exploratory study contributes to generating novel hypotheses about the development and maintenance of psychiatric symptoms in epilepsy. Future studies will be needed to further confirm our findings and investigate whether people with other forms of epilepsy, psychogenic non-epileptic seizures, or other chronic conditions experience these conditions similarly as limit situations. In larger samples, mixed-method approaches may provide meaningful complementary information on quantitative and qualitative aspects that can support the future development of psychotherapeutic approaches for people with (drug-resistant) epilepsy.

Conclusion

We analysed interviews with people with drug-resistant epilepsy who were candidates for epilepsy surgery using the concept of limit situations, which are characterised by a confrontation with the limits and challenges of life, above all its unpredictability, finitude, the need to fight, and guilt. Understanding drug-resistant epilepsy in surgical candidates as an existential challenge complements the neurobiological explanations for psychological comorbidities and can help tailor psychological interventions to the specific needs of people with epilepsy.

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Statement of Ethics

The study protocol was approved by the Ethics Committee of the University of Freiburg, Germany (Protocol number 578/19), and registered in the German register for clinical trials (Deutsches Register Klinische Studien number DRKS00021409). All participants provided written informed consent prior to study participation.

Conflict of Interest Statement

Prisca Rachel Bauer has received speaker fees from Novocure and APCO Worldwide.

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Author Contributions

Study design and conception: Prisca Rachel Bauer, Andreas Schulze-Bonhage, Dirk-Matthias Altenmüller, and Thomas Fuchs. Data collection (recruitment, inclusion, interviews, and transcription) and analysis: Prisca Rachel Bauer, Marie Lu Anaïs Bronnec, and Dirk-Matthias Altenmüller. Data interpretation and writing draft manuscript: Prisca Rachel Bauer, Marie Lu Anaïs Bronnec, and Thomas Fuchs. Editing and approving final manuscript: Marie Lu Anaïs Bronnec, Prisca Rachel Bauer, Dirk-Matthias Altenmüller, Andreas Schulze-Bonhage, and Thomas Fuchs.

Data Availability Statement

The data that support the findings of this study are not publicly available. Due to the personal nature of the interview data, the ethics approval does not allow the public sharing of these data. Anonymised data are available from Prisca Bauer upon reasonable request.

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