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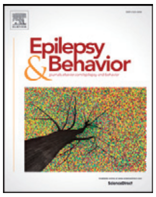

Review

Using artwork to understand and address the psychosocial challenges facing children and adolescents with epilepsy

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ABSTRACT

Artwork is a valuable and underutilized technique for exploring the self-esteem and psychological challenges facing children and adolescents with epilepsy and other chronic diseases. Having children with epilepsy draw a picture of their seizure correlates reliably with seizure type, provides insight into the child's developmental level, and allows expression of inner feelings such as helplessness, vulnerability, and self-concept. Art therapy focus groups are beneficial in helping children with epilepsy express their feelings nonverbally and get to know peers facing similar challenges. On the occasion of Epilepsy and Behavior's 20th anniversary, this article reviews the usefulness of art for exploring the self-concept of patients with epilepsy and acknowledges the journal's support of this informative, inexpensive, and empowering adjunctive technique.

"Special Issue: Epilepsy & Behavior's 20th Anniversary"

1. Introduction

The goals of treating people with epilepsy involve two major domains — biomedical and psychosocial. In the biomedical domain, we treat epilepsy to control seizures, monitor and minimize the side effects of medications, ensure patient safety, and optimize clinical outcome. Psychosocial goals include improving the sense of well-being and self-esteem of the patient, optimizing their educational program, diagnosing and treating comorbid psychological disorders such as those affecting mood and anxiety, and addressing important functions of daily life such as driving, socialization/relationships, sports, and vocation. Psychosocial function is assessed in a number of ways, including detailed history and discussion with families, surveys and checklists, and neuropsychological testing [1]. In addition, adjunctive methods have proven quite informative. These include assessment of the patient's self-concept and psychological function by artwork. Art allows a form of expression of one's internal feelings that can add to or emerge independently of verbal description [2]. In children, this form of self-expression has proven to be extremely informative with regard to epilepsy, as children may be unable or unwilling to express their innermost feelings freely, especially in the medical context. The goal of this article is to review some of the studies that have used artwork to assess neurological and neuropsychological function in children with epilepsy. I hope to convince the reader of the importance of this underutilized technique as an adjunct to the usual clinical assessment. Of note, studies of art in patients living with epilepsy have been an important part of Epilepsy and Behavior's history, making this article particularly timely on the occasion of the journal's 20th anniversary. Indeed, the chief editor and founder, Dr. Steven C. Schachter, has been instrumental in acknowledging and exploring the use of artwork in adults with epilepsy, particularly professional artists who also suffer from epilepsy [3–6]. It is in this spirit, and acknowledging Dr. Schachter's leadership and vision, that this article is dedicated.

2. Psychosocial challenges facing children with epilepsy

Psychosocial challenges facing children and adolescents with epilepsy are numerous and well-recognized [1,7,8]. These include increased incidence of depression, anxiety, social and emotional adjustment, and low self-esteem. Children with epilepsy must learn to cope with the unpredictable nature of seizure occurrence, need to take medications on a routine basis, deal with the multifarious side effects of medications often causing drowsiness and cognitive impairment, loss of independence with regard to usual peer activities, and the social stigma that accompanies this disorder [9]. For example, seizures may occur in public, without warning, and can involve embarrassing signs such as drooling, shaking, and abnormal vocalizations. When a seizure occurs at school, psychosocial ramifications can be particularly impactful on peer relationships. The need to be pulled out of class to receive medications, or worse yet, to have a seizure in the classroom with the attendant drama of emergency medical care, can negatively affect the self-esteem of children and adolescents. While each child copes with his or her challenges in a different way, the common features of epilepsy force all affected individuals to learn to cope with stresses and

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challenges, often without significant professional support. In that sense, focus groups have been helpful for introducing children to others with similar challenges, encourage a group dynamic to discuss strategies and learn coping skills [8,10–12]. Two striking observations have emerged from the literature and from clinical experience. First, many children with epilepsy have never met another person afflicted by seizures. Second, the impaired coping mechanisms and psychological effects of epilepsy far outpace those of other chronic disorders of childhood such as diabetes, asthma, and even cancer [13–16].

Because the specific psychosocial challenges of epilepsy can be embarrassing and are imbued with stigma, patients are often hesitant to discuss their inner thoughts, feelings, and fears with either family members or medical professionals. In that regard, the use of projective techniques such as art have proven to be quite illustrative in bringing out inner feelings in a nonverbal way. This information can be combined with the verbal information derived from the medical history to provide a more complete view of the child and his or her adjustment to epilepsy. Yet, the literature analyzing children's drawings and other art techniques is scant. Earlier studies evaluated art by children with epilepsy in terms of artistic technique, drawing errors attributed to transient motor or cognitive dysfunction caused by a seizure [17], the delayed developmental aspects of art produced by children with epilepsy [18], and visual phenomena experienced during a seizure [19]. Only recently has research begun to explore the subjective aspects of childhood seizures and what children's drawings may reveal about a child's self-concept, self-esteem, behavioral adjustment, and other psychological variables [20–23].

3. The role of art therapy in epilepsy

The field of art therapy has expanded our perspective and understanding of the inner lives of patients, including children with epilepsy. Art therapists are trained to analyze the emotional aspects of artwork produced by patients and are expert in interpreting the content and inferring meaning in terms of internal feelings and emotions, outlook, and self-esteem [24]. In addition, art therapists working with children provide a unique perspective on the developmental level of a young artist. Therapists utilize a number of specific, reproducible techniques and methods that have been validated within the art therapy community but which might not be as familiar to neurologists. These include the Formal Elements Art Therapy Scale (FEATS) [25] and the Levick Emotional and Cognitive Art Therapy Assessment (LECATA) [26].

In collaboration with an art therapist, Janice Havlena, Professor of Art at Edgewood College, Madison, Wisconsin (now retired), I have undertaken a number of studies of children's art and epilepsy. Our first study evaluated the self-esteem of children seizures and epilepsy [20]. As opposed to many medical disorders in which a patient is able to recollect an event or symptom, children with epilepsy cannot typically remember their episodes or seizures (with the exception of those having focal aware seizures, a distinct minority). Therefore, any information consciously accessible to a patient has been necessarily obtained by listening to others describe their ictal behavior. That is, parents or caretakers, physicians, nurses, or other observers may describe a child's seizure to others in the patient's presence, and whatever is discussed is internalized by the patient. For example, the mother of one of my patients nonchalantly described her son's generalized tonic–clonic (GTC) seizures as “looking like a fish flapping around on the ground.” That boy's self-esteem was influenced profoundly by this description. He displayed no outward signs of low self-esteem or depression and did not endorse depression or anxiety on standard screens, but when asked to draw a picture of his seizure, the boy drew the image seen in Fig. 1A, depicting himself as a fish out of water, shaking (indicated by wavy lines), struggling, and gasping. These artistic features are suggestive of low self-esteem. Such dramatic examples provided the rationale for more detailed analysis of seizure drawings, as described below.

4. How children interpret their seizures — the seizure drawing task

During pediatric neurology clinic visits, we asked 105 children, with epilepsy, ages 5 to 18 years, to draw a picture of what is like to have a seizure [20]. We gave no further directions so as not to introduce bias, but if the patient asked for more specific instructions, we suggested showing how they feel about the seizure experience (before, during, or after), what they might look like when they are having a seizure, and what type of seizure(s) they have. The results proved to be quite concordant with the actual seizure type and diagnosis. That is, children with GTC seizures drew themselves shaking or vibrating, those with absence seizures depicted blank stares, and those with focal unaware seizures depicted confusion or unresponsiveness (Fig. 1). Evaluation of these seizure drawings allowed several conclusions. First, as just described, seizure drawings were representative of the actual seizure type, and seizure type could be predicted by neurologists naïve to the clinical history. Therefore, children must be listening as their parent or others describe their seizures and they are internalizing this information, either consciously or subconsciously, to permit such an accurate correlation. Second, many children's drawings displayed distinct and sometimes disturbing emotional content. For example, a 10-year-old boy depicted himself sitting in a classroom, a tiny figure within the large frame, with a red liquid oozing down the wall; when asked about the red, he said it was blood (Fig. 7B in reference [20]). Another boy drew himself inside a box, with all extremities shaking; he depicted himself yelling “let me out” and said that the box was his coffin (Fig. 2B in reference [20]). Such dramatic artistic renditions and feelings were not forthcoming on routine clinical history, and these children obviously required prompt psychiatric evaluation. Therefore, art provides a window into a child's mental life that is not always apparent on routine neurological assessment. Third, many children with epilepsy, even those with normal intelligence, drew pictures that were immature for their age, in terms of expected developmental artistic markers. Examples include a 15-year-old girl who drew herself on her bed with Sponge Bob sheets and pillowcase (suggestive of a slightly lower developmental level or at least preference for a bedding style usually preferred by much younger children) (Fig. 1A in reference [27]). Her limbs lack joints, she is elevated above the bed (indicating a lack of “grounding”), and there is marked distortion of body proportions, especially head and neck. Even acknowledging that children display a wide spectrum of artistic abilities at any age, those with epilepsy produced artwork that was developmentally behind their age levels. We concluded that artwork produced by children with epilepsy depicted evidence of low self-esteem, helplessness, and vulnerability; the drawings were less developed for age; and that the drawing features were consistent with seizure type. Others have demonstrated specific depictions of anxiety in the drawings of children with seizures (distorted body images and omission of feet on the Draw-A-Person task) that correlated with psychometric measures of anxiety (State–Trait Anxiety Inventory for Children) [22].

5. Using artwork as a therapeutic modality — focus groups

Children and adolescents with epilepsy demonstrate ample evidence of lower self-esteem and a variety of psychological comorbidities, many obvious on their seizure drawings. In an attempt to translate these findings into a therapeutic intervention, we organized art therapy focus groups of children with epilepsy as an attempt to improve their self-esteem [27]. Groups of 4–5 participants of similar age met for four weekly sessions of 90 min each, working on a different art project each session, with facilitated discussion about their art and their feelings about their epilepsy by trained art therapists. The goals and methods of these art therapy focus groups are detailed elsewhere [28]. In brief, each session was designed with a particular purpose in mind (Table 1). Before and after the series of art therapy sessions, children and parents completed a set of assessments and screening questionnaires chosen to explore various measures of self-esteem and psychological status.

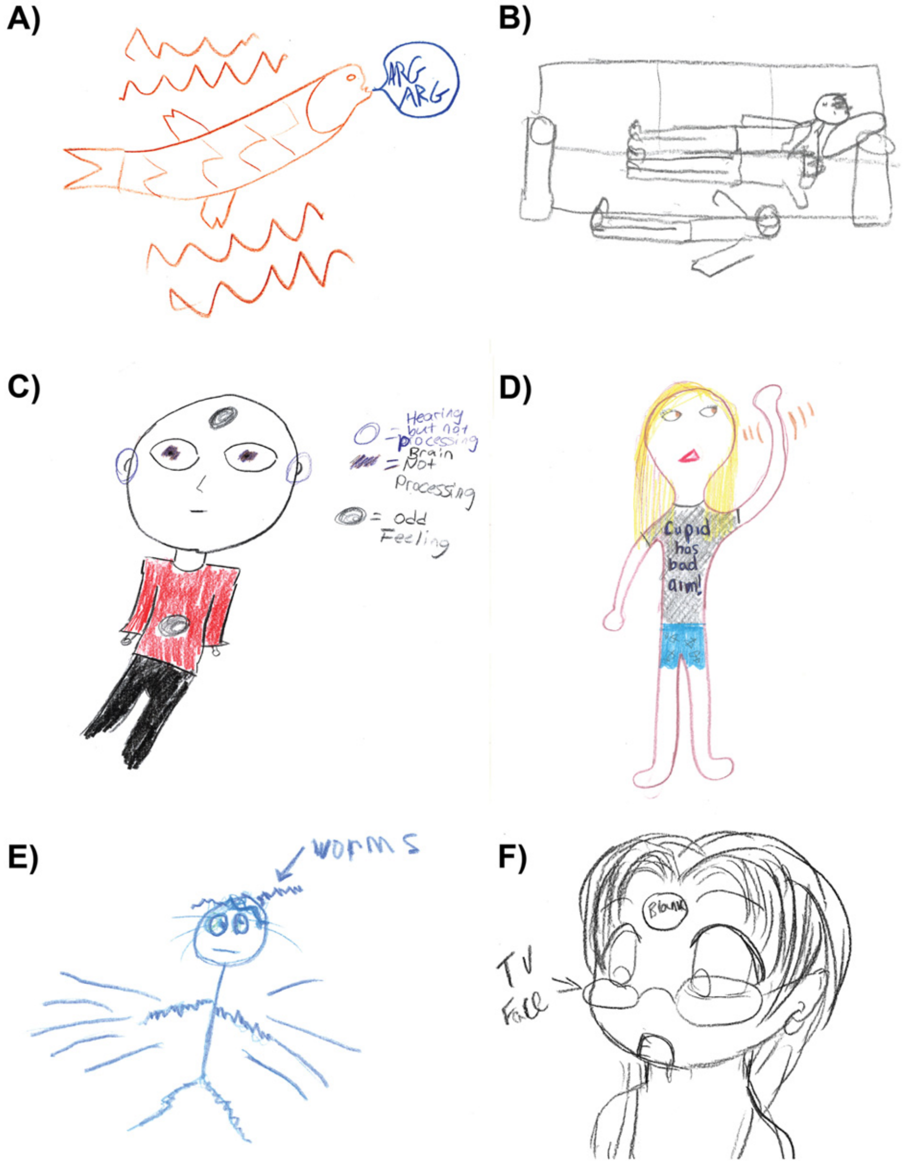

Fig. 1. Examples of children's seizure drawings to illustrate seizure type and developmental art level. A. Generalized tonic–clonic (GTC) seizure illustrated by 9-year-old boy whose mother described him as "looking like a fish flapping around on the ground." The fish/child is depicted as making gasping sounds related to impaired breathing. The wavy lines reflect shaking. B. 17-year-old boy with a brain tumor and focal unaware seizures that subsequently spread bilaterally; he illustrates himself falling off the couch with a GTC. Note the incomplete, irregular body outline and structure including poorly formed hands and feet, indicative of depression. C. 11-year-old boy with focal unaware seizures showing confusion and foggy thinking with poor "processing" (as indicated in his legend). He can hear but not process information. Hands and feet are tiny or nonexistent, again, representing signs of depression. D. 11-year-old girl with focal unaware seizures with motor component involving leftward head and eye version and extension and shaking of the left arm. Her T-shirt reads "Cupid has bad aim" suggesting low self-esteem that was verified clinically. E. 12-year-old boy with GTC depicts shaking of all of his extremities, as well as worms "crawling inside his head", the latter being evidence of abnormal thinking and implicating an external cause (worms). The body formation is below age level. F. Absence seizure in a 17-year-old girl, denoted by feeling "blank" and having a "TV face", that is, staring with lack of facial emotional expression. Her artistic ability is obviously quite good.

Pre- and postgroup assessments included psychological screens (Piers-Harris Children's Self-Concept Scale; Childhood Attitude Toward Illness Scale; Impact of Childhood Neurologic Disability Scale) and art therapy instruments (Seizure Drawing Task [20], FEATS, LECATA). Details of these assessments are available elsewhere [27,29,30].

At the first session, children were asked to produce a self-portrait in the form of an "inside–outside" box. They were asked to use pictures cut from magazines, freehand sketches, or any other media they chose to decorate their box. On the outside of the box, the children were asked to indicate how they present themselves to the world (external

Table 1
Art therapy focus groups.

Session	Theme	Art technique	Goal
1	Self-portrait: inside–outside box	Collage, drawings	Introduces participants to each other, encourages interpersonal engagement
2	Memory or feeling about epilepsy	Drawings, painting	Allows sharing of similar and dissimilar experiences and feelings about seizures
3	Mandala of personal symbols	Drawings	Endorses important relationships, values, beliefs, and ways to participate in the world
4	Dream or goal for the future	Digital photograph within diorama	Sharing of goals, dreams, and achievements

presentation) and how others see them, whereas inside the box, they should present their innermost feelings that they might hesitate to express to others. This session served as a way for the participants to get to know one another in a safe environment and develop rapport and trust in peers and facilitators as they share sensitive feelings. Of note, most of these children never previously met another child with epilepsy. Therefore, this art activity and discussion enhanced group dynamics and interaction. An example of an inside–outside box is seen in Fig. 2A. This 7-year-old girl places a picture of a doctor on the outside of the box, indicating her frequent exposure to the medical profession. Inside the box, she states that "I am afraid of the dark" (spelling corrected), reflecting one of her innermost fears.

The second session's project delved into more sensitive territory, involving a drawing or watercolor painting of a memory or feeling about epilepsy. Participants needed to recall a seizure or its aftermath, which, for most children, was quite emotionally laden, and dramatic artwork ensued. An example is seen in Fig. 2B, in which an 18-year-old young woman depicts her experience of a seizure, which caused her to fall in the shower and incur a black eye. Outside the shower, an image of her mother is seen, providing both a sense of security that there is a caretaker nearby but also portending the lack of independence for routine activities like showering, which, for most teenagers, does not require a parent hovering nearby. The unpredictability of seizures was a common theme discussed in the focus groups. Another teenager drew a picture that she called "the sleepover from hell." She had forgotten to bring her medication along to her friend's house for a sleepover and had a seizure in the middle of the night. She drew herself crawling away from her friends to find the host parent, while her friends slept peacefully (Fig. 4.2 in reference [28]). In the corner of the painting, an empty pillbox was depicted. Other drawings from this session illustrated similarly embarrassing situations such as falls, the sensation of walking in a thick fog and losing one's way home from school, and embarrassment about taking medication at school. Despite the emotional challenge of discussing these sensitive issues, group participants ended up sharing readily and derived positive reinforcement during the sessions from the other children. These dramatic illustrations reinforce the hypothesis that inner feelings about epilepsy can be expressed and discussed in art therapy focus groups.

In the third week, children were asked to produce a "mandala" indicating symbols of strength. A mandala is a circle with four quadrants, each quadrant indicating a symbol of empowerment for the patient. One quadrant required the child to indicate important persons in his or her life; another quadrant was to indicate a safe, comfortable location or place. In the third quadrant, participants were asked to indicate a value or belief that is good for the world or serves a source of strength for the person, and the fourth quadrant was to represent how the patient can contribute to the world or something they can do for others. As seen in Fig. 2C, a 12-year-old boy draws his parents as his main source of strength, camping with his grandpa, aunt, and uncle as a favorite and comforting activity, his religious affiliation as a value that is good for the world, and he contributes to society by volunteering at a nursing home, transporting people in wheelchairs around the facility. We found that parents were most often illustrated as the relationships most important to the child, with friends and pets also drawn frequently as sources of strength and support. It was quite revealing that, despite the challenges and disabilities of their own epilepsy, these young people

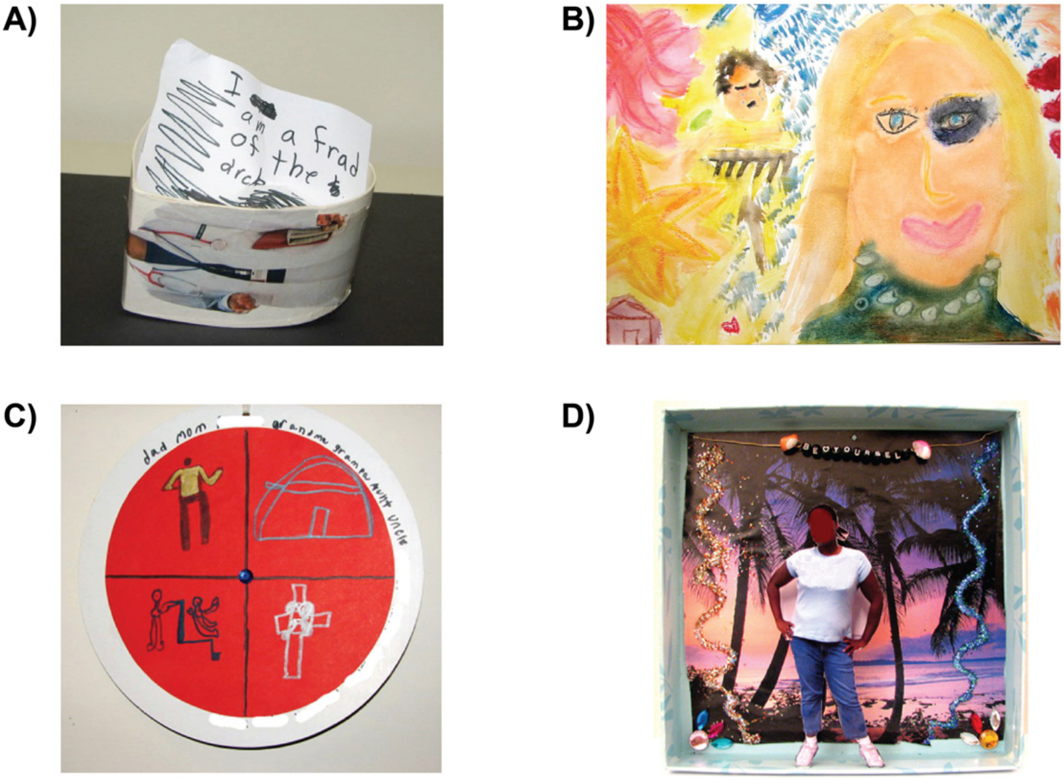

Fig. 2. Examples of art focus group creations by four children with epilepsy. A. First session: 7-year-old girl shows an inside–outside box to introduce herself to the group and illustrate her outer presentation to the world as well as inner feelings, thoughts, and fears. On the outside of the box, a physician is depicted, indicating the girl's frequent and ongoing exposures to the medical system. Inside the box, she is "afraid of the dark" an expression of inner fear and anxiety. B. Second session: A "feeling or memory of epilepsy" was illustrated by an 18-year-old girl who fell in the shower and incurred a black eye. Her mother (with stern/concerned facial expression) is right outside the shower (blue lines), offering assistance but also indicating her daughter's limited independence. C. Third session: A "mandala of personal symbols", with a 12-year-old boy indicting, in the four successive quadrants (clockwise from upper left): close personal relationship and dependence upon his parents, comfort and pleasure derived from camping with relatives, importance of religion is a strong value, and contribution to society by volunteering at a nursing home, transporting elderly clients their wheelchairs. D. Fourth session: A "vision or goal for the future" is depicted by a teenage girl (face blurred digitally). She has traveled to a tropical region with a beautiful sunset, glittery designs and jewels, and an admonition to "Be yourself." A and B are reproduced from reference [27], with permission from Elsevier.

Table 2
Selected quotes from focus group participants.

"Our daughter excitedly showed us her artwork and told us what you did each week. Until now, she has refused to talk to us about her epilepsy. She always ran from the room, crying."
— Father of 12-year-old girl
"This was relaxing. It was good to talk about how hard it is to tell your friends you just can't hang out and party, with people who know what you're up against."
— 17-year-old girl
"The final session's art project asked us to think about our future, which we don't do at school, and I liked that."
— 13-year-old boy

often gave freely of their time to volunteer and pursue charitable activities.

Finally, the fourth session involved setting a dream or goal for the future. Children obtained "selfies" on their cell phones and placed the image inside a panorama scene depicting a goal or dream. This empowering activity ended the focus groups on a positive note, with each young person envisioning their future and working toward it, symbolically. By far, this project was the favorite session for most children. They depicted themselves as independent adults, often married, traveling, or living in another part of the country, and engaged in an occupation of choice. One boy drew himself amidst a bug collection at a science fair; he wants to become an entomologist (see Fig. 2D of reference [27]). In Fig. 2D of this article, a teenager depicts herself rather confidently, hands on hips, enmeshed in a diorama box of a tropical scene with palm trees, sparkles, and jewels, with the admonition to "Be yourself." Others were similarly positive with statements such as "Live life", "Be the change you want to see in the world", and "Just try it!" These dioramas suggest that, despite all of the challenges faced by children and adolescents with epilepsy, they maintain resiliency and inherent optimism that is reassuring and encouraging.

In our small cohort of patients, none of the pre- or postscores on the neuropsychological assessments listed above reached statistical significance. We suspect that overall, the children who chose to participate in the focus groups, recruited from the author's pediatric neurology clinics, were already somewhat higher functioning than a random population of children with epilepsy. This notion was verified by the relatively high prescores on the Childhood Attitude Toward Illness Scale (CATIS) [27]. Also, the sample size of participants who completed the series of focus groups was quite small ($n = 16$). Despite the lack of statistical significance on these measures, qualitative analysis of postfocus group comments revealed uniformly positive feelings about group participation (examples, Table 2), and participants were unanimous when asked if they would recommend such groups to others.

Therefore, although this preliminary study involved only 16 participants, some clinically relevant findings emerged. We conclude that art is an enjoyable way for people of all ages to express their feelings and emotions about epilepsy. Focus groups let children bond with others who face similar challenges and strengthen their self-image in a supportive environment. The enthusiasm of the participants was palpable.

6. Discussion

Our studies of artwork in children with epilepsy add to the numerous other chronic disorders in which art has been found to be useful subjectively and objectively. Such disorders include physical or mental abuse, chronic pain, and headache [31–36]. While each of these disorders is chronic in nature, epilepsy presents unique psychosocial challenges to affected patients and families. Children are not aware of most aspects of their seizures; they occur unpredictably and often in contexts that are embarrassing or inconvenient, and the historical and persisting stigma of epilepsy differs from other chronic disorders. Therefore, it is imperative to consider all of the psychosocial aspects of the patient's experience, and medical care providers dealing with epilepsy on a daily basis should consider using a variety of art techniques to enhance our practice and optimize the lives and function of our patients. The technique is inexpensive and easy to perform and, in my experience, does not add substantially if at all to the duration of the clinic visit. And the information obtained is fascinating, actionable, and empowering for children.

Artwork produced by children with epilepsy, who are by no means professional artists, in my view, is as poignant and informative as that produced by professional artists [3–5]. Furthermore, pathophysiological as well as psychosocial insights might be obtainable from children's art. For instance, differences may exist between the visual phenomena experienced by children with migraines and those with seizures; migraineurs most often depict their visual auras by zig zag lines and fortification designs [31,37], while those with occipital lobe seizures tend to draw circular colored blobs [38]. To support the contention that artwork can help to understand pathophysiology, a creative study used art to explore epilepsy in inpatients on an epilepsy monitoring unit (EMU) [39]. In a free-drawing task, the EMU patients were asked to draw "anything of their choosing." The FEATS analysis revealed that certain artistic features could distinguish temporal lobe seizures from other seizure types. Drawings of patients with temporal lobe seizures were more "unbalanced" and "lacked integration" compared with drawings of patients with epilepsy with other seizure types of with nonepileptic events (NEE; abbreviation per authors [39]). Intriguingly, patients with NEE differed markedly from patients with epilepsy regardless of site of epileptic focus or seizure type — NEE drawings used significantly more colors and employed them much more boldly and dramatically than patients without NEE. Furthermore, NEE drawings contained more complex body outlines. Another EMU study used sculptures – standardized Styrofoam heads devoid of facial features – which patients could draw on and decorate using a variety of media such as colored pipe cleaners and feathers [40]. The authors found marked differences between sculptures created by patients with epilepsy versus those with psychogenic nonepileptic seizures (PNES), concluding that patients with PNES focused more on the emotional experience of a seizure-like event whereas those with epilepsy focused on physical sensations of a seizure. For example, patients with epilepsy might fold pipe cleaners into zigzag shapes resembling lightning bolts to indicate the shock-like aspects of an epileptic seizure, whereas those with PNES more often depicted indicators of trauma such as bruised eyes or depressive features, focusing on dark colors such as black and brown. Both of these EMU studies just touch the tip of the iceberg with regard to opportunities to explore psychosocial and even pathophysiological aspects of epilepsy. Prolonged hospitalization of EMU patients, waiting for seizures to occur, provides an inherently "captive audience" in which to enact art-related investigations and therapeutic interventions.

Of course, the production of artwork by persons with epilepsy is not new. Through history, persons with epilepsy have illustrated their affliction in most dramatic forms [41,42]. One has only to recall some of the art of Vincent van Gogh to appreciate the depth of self-expression among epilepsy sufferers [43]. Dr. Schachter has facilitated the vision of using artwork of adults with epilepsy, and there is so much more to be learned with this modality. One approach is the Studio E project of the Epilepsy Foundation, a program aiming to engage people with epilepsy in art therapy groups over several weeks, using a wide variety of artistic modalities; participants create art using media such as painting, drawing, collage, and sculpting, and work with professional art therapists to explore their feelings and symptoms (www.epilepsy.com/living-epilepsy/our-programs/studio-e-epilepsy-art-program, accessed September 10, 2019). The accumulating data from artistic self-depictions of seizure activity inform our understanding of consequences of seizures and epilepsy on a patient's daily life and can provide invaluable insights into a child's or adult's ongoing adaptation to their chronic condition [28]. The techniques described here are simple, inexpensive, and thoroughly enjoyable for children, and add immeasurably to our ability to care for these patients.

Declaration of competing interest

None.

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