I. Introduction

Epilepsy is one of the most common neurological disorders encountered in clinical practice, affecting approximately 1 of 50 children and 1 of 100 adults in developed countries, with a higher prevalence in developing countries.

Epilepsy is called a hidden disability because people with the condition usually appear normal between seizures. Yet, ironically, the appearance of someone having a seizure is anything but hidden from view and is often dramatic and frightening. Consequently, epileptic seizures have been depicted in art through the ages, colored by views on its medical, social, and psychological aspects. The history of epilepsy in pictorial art was reviewed during the last Mansell Bequest symposium (Engelsen, 2004) as well as elsewhere (Schachter, 1996) and will not be further explored in this chapter.

Artists who themselves have epilepsy present a unique view of their condition. Over the years, I have collected the works of contemporary artists with epilepsy, compiling much of it along with the artists’ written comments in a book (Schachter, 2003). In addition to its pictorial qualities, the art is replete with insights into the experiences of having seizures and living with epilepsy. This chapter presents examples from my collection, organized by the apparent connection between the pictorial subject and epilepsy as currently understood from a medical perspective.
II. Background to the Collection

In 1992, Jennifer Hall, a gifted Boston artist with epilepsy, organized a show at her gallery (http://www.dowhile.org/) called “From the Storm” (http://www.dowhile.org/physical/overview/presentations/asci/storm.html). Her hope was that curating the show would help her to better understand herself through the collective voice of other artists with epilepsy “working under similar conditions” and would provide a guide to the “rich, randomly mapped terrain” of creativity and epilepsy (Hall, 1992). In assembling the show, she “found an abundance of creative people eager to share of themselves in an intimate and vulnerable way,” who were willing to share, through their art, “the problems of negotiating basic life and the cultural stigmas of having any form of epilepsy.” The collected works demonstrated to her the relationships between the art and seizures, the process of diagnosis, and the lifestyle of people with epilepsy, amplified by the personal statements of the artists that were displayed alongside their work and in the show’s catalogue.

Based on a successful run in Boston, “From the Storm” toured USA, Canada, and Australia, where it was on display in conjunction with the 1995 meeting of the International League Against Epilepsy.

I was pleased to help sponsor the show and its worldwide journey from its inception, and in doing so I came to appreciate the multifaceted significance of the collected works. Particularly aware of the value the art held for health care providers and the epilepsy community, I launched a series of calendars, initially featuring the art from the show, which were distributed to physicians, nurses, and epilepsy advocacy groups. Soon, dozens of artists with epilepsy from around the world, many encouraged by their physicians, began to send me photographs, digital files, and slides of their work, as well as canvases and prints, often with lengthy personal statements. Currently, there are approximately 1200 pieces in the collection from over 50 artists. I have featured selected works on the covers of books and issues of Epilepsy & Behavior (Academic Press).

III. Artistic Themes in the Works of Contemporary Artists with Epilepsy

The art in the collection can be organized under four general themes: seizure experiences, psychiatric comorbidity, psychosocial aspects of epilepsy, and nonepilepsy related.
A. SEIZURE EXPERIENCES

Seizures are experienced variously by different patients, and having a seizure is central to a number of the art pieces in the collection. As background to these works, there are two main types of seizures, generalized and partial. Whereas generalized seizures affect both sides of the brain simultaneously, partial seizures affect a restricted area of cortex. Symptoms that patients consciously experience with partial seizures are often called auras or warnings and are classified as simple partial seizures—“simple” meaning consciousness is not impaired. Typical simple partial seizures include nausea, fear, jerking of one side of the body, or a metallic taste, although a wide variety of other cognitive, perceptual, and emotional auras have been described (Schachter, 1993). For example, some patients have visual symptoms, such as shown in Fig. 1, while others have complex distortions of body image (Figs. 2 and 3).

If patients do not have conscious symptoms as the manifestations of their seizures, then they abruptly lose consciousness, often described as a fadeout or blackout. Patients are unconscious during these types of seizures, so they have no memory of what happened and describe a gap of time for which they have no recollection. This interruption of time is shown dramatically in Fig. 4 as cracks in a bridge in which the bridge symbolizes a day in the life of someone with seizures.

The complex partial seizure (known in the past as temporal lobe seizures and psychomotor seizures) is the most common type of seizure in adults with epilepsy. During complex partial seizures, patients typically appear awake but do not meaningfully interact with people around them or respond normally to instructions or questions. Generalized tonic-clonic seizures (also called grand mal

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Fig. 1. Brainstorm #20, Craig Getzlaff, 2002, Acrylic, Dptyc 36 × 24 for each piece. Reprinted from (Schachter, 2003) with permission.
seizures or convulsions) may begin with a loud scream. The limbs then stiffen (tonic phase), the patient falls to the ground, cyanosis ensues, and the extremities jerk (clonic phase). Bloody, frothy sputum may be seen. The termination of the clonic phase represents the onset of the postictal period. After complex partial or generalized tonic-clonic seizures, patients may appear to be in a deep sleep, or confused, and may complain of a headache. Other symptoms commonly experienced during the postictal period include shame, embarrassment, depression, loss of contact with reality, and visual perceptual distortions (Fig. 5).

B. PSYCHIATRIC COMORBIDITY

Depression, anxiety, and psychosocial aspects are the three most common psychiatric disorders that occur in people with epilepsy. Many of the pieces in the collection reflect an awareness of one or more of these disorders.
Depression occurs in nearly one in five patients whose seizures are controlled and more than half of patients whose seizures continue despite treatment (Mendez et al., 1986; O’Donoghue et al., 1999). Depression, conveyed beautifully in Fig. 6, is underrecognized and, when diagnosed, usually undertreated (Kanner and Barry, 2003). It may arise from epilepsy-related brain dysfunction as well as social or vocational disabilities (Gilliam and Kanner, 2002). Neurologists do not appreciate well enough that depression negatively impacts on the quality of life, independent of seizure frequency (Hermann et al., 2000).

Nearly one in four people with epilepsy have an anxiety disorder; higher rates have been reported in patients with medication-resistant seizures (Vazquez and Devinsky, 2003). Like depression, anxiety significantly impacts on the quality of life (Cramer et al., 2005). Anxiety disorders, most commonly present as a generalized anxiety disorder, the degree and persistence of which may not correlate with seizure frequency (Goldstein and Harden, 2000). Some patients experience anxiety as a symptom of their seizures, as illustrated in Fig. 7 and described by another individual: “I experience a combination of déjá vu with extreme fear. Nothing I can do takes me out of it. Everything that happens becomes a part of it. The general feeling is like being in front of an oncoming train with no way to escape” (Schachter, 1993).

Paradoxically, anxiety may develop after a patient attains seizure freedom and, therefore, when they take on, as Bladin and colleagues have described, the
“burden of normality” (Wilson et al., 2004). Complete control of epilepsy may be anxiety provoking and requires, as stated by the sculptor Betsy Elliott Zukin, both medical and physical control, which she incorporates into her tightly woven self-portrait (Fig. 8).

C. **Psychosocial Aspects of Epilepsy**

There are very few, if any, aspects of daily living not affected by the diagnosis of epilepsy. Restrictions on independence can be the most socially disabling—in particular effects on employment, driving an automobile, life insurance, and lifestyle. The majority of works in the collection that relate to epilepsy pertain to the day-to-day experiences, in between seizures, of living in society with a
diagnosis of epilepsy. Common subthemes are isolation, stigma, and the impact of epilepsy treatments.

Persons with epilepsy often feel isolated and alone, whether in their own home (Fig. 9) or out in social settings.

Fear of and worrying about having a seizure in public are common among people with epilepsy. Nearly half of a sample of community-based people with epilepsy responding to a survey reported that fear was “the worst thing about having epilepsy” (Fisher et al., 2000a,b). Fear was further described by some respondents as fear that others would witness a seizure, with the embarrassment and humiliation of awakening from a fit with strangers peering down.

Stigma affects the quality of life of people with epilepsy at any age and in every country (Baker et al., 1997; Jacoby, 2002; MacLeod and Austin, 2003; Morrell, 2002). It results in discrimination in the course of everyday activities such as attending school, driving, and working (Jacoby and Jacoby, 2004). Persons with epilepsy may perceive stigma in connection with visible

Fig. 5. Postictal, Jacqui Streeton, 1993, Ink (watercolor wash), 14 × 14 inches. Reprinted from (Schachter, 2003) with permission.


reminders of their epilepsy such as the need for brain surgery (Fig. 10) or taking pills (Fig. 11).

D. Nonepilepsy Related

The subject matter of the majority of the pieces in the collection is unrelated to specific aspects of epilepsy such as shown in Figs. 12 and 13. The importance of sharing this work with society and people with epilepsy and their families cannot be underestimated because it demonstrates that persons with epilepsy can be creative and productive, and can meaningfully contribute to society. This counters the stigma of epilepsy, that is, the notion that persons with epilepsy are defective in some way, with a spoiled identity (Goffman, 1963).
Fig. 11. Imari and Orbs, Roxanne Hilsman, 2003; Oil on canvas. Reprinted from (Schachter, 2003) with permission.

Fig. 12. Springtime, Patricia Bernard, 2000, Acrylic, 16 × 30 inches. Reprinted from (Schachter, 2003) with permission.
IV. Conclusions

The works of contemporary artists with epilepsy offer insightful perspectives into the varied experiences of people with this disorder through the expression of epilepsy-related experiences and demonstration that people with epilepsy can contribute to culture. Interesting research questions are raised as well such as:

Are persons with epilepsy particularly likely to engage in artistic activities? If so, are there specific characteristics to the art or correlations with seizure focus, age of onset, other related cognitive/affective factors, and so on? What testable hypotheses are suggested by the art regarding brain functions (e.g., visual perception, consciousness, affect)?

Answering these questions with further study may bring us closer to a deeper understanding of the meaning of the art of contemporary artists with epilepsy. Even before the answers are forthcoming, however, physicians and the epilepsy community can learn much from the art and appreciate its beauty and value.

References


