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Group Art Therapy for the Psychosocial Dimension of Epilepsy: A Perspective and a Preliminary Mixed-Methods Study
L'art-thérapie de groupe en lien avec la dimension psychosociale de l'épilepsie : une étude préliminaire à méthodes mixtes et le point de vue qu'elle propose

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ABSTRACT

This article consists of a preliminary study that chronicles an 8-week group art therapy program for people with epilepsy, located in a fine-art museum setting. The study is situated in theories of psychosocial stigma. The primary purpose was to explore whether art therapy could be an effective method to address the psychosocial component of epilepsy treatment in Canada. Secondary questions explored the roles of an open-studio approach and an art therapy program delivered in a fine-art museum context. A mixed-methods (convergent, parallel) design examined the program's impact for six adults between the ages of 18 and 45 with epilepsy. Psychosocial questionnaires and interviews were administered before and after the group program, and session artworks were examined with Appleton's (2001) art therapy trauma paradigm. Two groups were compared based on attendance (i.e., attend versus no-attend). Participants who had attended group sessions had substantially reduced scores on questionnaires assessing stress and depression and increased scores on questionnaires assessing self-esteem and quality of life compared to participants who did not attend. The interviews revealed that art therapy increased the attend group's ability to talk about the impact of epilepsy, to express grief, to make social connections, to navigate treatment stress, and to foster emotional regulation. Group art therapy may improve the psychosocial treatment dimension of epilepsy while acknowledging systemic stigma and social barriers.

RÉSUMÉ

On présente une étude préliminaire qui relate sous forme de chronique un programme d'art-thérapie de groupe échelonné sur 8 semaines se déroulant dans le contexte d'un musée des beaux-arts et qui est destiné à des personnes souffrant d'épilepsie. L'étude s'inspire des théories sur la stigmatisation psychosociale. Elle a pour principal objectif d'explorer si l'art-thérapie pourrait constituer une méthode efficace pour aborder la composante psychosociale du traitement de l'épilepsie au Canada. Parmi les questions secondaires, citons l'exploration des rôles dans une approche de studio ouvert et un programme d'art-thérapie se déroulant dans le contexte d'un musée des beaux arts. On a eu recours à un concept de méthodes mixtes (convergente, parallèle) pour examiner l'impact du programme sur six adultes âgés de 18 à 45 ans et atteints d'épilepsie. On a mené des entrevues psychosociales et soumis des questionnaires avant et après le programme de groupe, puis on a utilisé le paradigme d'Appleton pour faire les comparaisons. On a comparé deux groupes en fonction de leurs présences (c.-à-d. les personnes qui étaient présentes comparativement à celles qui ne l'étaient pas). Les personnes qui étaient présentes aux rencontres de groupe présentaient des scores considérablement moins élevés dans leurs réponses aux questionnaires sur le stress et la dépression, ainsi que des scores plus élevés dans les questionnaires d'évaluation de l'estime de soi et de la qualité de vie comparativement aux membres qui étaient absents. Les entrevues ont révélé que l'art-thérapie avait permis d'accroître l'aptitude des membres du premier groupe à discuter des effets de l'épilepsie, à exprimer leur douleur, à établir des liens sociaux, à s'adapter au stress du traitement et à favoriser la régulation des émotions. L'art-thérapie de groupe peut améliorer la dimension psychosociale du traitement de l'épilepsie, tout en reconnaissant la stigmatisation systémique et les obstacles sociaux.

The following is a research report on a mixed-methods pilot study that investigated how group art therapy offered in a clinical-community setting may affect the experiences of adults (aged 18 to 45) with epilepsy. Inspired by Studio E (Epilepsy Foundation, 2018), this preliminary study explored the integration of art therapy as a psychosocial treatment modality of epilepsy in Canada. It investigates how group art therapy can positively impact the psychosocial dimension of epilepsy, including effects on self-esteem, depression, and overall quality of life.

Multiple factors can contribute to the systemic exclusion of people with epilepsy with resulting detriments to their mental health. Chew et al. (2019) described three interconnected factors that relate to self-esteem for young adults with epilepsy as "barriers to doing," "barriers to being," and impairment effects. If unaddressed, these factors can lead to social isolation, reduce self-esteem, and limit the participation of young adults with epilepsy in the world around them (Chew et al., 2019). Mondanaro (2008) emphasized a "symbiotic" affiliation between epilepsy and depression. This is illustrated by Canada's comorbid epilepsy and depression rates at up to four times higher than the general population's (Macrodimitris et al., 2011) and with a significantly higher risk for suicide than the general Danish population (Christensen et al., 2007). From a theoretical lens, Brofenbrenner's (2005) bioecological systems theory is applied to the historical and psychosocial contexts of epilepsy to examine the complexities of perceived and enacted stigma (Baker, 2002).

Group art therapy is presented as an appropriate modality to engage people with epilepsy who have experienced psychosocial stigma and related traumatic stress. Bruckland (2015) stated that "art therapy provides a way of working with illness-related experiences when words alone feel too challenging or painful" (p. 176). In particular, the community studio model of art therapy is employed based on its emphasis on social inclusion, engagement, integration, and the creation of a safe space (Timm-Bottos, 2006). In addition, the potential for revisiting memories of psychosocial stigma using a clinical-community art therapy framework is explored. This may provide for the formulation of new neural pathways (Lobban, 2014) and for opportunities to rescript one's personal narrative. Case vignettes of group engagement with the museum landscape as a co-facilitator will be highlighted (Salom, 2008).

The power of integration is discussed concerning how a collaborative process can address systemic exclusion and take agency to reshape and redefine institutions, bridging hierarchies in order to create a more inclusive society. As we move toward a more representative paradigm, collaborative art therapy programs in museums (i.e., engaging systems of health care, education, culture, and government via research) may represent a shift toward dialoguing with such hierarchies and a portal toward healing psychosocial stigma.

Situating the Primary Researcher

My own experience as someone who developed epilepsy at age 13 and lived with it until the removal of a benign brain tumour at age 25 (14 years ago) has framed this research project. I experienced psychosocial stigma in my formative years with only a fictional character (Caitlin) on the television program *Degrassi Junior High* (Degrassi Wiki, n.d.) as my epilepsy reference. Not knowing anyone else with the condition for most of my adolescent years, I learned that disclosure could mean exclusion and ostracization; as a result, I found epilepsy very difficult to discuss. Once I understood that I needed psychosocial support, I realized that it was not offered widely within the epilepsy treatment model. Following my successful neurosurgery, I began a self-directed, multimodal creative healing process. What started as independent healing work became a collaborative performance with a community of artists. Ten years later, this inspired me to become an art therapist and to specialize in working on the psychosocial dimension of epilepsy and of other chronic conditions through my research.

Epilepsy

Hermann et al. (1992) characterize the impact that epilepsy has on one's life in terms of three dimensions: the neuroepilepsy dimension (which includes neurological diagnostic information and physical characteristics), the medication dimension (which covers the chemical interventions of anticonvulsants and their interactions with the body's chemistry), and the psychosocial dimension (which includes dynamic psychological variables such as the wide spectrum of perceived stigma and discrimination, social isolation, concepts of control, levels of independence, family support, the home environment, socio-economic status, and the acceptance and adjustment to the condition).

For those undergoing treatment for epilepsy, seizures often are only the tip of the iceberg (Havlena & Stafstrom, 2013). About 1% of the American population has a formal epilepsy diagnosis, making it the fourth most common neurological disorder in the U.S., with over 40 different types of epilepsy and 20 different types of seizures (Epilepsy Foundation of Michigan, 2016).

In 2014, the International League Against Epilepsy offered an operational definition of epilepsy and included parameters for people to lose the diagnosis, partially in the interest of reducing social barriers and comorbidities.

Epilepsy is a disease of the brain defined by any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring more than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome. Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but who are now past the applicable age or those who have remained seizure-free for the last 10 years and who have not taken any seizure medication over the last 5 years (Fisher et al., 2014, p. 476).

A diagnosis of epilepsy can bring negative changes in feelings of self-worth as well as a fragmentation in the sense of self, personal identity, and sense of control (Bruckland, 2015). People living with this condition often experience psychological consequences such as anxiety and depression. Macrodimitris et al. (2011) reported rates of anxiety at 15–25% in people with epilepsy, compared to rates of 2.5–6.5% in the general Canadian population. In Canada, depression affects 4.5% of the general population. However, for people with epilepsy, the rates of depression are estimated at 9–22% in community settings and at 27–58% in tertiary care epilepsy centres (Macrodimitris et al., 2011). Mondanaro (2008) contended that a lack of focus on psychotherapeutic dimensions of treatment and perhaps an overemphasis on symptom prevention have led to a high rate of non-compliance with young adults, which has been found to account for 50% of Sudden Unexpected Death from Epilepsy (SUDEP) cases (p. 106).

Other psychosocial consequences can include social isolation, discrimination, low self-esteem, and underemployment (Baker, 2002; Chew et al., 2019). As such, epilepsy is a condition that carries the weight of psychosocial stigma. Understandably, much of the research on the treatment of epilepsy has focused on the neurological underpinnings of the condition, perhaps at the expense of targeting its psychosocial dimension. The research reported here is an attempt to contribute to the growing focus on the psychosocial dimension.

Theoretical Framework of the Psychosocial Dimension of Epilepsy

Hermann and Jacoby (2009) asserted that in the social context of epilepsy, "there are different ways of 'knowing,' different social values assigned to people with epilepsy, different healthcare systems, and different social structural factors at work" (p. S15). To frame this, Bronfenbrenner's (2005) bioecological theory is employed to provide a comprehensive understanding of the social mechanisms of stigma and of the impact of stigma on human development. The theory states that there are nested, interactive layers of environmental systems that influence human development: the microsystem, the mesosystem, the exosystem, and the macrosystem (Bronfenbrenner, 2005; Paquette & Ryan, 2001) and that the interplay of these systemic layers can mobilize or inhibit stigmatizing factors.

The layers include the microsystem, which is comprised of the body (biological factors), emotional systems, and cognitive functions. This layer also includes bodies of contact in the immediate environment such as family, school, daycare, and neighbourhood (Berk, 2000). The mesosystem layer encircles the microsystem, providing a realm of influence between different interpersonal structures, including one's parents and school (Paquette & Ryan, 2001). The exosystem represents larger social spaces such as a community or society at large. It impacts development by influencing structures in the microsystem, including parents, school environments, and religious bodies where relevant (Berk, 2000). The exosystem interacts with the outermost macrosystem, which encompasses cultural values, customs, and laws (Berk, 2000). All of these nested layers are influenced in turn by the passage of time in both personal and historical contexts (Brofenbrenner, 2005).

The Stigma of Epilepsy as an Invisible Disability

Hirschberger et al. (2005) drew on terror management theory to describe the social prejudice against people with disabilities, positing that people "avoid individuals with disabilities because disability reminds observers of their own physical, vulnerable nature, which will lead to decreased compassion, especially when thoughts of death are aroused" (p. 246). Epilepsy can be described as an invisible disability in the sense that, when latent, it does not have any visible symptoms. This leads to a kind of stigma. Lortie et al. (2007) contended that the stigma toward people with epilepsy encompasses negative views of epilepsy as being unacceptable and disturbing and that these prejudices are rooted often in ignorance and fear, reinforced by the unpredictable, "surprise" nature of seizures, particularly tonic-clonic seizures during which people's bodies convulse.

According to Baker (2002), there are two types of stigma involved when discussing the quality of life for patients. Perceived stigma describes people's fears of how others will react to their condition, whereas the enacted stigma, which involves the actual reactions of others, can be the manifestation of these fears.

Traumatic Stress in Chronic Conditions

Chronic conditions such as epilepsy can disrupt the development of a person's sense of self-identity (Carr, 2014). McCann and Pearlman (1990) put forward Figley's (1986) description of "trauma as the response rather than the stressor," representing "*an emotional state of discomfort and stress resulting from memories of an extraordinary, catastrophic experience which shattered the survivor's sense of invulnerability to harm*" (p. 13). In terms of epilepsy, this could represent threatening events and cognitions regarding the psychosocial, neurobiological, and chemical dimensions of the condition (Hermann et al, 1992). Traumatic seizures could involve the internal source of Edmondson's (2014) "enduring somatic threat" that includes threatening cognitions as temporal-based stress responses to chronic conditions yet can occur in an external social context (Hermann & Jacoby, 2009), instigating an internal psychosocial response that can diminish self-esteem (Chew et al., 2019). In a study assessing the relationship between trauma, post-traumatic stress disorder (PTSD), and chronic medical illnesses (including epilepsy), Sledjeski et al. (2008) found a graded relationship between PTSD and the frequency of traumas. In terms of chronic illness, cumulative trauma could build across a lifespan, including periods when seizures may not be under control.

Art Therapy

According to the Canadian Art Therapy Association, art therapy "combines the creative process and psychotherapy, facilitating self-exploration and understanding. Using imagery, colour and shape as part of this creative therapeutic process, thoughts and feelings can be expressed that would otherwise be difficult to articulate" (Canadian Art Therapy Association, n.d.). Riley (2001) contended that art can be a therapeutic tool for change, positing that "art as an integral part of the communication in group is invaluable. It is a support and provocation to change" (p. 32).

Processing Psychosocial Stigma and Medical Trauma

Bruckland (2015) stated that "art therapy provides a way of working with illness-related experiences when words alone feel too challenging or painful" (p. 176). Whether such experiences involve trauma related to seizures, stressors regarding epilepsy treatment, negative experiences associated with psychosocial stigma, or complex feelings regarding survivor's guilt, art can provide a container for intense emotions (Czamanski-Cohen & Weihs, 2016). Artmaking acts as a mediator (Morgan et al., 2012), providing an "intermediate step that facilitates the externalization of somatic knowledge" (Czamanski-Cohen & Weihs, 2016, p. 65).

Regarding epilepsy, art therapist Michel Ledoux referred to such experiences as "body memories" (Jones, 2005, p. 23). Bruckland (2015) asserted that individual case study work with a 28-year-old man with epilepsy (using collage and drawing) "offered a chance to understand the complex efforts to normalise the daily aspects of his changed identity, self-image and shame associated with a lack of control" (p. 182). Art therapy allowed the client to address feelings of vulnerability and frustration about the loss of time, incorporating an outlet of artistic exploration via journaling that helped regulate affect even after the therapy sessions came to an end (Bruckland, 2015). Keller (2001) relayed that relaxation techniques and body-sensing-imagery exercises can help patients visually address medical-related trauma that they may not be ready to discuss.

In art therapy, past traumatic events can manifest in art media without being verbalized (Saltzman et al., 2013). As the survivor's brain systems related to trauma are activated, artwork serves as a container for the memory (Saltzman et al., 2013). The survivor engages with the artwork/memory to the extent that is personally tolerable and over multiple exposures can become desensitized (Saltzman et al., 2013). Working with combat veterans who had multiple and prolonged exposures to traumatic stress, Lobban (2014) conducted a 2-hour group art therapy program whose first hour was spent in open-studio artmaking and whose second hour was spent in a group discussion of artworks. Participants stated later that they felt connected, spontaneous in the process, open to addressing emotional material and finding meaning, and inspired by the ability to convey bodily sensations (stress responses) through art materials such as clay. These statements suggest the formation of new neural pathways, enabling participants to gain mastery over their traumatic memories in order to create a verbal narrative to help promote structural reintegration (Lobban, 2014).

Artmaking and witnessing processes are essential to work toward the reintegration of traumatic experiences (Hinz, 2009; Lusebrink, 2004; Moon, 2016). In a group setting, such processes provide opportunities for community building and social integration (Yalom & Leszcz, 2005) that are essential for treating chronic traumatic stress (van der Kolk, 1987). Community art studios or art hives (Timm-Bottos & Chainey, 2015) provide a forum for people to connect and to "rebuild the organization of the brain—from the bottom up" (Timm-Bottos, 2006, p. 18), allowing participants to work toward mastery of trauma (Lobban, 2014), to reconstruct their personal narrative by finding meaning (Allen, 1995), to engage symbolically to gain self-understanding (Hinz, 2009) and to "validat[e] and reinforc[e] new behaviors and identities" (Gussak, 2007, p. 155).

Appleton's (2001) art therapy trauma intervention assessment (created for burn victims) is based on Lee's (1970) assertion of the importance of treating the psychosocial dimension of chronic conditions. There are four stages to address the psychosocial implications of a traumatic event—impact, retreat, acknowledgement, and reconstruction—which range from illustrating the effects of the event, withdrawal, grieving, and reintegrating memories.

Group Art Therapy and Epilepsy

Studio E is a national art therapy program through the Epilepsy Foundation of the United States that, at the time of writing, was offered in 47 cities. Each program is facilitated by an art therapist operating in an open studio model. The goals of the program are "artistic expression," "building autonomy," "art as empowerment," "emotional stability," "sense of self-worth," and "connection with others" (Epilepsy Foundation, 2018). A 2014 study evaluated 67 participants on the Rosenberg Self-Esteem Scale (RSES) and the Quality of Life in Epilepsy Inventory-10 (QOLIE-10) both before and after Studio E (Epilepsy Foundation, 2014b). After the program, participants showed statistically significant improvements on these measures, indicating a rise in self-esteem, feelings of self-worth, notions of self-respect, and confidence in their ability to perform daily tasks (Buelow et al., 2014). In open studio sessions, Gregg's (2015) work with young adults with epilepsy and with intellectual disabilities found that identification with fantasy characters was prevalent, and clients used this coping strategy to boost their sense of self when complications of epilepsy would arise.

Creating Spaces to Address Psychosocial Stigma

Elmborg (2011) drew distinctions within Lefebvre's (2014) three-part framework of how people experience and consider space in contemporary society—as spatial practices, as representations of space, and as representational space, all of which can exist simultaneously. Spatial practices are how the body's senses resonate with, move toward, connect with, and experience a space. Representations of space as dominated spaces are created by governing bodies and planners (through their lens) that shape implicitly what activities, social structures, and behaviours are deemed "normal" from their systemic perspective (Elmborg, 2011). Representational space is the lived experience of people in contact with a space, originating in an individual's imagination where they may reclaim a dominated space and rework it to meet their values, attribute their perspectives, and address their needs better (Elmborg, 2011).

Representational space (Elmborg, 2011) creates a realm to address the psychosocial stigma that was created and perpetuated by governing bodies who enact representations of space via patterns of historical discrimination and institutionalization (Baker, 2002; Sampert, 2017). The potential to connect with and explore through this arena is of great importance as people with epilepsy also experience cyclical disconnections on the avenue of spatial practices when having a seizure, which can mean losing consciousness, losing the ability to control one's body, and experiencing cognitive interruptions (Epilepsy Foundation, 2014a), all which may affect one's sense of time in a space.

Art therapy can offer people with epilepsy a space in which to build community. Art hives are community art studios in which there is an emphasis on social inclusion, engagement, integration, and the creation of a safe space (Timm-Bottos, 2006). Art hives are conceived as public home places (Belenky, 1996; Timm-Bottos, 2005; Timm-Bottos & Reilly, 2015) that are welcoming spaces in which the psychological and physical safety of the community is prioritized, particularly for groups of people who may experience marginalization. Self-expression, personal development, social inclusion, and diverse perspectives are nurtured and encouraged.

Institutional Partnerships

Given the emphasis in this study on exploring the themes of stigma and social inclusion, the environment was an important consideration. While museum-based art therapy remains relatively novel in art therapy practice, the setting has been gaining momentum worldwide (Canas, 2011; Coles & Harrison, 2018; Pantagoutsou et al., 2017; Treadon, 2015). Museums are being reconsidered as places of inclusion and social connection and as partners in health care (Ander et al., 2011; Hamil, 2016; Jury et al., 2015; Parashak, 1997). The Montreal Museum of Fine Arts was selected as an ideal site given the presence of numerous factors, including a full-time art therapy program grounded in community partnerships, a community studio (Art Hive) that could replicate some of the open studio practices of Studio E, and a commitment to collaborations in research in museum-based art therapy serving vulnerable populations (Baddeley et al., 2017; Henry et al., 2019; Thaler et al., 2017).

The emerging establishment of art therapy departments in museums signals a movement toward discovery and an effort to become more accessible to all populations (Peacock, 2012), to improve self-concept in children, particularly those at risk for lower self-esteem such as children with epilepsy (Kaufman et al., 2014), and to address a variety of mental health and chronic conditions via art therapy for people of all ages (Bennington et al., 2016; Thaler et al., 2017). Conrad and Barker (2010) asserted that both culture and individual personality play a role in long-term illness via social construction. "For some people, a long-term illness can have the effect of making their world smaller, more defined by the illness than anything else. For others, illness can be a chance for discovery, for re-imagining a new self" (Little, 2016).

On a spatial level, a museum can engage the setting as a co-facilitator (Salom, 2008), offering stimulation such as artistic diversity, the collectivity of images, architectural inspiration, and a range of metaphors and narratives. These elements can model individuality and mirror Yalom and Leczcz's (2005) group psychotherapy concepts such as "universality," "installation of hope," and "imparting of information" (Salom, 2011).

Regarding the collectivity of images and the implicit interconnectedness of the creative process, Moon (2016) described Janson's (1971) metaphor, which consists of

> a web of art comprised of all the strands of artistic tradition: Each new artwork emerges from those that came before. Thus, as group members make art, they add strands to the web of tradition, thereby connecting themselves with all that has already occurred in the history of art—and all that will be in the future—as they create in the present. (p. 116)

For people with invisible disabilities and chronic conditions, art therapy programs in museums may offer the chance to embody the slogan of the International League Against Epilepsy, inviting people to come "out of the shadows" (World Health Organization, 1997).

Methods

Research Design

A preliminary pilot study was conducted to evaluate art therapy as an intervention for the psychosocial dimension of epilepsy, situated as a closed group in a museum-based open studio (art hive). The art therapy intervention was an 8-week program with pre- and post-therapy testing sessions conducted using a convergent parallel design that included collecting quantitative and qualitative data. This experiment was approved by the University Human Research Ethics Committee (UHREC) at Concordia University and conducted by an art therapy master's student (researcher/facilitator) to complete the program requirement.

Methodological Rationale

To address the limitations of quantitative and qualitative methodologies, we took a mixed-methods research approach (Kapitan, 2017). As described by Creswell (2014), this approach is an opportunity to "offset the weaknesses inherent within one method with the strengths of the other method" (p. 17). It provides an opportunity to explore outcomes through various lenses, which is conducive to the multi-faceted complexities that exist within the field of art therapy (Kapitan, 2017). Qualitatively, Creswell (2014) emphasized thematic or meaning clusters as important to translating one's lived experience, which in this case would be the experience of living with epilepsy and participating in group art therapy.

Participants

Participants, all of whom were between the ages of 18 and 45 and were with confirmed epilepsy (see Table 1 for assigned pseudonyms, demographic information, seizure characteristics, and indicated treatment or psychosocial stressors), were referred by neurologists and neuropsychologists at two city hospitals and via a poster in both French and English on social media support groups. One participant withdrew following the pretest and the first art therapy session and was not included in the analysis. Six participants completed testing sessions before and after the art therapy sessions, but there was variance in how often the participants attended the sessions and thus these participants were further divided into those who attended regularly (6–8 sessions, *n* = 4) and those who did not (1–2 sessions, *n* = 2).

Measures and Procedure

Pre- and Post-Therapy Sessions

As part of a larger test battery, participants completed a series of questionnaires to assess psychosocial functions at these two points in time. The questionnaire data included the following:

1. The Rosenberg Self-Esteem Scale (Rosenberg, 1965).
2. The Quality of Life Inventory for Epilepsy-31 (QOLIE-31) to assess emotional well-being, social functioning, cognitive functioning, energy and fatigue, seizure worry, medication effects, and overall quality of life (Devinsky & Cramer, 1993).
3. The Beck Depression Inventory-II (BDI-II) (Beck et al., 1996).
4. The Generalized Anxiety Scale (GAD) (Spitzer et al., 2006).
5. The Trier Inventory of Chronic Stress Scales (TICS; Schulz et al., 2004).

Exploratory qualitative data were collected via an Autobiographical Memory Test (AMT) to examine how the therapy affects the ability to access emotional experiences from one's own life since memory is key for identity, social cognition, and self-esteem (Wilson & Ross, 2003). Here, participants are presented with positive, negative, and neutral cue words (i.e., joyful, amazed, awful, upset, concentrated, busy) and asked to use them to retrieve a past personal memory. The reaction time to access this memory is recorded.

Participants were interviewed with a series of open-ended, close-ended, and multiple-choice questions to determine their epilepsy history, their quality of life, the levels of their disclosure, and their levels of social engagement before the study, as well as potential accounts of discrimination or perceptions of the ways that epilepsy limits their life. This interview was administered a second time after the art therapy sessions had concluded, with additional open-ended questions regarding the participants' experience as well as a scale rating the quality of their museum experience. These interviews were recorded, transcribed, and scored for themes relating to epilepsy impact on wellness, self-esteem, and quality of life as determined by the primary researcher.

Art Therapy

This was an 8-week group art therapy program that occurred for three hours per week in a clinical-community art setting (the Montreal Museum of Fine Arts Art Hive). Sessions consisted of open studio time with weekly themes and biweekly visits to incorporate elements of the museum's collection for creative exploration. Themes were chosen to promote exploration, resiliency, and community building while examining identity, social spheres, and sense of self. Themes and sharing of work were always optional, and participants were encouraged to share only what they felt comfortable with and to follow their creative vision. The uniqueness of each participant's experience was emphasized, and there was a continuous focus on validating individual experiences and challenges. Group dialogue about the artwork was encouraged, and a period of 30 minutes was set aside toward the end of each session for participants to share work as desired.

Qualitative data consisted of field observations by the art therapy facilitator, recorded in a clinical progress note for each participant and derived from session audio recordings. Sessions were transcribed, and data were scored for thematic clusters and meanings. The artwork was photographed following each session, and the researcher reviewed the content for common symbols or themes, comparing to Appleton's (2001) art therapy trauma and assessment paradigm in a theoretical sense for a contextual thematic analysis (Braun & Clarke, 2006). Appleton's (2001) model includes the following four stages:

1. Impact (depiction of trauma event).
2. Retreat (dependence, social withdrawal).
3. Acknowledgement (psychological pain, resources examined, and grief).
4. Reconstruction (values and spiritual clarifications, social interactions, and coping strategies).

Validity

Quantitative measures have been corroborated and are standardized; however, due to the small sample size, only numerical comparisons are made. Qualitative data were scored for themes by the researcher, injecting a degree of subjectivity to the interpretation of themes.

Data Analysis

Given the small sample size and the exploratory nature of this study, only numerical comparisons are made rather than statistical comparisons. Qualitative (thematic analysis) and quantitative data are analyzed separately and then merged at the interpretation level in a graphic, with an equal emphasis on both datasets (Creswell, 2014).

Table 1
Participant Summaries (Self-Report)

Patient pseudonym	Current age/ age of onset	Years of epilepsy	Seizure types*	Seizure frequency*	Effect on work/ education	Discrimination or bullying	Treatment stress	Protective factors
Ben	33/30	3	TC (nocturnal), P	4 TC/year 1 P/week	No	No (but fears it could happen)	Possible neurosurgery; weighing potential costs (loss of memory)	Father of two young children; partner support
Luc	45/7 months	44	TC (Dx 7 months), comorbid PNES (Dx early 20s)	3 TC/year, 2–3 PNES/ month	Yes (both)	Yes (“I always had to fight prejudice about epilepsy”)	Strained dialogue with care team; panic attacks	Partner, friends, yoga, disability advocacy
Camille	40/12	28	TC, PA	3–4 TC/month 10 PA/day	Yes (both): on leave from studies; avoids social contact	Yes (experienced “psychological violence”)	Medication resistant epilepsy; waiting for vagus nerve stimulator	Friends, social justice, advocacy
Nicole	40/7	33	TC, PA	1 TC in 2017, first since childhood; PA every few months over past year	Yes (both): difficulty in school	Reports minimal in initial interview; discloses bullying in Session 4	Return of seizures after many years; trying to re-assemble care team	Partner support

Patient pseudonym	Current age/ age of onset	Years of epilepsy	Seizure types*	Seizure frequency*	Effect on work/ education	Discrimination or bullying	Treatment stress	Protective factors
Joe	36/18	18	PA	1 PA/month since 2017 (last surgery)	Yes (education): affected by memory problems	No	Had three neuro-surgeries; short-term memory issues.	Family, religion, support at work (co-worker with epilepsy)
Lauren	37/15	22	TC	No TC for 2 years	Yes (discrimination at university)	Yes (interference with education and career)	No seizures for 2 years; still worried due to work stress/ travelling.	Partner, social justice, career, friends, advocacy

Note. TC = Tonic clonic seizure. PNES = psychogenic non-epileptic seizure. Dx = Diagnosis. P = Partial. PA = Partial absence.

* Information regarding types and frequency of seizures was collected as self-report. As a result, terminology does not conform to the 2017 International League Against Epilepsy seizure classifications. However, it was considered important to maintain the terms that participants used to describe their experiences.

Results

Pre- and Post-Therapy Test Scores

Changes in questionnaire scores from pre- and post-therapy test sessions were compared between the participants who attended the art therapy sessions regularly (more than six out of eight sessions, *n* = 4) versus those who did not attend sessions regularly (fewer than two sessions, *n* = 2). Figure 1 plots the means and the individual change scores. Focusing on scores with the least overlap between the groups, it appears that those who attended art therapy sessions had an increase in self-esteem on the RSES (*M* = 1.75) and those who did not attend showed a decrease in self-esteem (*M* = -3.0).

Moreover, participants who attended art therapy sessions had a substantial decrease in the TICS scores, indicating lower reported levels of stress (*M* = -8.25) compared to those who did not attend (*M* = 11.5). The overall QOLIE-31 was reduced in the group of participants who did not attend, and it was variable how this score was affected by art therapy in the group of participants who did attend, with some reporting an increase and others reporting a decrease to these scores. Those who attended art therapy also had a higher increase in the QOLIE-31 quality of life dimension (*M* = 10.3), with variability in how this score was affected in those who did not attend.

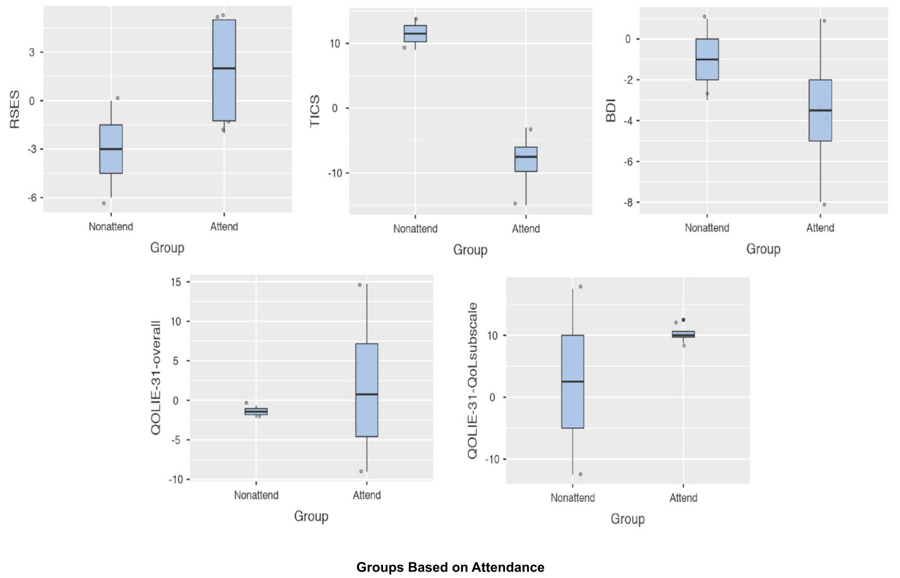
Finally, participants who attended art therapy tended to have greater decreases in BDI-II scores (*M* = -3.50) than those who did not attend (*M* = -1.00), indicating a greater change to depressive thoughts; however, there was variability in these change scores in the group of participants who did attend regularly (see Figure 1). Change scores in the reaction time to access autobiographical memories to the cues of different emotional valence were also calculated and compared between the groups. One individual's values for one positive and one negative cue were removed because of reaction times over one minute (a participant in the attend group).

We found a reduction in the reaction time for positively valenced memory cues of those who attended art therapy (*M* = -7 seconds) that was larger than the cues of those who did not attend (*M* = -4 seconds), suggesting that positive memories may be available more readily for those who attended. The reaction time difference to access memories in the post- to pre-sessions to the negatively valenced memory cues was 6 seconds and 0.5 seconds for the attend and non-attend group. The reaction time to access memories to the neutral cues was -1 second and 8 seconds for the attend group and the non-attend group, respectively.

Assessment of Themes Contained in Art Therapy

The artwork was examined according to Appleton's (2001) art therapy trauma intervention and assessment paradigm. The analysis of images, transcriptions of participants' accounts of their works, and clinical observations were scored

Figure 1
Changes in Self-Report Questionnaire Measures (Post- and Pre-Testing Session Score Differences



Note. Boxplots of the pre- to post-test changes in the RSES (Rosenberg Self-Esteem Scale), TICS (Trier Inventory for Chronic Stress), BDI-II (Beck Depression Inventory), and the QOLIE-31 (Quality of Life in Epilepsy) full scale and quality of life subscale scores for the participants in the non-attend and attend groups. Individual change scores outside the indicated range are represented by grey points. Group averages are represented by line within the box plot for illustrative purposes. Higher scores on RSES and QOLIE-31 indicate higher levels of self-esteem and quality of life, while lower scores on BDI-II and TICS indicates lower levels of depression and chronic stress.

for psychosocial themes and assigned to the corresponding stages of Appleton's framework (see Table 2 for an example of the scoring system). In early art therapy sessions, it was more prevalent for participants to depict a specific seizure story or a traumatic seizure event along with the psychological pain they were experiencing from the condition. Thus, common themes of early artwork included a portrayal of a traumatic stress event, of grief, and of the seizure cycle. For example, participants would represent tonic-clonic seizures through elemental symbols such as lightning bolts, volcanoes, electrical shots or storms, tornadoes, and whirlpools, often attacking the head of the participant (see Figures 2 and 3), while absence seizures were depicted as blue or as underwater.

On the biweekly visits to the museum's collection, participants would often reference the setting as inspiration. For example, viewing portraiture seemed to encourage Ben to portray an image he said he had "had in his head for a while"

Table 2
Psychosocial Theme Scoring Examples of Appleton's (2001) Art Therapy Trauma Assessment

Figure	Artwork by Participant Pseudonym	Session Created	Appleton Stage Trauma Assessment	Participant's Verbal Description	Psychosocial Themes
2	Ben	1	1, 3	"Like a gunshot"; "it's internal"; "symbolic of changes to come"	Seizure cycle, invisible disability, treatment stress, psychological pain
3	Camille	1	1, 2, 3	"Worst seizure"; "social isolation"; anxiety regarding impact on school	Traumatic seizure event, withdrawal from school and social circles, grief, seizure worry
4	Ben	2	1, 2, 3	Inspired by museum setting to capture lost time in VEEG; "it's like my brain stopped keeping track. It's lost time."	Traumatic seizure events, loss of control, grief, treatment stress, social withdrawal, psychological pain
5	Nicole	4	2, 3	"When I started to have epilepsy people just rolled away"; "I don't share; I keep it to myself."	Childhood bullying, grief, social withdrawal and isolation, stigma, psychological pain
6	Luc	1	2, 3, 4	Epilepsy as "a negative word; it's a word that just adds weight to the bag. I often say to people that I have a challenge."	Invisible disability, social barriers, withdrawal, communication about stigma, psychological pain, coping strategies (mindfulness)
7	Camille	5	1, 2, 3, 4	"Not something that happened in our lives, but what we wanted, what we could have had"; "I will fight them."	Seizure cycle, grief, social withdrawal, psychological pain, superhero for agency, identifying stressors.

Figure	Artwork by Participant Pseudonym	Session Created	Appleton Stage Trauma Assessment	Participant's Verbal Description	Psychosocial Themes
8	Ben	8	3, 4	"Shit happens"; "You're strong"; "It takes care of you … to protect on the hard days, to encourage."	Coping strategy, grief of seizure cycle, shifts in attentional bias and emotional regulation, superhero for agency, positive self-talk
10	Camille	6, 7, 8	2, 3, 4	Inspired by museum setting for resiliency, integration of coping strategies; "It's never too late to change."	Identifying stressors, social grief, restoration of agency, shifts in attentional bias and emotional regulation, positive self-talk

Note. Qualitative data is presented as examples of psychosocial themes scored with Appleton's (2001) Trauma Assessment Paradigm. Stage 1: Impact (depiction of trauma event). Stage 2: Retreat (dependence, social withdrawal). Stage 3: Acknowledgement (psychological pain, resources examined, grief). Stage 4: Reconstruction (values and spiritual clarifications, social interactions, coping strategies).

(see Figure 4). Ben's depiction of him watching himself have a seizure on the video electroencephalogram (VEEG) monitoring unit at the hospital provided a unique opportunity to explore the emotions involved with the loss of control, feelings associated with not remembering something (yet seeing it happen on video) and the somatic sensations involved. As Ben explained,

> Sort of towards the things we saw upstairs (museum tour), it was just a moment that someone saw once, but the person was able to preserve or copy it—I'm inspired a bit by it. I don't know why I wanted a copy of that to see again; it's a bit haunting … My post-seizure phases can last super long, like hours and hours. I've already heard stories about how I was aggressive in the emergency room. I wanted to see that … it's weird to have done things for hours and hours. It's not that I drank too much, but it's like my brain stopped keeping track. It's lost time.

Ben's explanation provided an opportunity for the group to discuss the VEEG experience: how bizarre it can be to want actively to have seizures while in the unit (in order to shorten the stay) and how frustrating it can be to go off medication and then not have seizures in the hospital. As this was Session 2, Ben's explanation

Figure 2
Ben's Work in Session 1 to Introduce Himself and His Situation

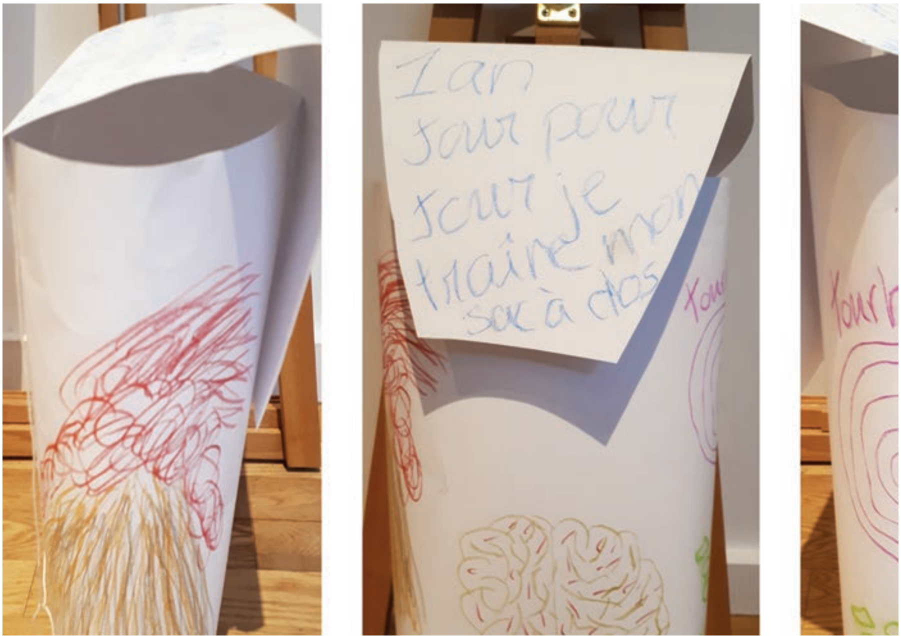
Note. Ben said, "I wanted to symbolize the drama and the changes coming … I wanted it to be a bit violent … like electric but also like a gunshot."

allowed the group to discuss experiences in treatment, witness a range of experiences, and offer peer support for vulnerability. For most of the group, it was their first time encountering another person with epilepsy and was an important aspect of solidifying group alliance.

In early to mid-treatment, Appleton's (2001) first three stages often appeared together, perhaps due to the cyclical nature of the condition. Psychosocial trauma of seizure events was conveyed (impact stage), while issues of dependence, ruptures in treatment alliances, and social withdrawal of the retreat stage were examined, such as Nicole's experiences with childhood bullying due to epilepsy (see Figure 5). In the acknowledgement stage, explorations included psychological pain of the seizure cycle, loss of control, treatment stress, and the grief associated with stigma, invisible disability, and social isolation.

Luc's introductory piece (see Figure 6) evoked a reflection on invisible disability, epilepsy as a "way of knowing" in a social context, and the mentalization of emotions (of the self and of others) in terms of both communication and coping strategies regarding psychosocial stigma. As he stated,

Figure 3
Camille's Work in Session 1 to Introduce Herself and Her Situation



Note. This consists of a paper backpack with an erupting volcano on the right side, a brain in an electrical storm on the front ("1 year since my worst seizure, I carry my backpack day-by-day") and on the left side a whirlpool and medication.

> I am always told that epilepsy has a visible dimension and an invisible dimension. My wife, who is in a wheelchair, and I once were choosing a car that we wanted to buy. But they (the dealership) think that I am going to drive, and every person who sees us thinks that I am going to drive. It's my wife who has the license. Instinctively, they address me thinking that I have the license, in the end, I always jokingly tell them, "This is an illusion. You can talk to her. She has the license; I am the disabled person." So it's just a concrete example, but I think it's a very good image of what we sometimes live socially to share our experiences in how to communicate about epilepsy and how to raise the subject to establish a dialogue about our lives and our emotions that are collectively not always pleasant to share … I then decided in my twenties to see epilepsy as a challenge because, for me, a challenge is something you overcome. It's, like, as we can get up the mountain and get to the top and then it's problematic, it can stagnate … It's a negative word; it's a word that just adds weight to the bag. And so often I even say to people instead, "I have a challenge." For the

Figure 4
Ben's Work in Session 2

Note. Ben depicts a memory of watching his VEEG footage of him having a seizure.

> understanding of social things, I tell them it's a social problem but [*laughs, gestures to art*]. It's a feeling, and between that, there are letters, words, and there are colours.

This reflection engaged Luc in the acknowledgement stage (Appleton, 2001) as he explored and examined social barriers that he had experienced over decades with the condition, alluded to negative emotions, and shared his attempts to construct and to reframe a personal narrative that is based on resiliency and available resources (moving toward the reconstruction stage). His communication regarding dependency and the indication of communication obstacles that promote social withdrawal or alienation also engage in the retreat stage (Appleton, 2001).

In later art therapy sessions, the artwork and discussion content became more representative of reconstruction, resiliency, and community (see Figure 7), with more overlap of the acknowledgement and the reconstruction stages. This would include identifying stressors, pinpointing coping strategies (such as mindfulness), examining goals, and articulating shifts in attentional biases to include positive

Figure 5
Nicole's Work in Session 4

Note. Nicole portrays childhood bullying regarding her epilepsy experience and the impact of social isolation.

representations of self and of community. Challenges were still addressed, but within a framework that seemed to restore agency, to realign the point of control, and to involve both positive and negative emotional material. As the group identified triggers such as stress, strategies of self-care were put forward and participants became more empowered to take agency in their own lives.

Luc's work continued to engage in a somatic-driven process, working sensorially and kinesthetically and incorporating a mindfulness practice toward his mastery of being in the present moment with epilepsy. He reflected on his journey in both art therapy and epilepsy, finding meaning in his experiences in the past and the present and expressing more confidence in his ability to meet challenges moving forward. As Ben navigated treatment stress (whether or not he would have neurosurgery), he reflected that he felt greater ability to voice his needs for support and to feel comfortable in his situation, referencing increased comfort in discussing epilepsy with family, friends, and co-workers. He also expressed relief from his neurosurgeon's suggestion that what he had thought were smaller seizures

Figure 6

Luc's Paper Sculpture/Drawing in Session 1 to Introduce Himself and His Situation

Note. Luc wrote the following on the inside: "In life, a page opens every day in the present moment. And so we always have our choice to open or close a thought. It is considered useful or not useful."

might have been psychosomatic episodes related to PTSD. In the final session, Ben alluded to how much he valued his experience in the group:

> I think I've made progress. And to talk here with you, it makes me think of things to share. It makes me practise. At first, I thought that in art therapy, we would simply draw. But it's more the discussion, I find. Drawing is good but to have a place to discuss, to process … It helps me.

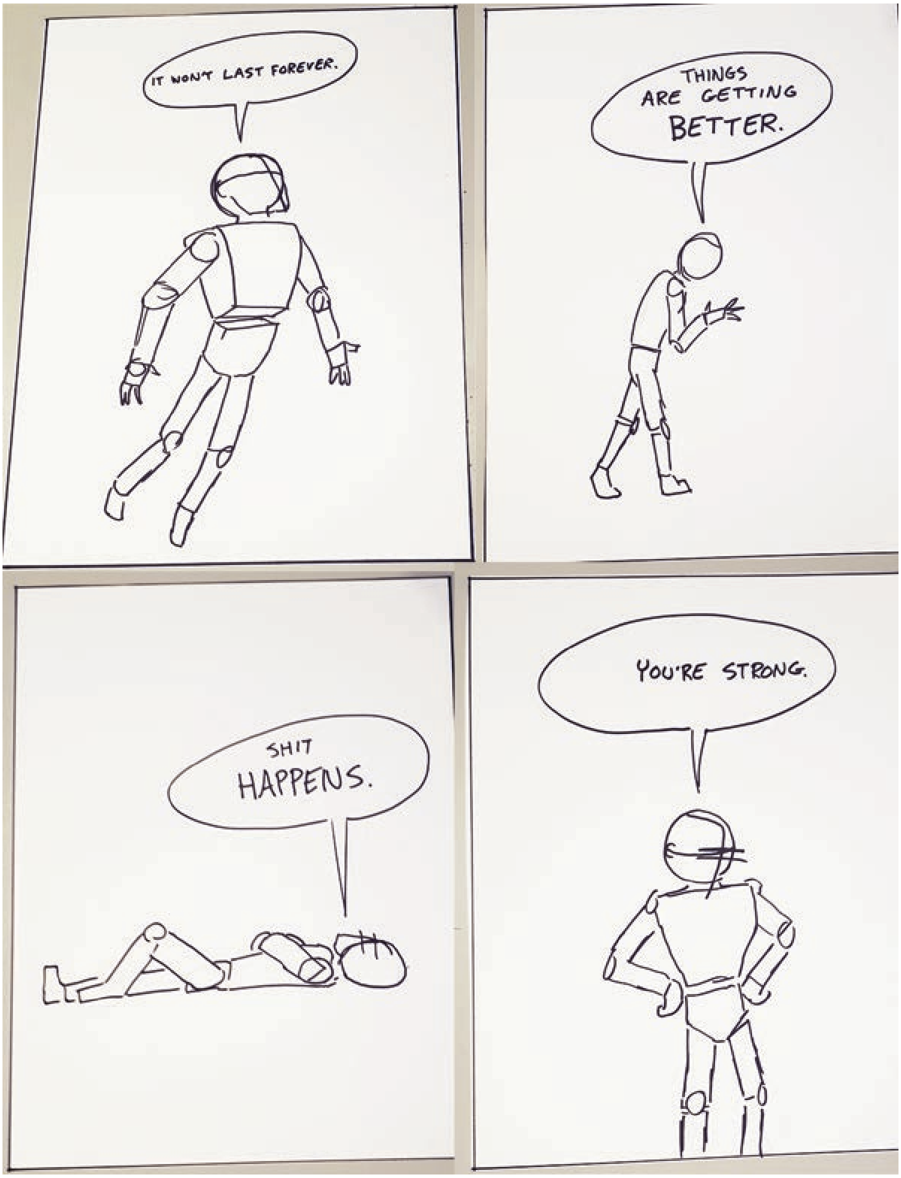
For Ben's final piece (see Figure 8), he made four panels that could be rearranged as a coping strategy to foster resiliency and to reconstruct his personal narrative in the face of recurring challenges. As he stated,

> I wanted to show that you can change the order, and it changes what it says. Now it's like "Shit happens, you're strong, things get better," but if you change the order, it's 'Things are getting better, it won't last forever," so it changes the meaning. So, it's to show that I feel good now at the end of it all, but I have

Figure 7
Camille's Work in Session 5

Note. Camille portrays a superhero to confront the epilepsy "tornado," saying, "I will fight them."

Figure 8
Ben's Work in Session 8



Note. Ben shows rearrangeable panels as an adaptive coping strategy to reconstruct his personal narrative. "Shit happens. You're strong. Things get better. It won't last forever."

Figure 9
Group Termination Piece: Making a Piece of the Collective Pie

Note. From the top right: Ben shows a group on a museum tour; Camille references each of her works and says “thank you”; Luc writes, “Art comes with self-transcendence. Surpassing yourself, hope opens, words carry levity, colours,”; Nicole shows the table in the art hive with a speech bubble that says “Epilepsy”; the facilitator/primary researcher’s and the research assistant’s piece, which focused on the experience of connection and growth in the group setting.

> to keep that attitude at the same time. It takes care of you … to protect on the hard days, to encourage.

Ben also alluded to the importance of the group in a final collective artwork, showing the group on a museum tour with speech bubbles coming out, saying, “The art is important, but it’s the discussion that comes out of it” (see Figure 9).

Camille’s final piece (see Figure 10) presented an evolution from processing her grief and her traumatic stress (represented in her first piece, a paper backpack; see Figure 3) to applying more energy to nurturing herself. Inspired by the

Figure 10

Camille's Work in Sessions 6–8 Serves as a Vision Board for Emotional Regulation

Note. Camille identified with a sculpture she had viewed on a museum tour and drew it in the centre, surrounding it with collaged phrases such as "Confidence is a privilege," "It's never too late to change," and "Live at full force."

museum tour, Camille said, "I wanted to do like the sculpture we saw upstairs on emotions, on the person, on the behaviours and all, but it's because this week I had a lot of stress."

Camille had reported that she had had a tonic-clonic seizure during the week at a bus stop, which caused her to have a large bruise on her knee. Despite this happening, after resting at home to recover, Camille went out again on her original mission, to buy the paint she would use to repaint her apartment "for her new life." She explains, "I think it is connected to my seizure finally. When I saw the sculpture upstairs, it seemed to represent me. Although it is crooked, at the same time, it is filled with great emotions—it's sentimental."

Camille ended up with a vision board for daily emotional regulation at home, created with collage words such as "Confidence is a privilege," "It's never too late to change," and "Live at full force." When reviewing her body of work, Camille said she could see that her work had become more positive as she went on. Seeing her backpack again seemed to take Camille by surprise:

> If I were to come back for the first time, I would probably not make the same one … I would not do the same. I don't know; I see things as a bit more positive. But I think you have to take it more positive too … The backpack, well, it's filled with negativity because when I made it, it was negative. So, I don't even want to take it home. This piece [the backpack], well, it seems to me something that doesn't represent the truth, as of now.

The decision was made to leave the backpack with the researcher, as Camille felt that her story had changed (Smallwood, 2019).

Discussion

The key findings from the reported study were as follows. First, there was evidence for a change to self-report ratings of chronic stress for persons with epilepsy who engaged in group art therapy. Second, for people who reported epilepsy-related traumatic stress, the importance of artmaking and discussion in the group setting were noted as key for emotional and social integration (examining the impact of stressors, acknowledging psychosocial implications, and exploring coping strategies for emotional regulation). Sensorial engagement and mindfulness were referenced in both art and discussion, appearing key to rescript personal narratives and to foster resiliency through art. This increased positive statements regarding the sense of self and feelings of agency over current situations suggested shifts in attentional biases and enhanced psychosocial functioning.

Impact on Chronic Stress

Analyses of quantitative and qualitative data from pre- and post-therapy test sessions suggested that attending art therapy regularly was effective in reducing stress and elevating mood. The participants who attended regularly showed decreases in chronic stress, as measured by the TICS, combined with the increases in levels of disclosure and decreases in the self-reported level of seizure worry.

Impact on Psychosocial Functioning

From the art produced, there are indications of how art therapy improved psychosocial functioning. It was common for the participants to begin the therapy session by depicting a traumatic seizure event in their art, expressing grief over the loss of control and independence that they had faced, or introducing themselves and their situation to the group. This was more common for participants who were undergoing treatment stress such as changes in medication or were contemplating neurosurgery and for participants who were experiencing a higher frequency and severity of seizures.

In later sessions, participants were examining coping strategies and cultivating resiliency via their art, which represents the cultivation of their goals. In Session 1, Camille began by presenting a traumatic memory (her worst seizure) via her paper backpack. By the last session, she declared that she would not tell that story the same way, recognizing that there had been shifts in her perspective and that she felt more positive. She no longer identified with that piece to introduce herself to the group and had started to identify feelings of greater agency in her life. In the post-sessions interview, Camille reported that she had hung her final art as a vision board for daily reminders of her goals, of self-care, and of emotional regulation, indicating effects of the art process continuing beyond the group. It is possible that symbolic interactions (as defined by Gussak, 2007) allowed Camille to formulate and to test out new visions of her identity, exploring her journey through her art process.

Shifts in Attentional Bias

As participants became more aware of negative cognitions that they associated with their seizures, there seemed to be a restored sense of agency in other parts of their lives. This restoration of agency was depicted visually by Camille in Figure 7 as having more choices in terms of her emotional reactions to epilepsy, as she depicted a tornado to represent not only the seizures but also the choice she stated she now recognized, either to pursue “dark thoughts” or to move toward self-care.

Mindfulness and Sensorial Engagement

Mindfulness and sensorial engagement helped the group stay in the moment, with the discussion section allowing an application to real-life experiences. As the group transitioned from exploring psychosocial trauma to more positive material such as coping strategies and future goals, reports of well-being increased.

Sensorial engagement with art materials such as clay may have provided a portal to explore bodily memories (Hinz, 2009; Jones, 2005; Lobban, 2014), which may have led to decreases in traumatic stress and increases in verbalization (Czamanski-Cohen & Weihs, 2016). Substantial engagement and experimentation with art media can indicate the integration of both right-brain and left-brain hemispheres in the artmaking and witnessing processes, which is essential in working toward the reintegration of traumatic experiences (Hinz, 2009; Lusebrink, 2004; Moon, 2016). As stress was identified as a seizure trigger for multiple participants, this may have led to decreases in seizure activity (as reported by Camille and by Luc) or in the perception of seizures in psychosomatic episodes (as reported by Ben).

Fostering Resiliency Through Art

Having a space in which to discuss treatment stress and loss of control may have alleviated anxiety regarding the need to present a false self to the world in order to protect oneself against vulnerability (as suggested by Lobban, 2014). The growth between Ben's introductory piece (see Figure 2, with no mouth or eyes visible under the glasses and a shot to the head indicating "something explosive going on inside") to his final piece, a dynamic series that acted as a coping strategy, created space for vulnerability ("shit happens"), encouraged resiliency ("this won't last forever"; "you're strong"), and suggested decreases in depression and anxiety ("things are getting better").

Ben reported decreases in seizure worry and anxiety, corroborated by less anxiety on dimensions of the QOLIE-31, the GAD, and the TICS, stating that he worried less and that "even if I do have [a seizure], I have found people who understand." Ben reported about halfway through the group that he had put up a seizure first-aid sign in his cubicle at work and had increased levels of disclosure regarding epilepsy. Additionally, he no longer had nightly reports of anxiety before bed, which were posited by his neurosurgeon to be psychosomatic episodes. Ben's final piece would be adaptive to his needs on a particular week, as he would place it at his desk as a tool for emotional regulation in more challenging times of treatment, consistent with Gregg's (2015) finding of the use of heroes as a symbol and a sign of empowerment.

Group Setting and Social Integration

Participants shared painful memories in a group setting, which provided them with the opportunity to gain further mastery over them (as posited by Lobban, 2014). Yalom and Leszcz (2005) and Vinogradov and Yalom (1989) described the imperative power of the group as a place of social rehearsal. It is a place where connections can form, enabling a sense of community (integral to treating chronic traumatic stress; van der Kolk, 1987), of safety (Rubin, 2005), and of support and witnessing (Moon, 2016), therefore creating a portal to processing and healing psychosocial stigma. Ben, for example, alluded to the element of social rehearsal and to the importance of the discussion section of the group, in addition to the artmaking.

As participants moved through the group, social integration occurred, and witnessing each other's stories in the safety of the community studio helped to bolster connections between group members. Upon recognition of similarities in challenges they faced, participants' peer support statements increased to deal with treatment stress, suggesting increases in self-esteem and quality of life (Chew et al., 2017, 2019). For some participants, greater feelings of self-efficacy and self-expression translated into a higher reading of self-esteem on the RSES and into higher readings of overall quality of life on the QOLIE-31, consistent with research by Buelow et al. (2014) on Studio E.

Luc, Nicole, and Camille's experiences of invisible disability, bullying, and social exclusion evoke terror management theory (Greenberg et al., 1997; Hirschberger et al., 2005) as well as internal and external factors that affect emotional regulation, such as the pressure to perform in society (Foucault, 1990); the enduring somatic threat (Edmondson, 2014) and increased social comparison for people with chronic conditions (Twenge & Crocker, 2002); the unwanted identity caused by discrimination threats (Olthof et al., 2004; Sabini et al., 2001); and the interdependent triad of impairment effects, "barriers to doing" (systemic and social exclusion), and "barriers to being" (effects on self-esteem; Chew et al., 2019). Negative psychosocial experiences that occurred in childhood and in young adulthood continued to impact participants' self-concept and social selves well into adulthood, suggesting that early psychosocial interventions could be key for mental health across the lifespan for people with epilepsy.

As psychosocial stigma has been perpetuated historically and systemically by government and religious institutions, perhaps the modern notion of "an institution" could be used to dismantle the effects of psychosocial stigma. Integrating Bronfenbrenner's (2005) bioecological systems theory with concepts of representational space (Elmborg, 2011; Lefebvre, 2014) could provide a navigational pathway to deconstruct the systemic hierarchies that may have been enforced to the detriment of people with epilepsy.

By fostering spaces in institutions such as art hives in museums (Elmborg, 2011; Timm-Bottos, 2006), we provide a portal to healing and to addressing elements of the psychosocial stigma that were bred in dominant spaces. Historically, museums have been institutions that are representative of societal values and culture, funded by governments, supplied by empires of colonization, and sustained by the dominant class. As we move toward a more representative and inclusive society, art hives in museums represent a shift toward dialoguing with such hierarchies and a portal to healing psychosocial stigma. Cultivating multiple ways of knowing and diverse representations of being could help unpack psychosocial stigma via a clinical-community framework involving various levels of art therapy, set in institutions of both health care (hospital/clinical) and culture (museum/community).

Practical Implications

A clinical-community model of art therapy could empower people with epilepsy to gravitate toward the avenue that suits their needs best, whether it is in-patient individual art therapy in the VEEG setting, a drop-in oriented art hive in the hospital where they can bring their family members, or a closed art therapy group set in an art hive within a museum (such as the environment described in this study). For patients who have not experienced psychosocial trauma relating to epilepsy, a drop-in hive environment allows them to explore art as a coping strategy for self-care, stress reduction, emotional regulation, and social connection. If people have not experienced psychosocial stigma or trauma as part of their epilepsy experience, it may not be helpful for them to attend a closed group where treatment stress becomes the focus. However, if people have experienced psychosocial stigma or traumatic stress as part of their experience, making artwork in a closed setting with a focus on discussion may be integral to processing their experiences.

The integration of this model would allow people to move at their own pace and to have a community support structure in place for the termination of limited duration, closed treatment groups. The juxtaposition of a clinical-community setting is a key factor in addressing the complexities of psychosocial stigma and the fluctuations in both physical and emotional wellness that accompany chronic conditions. As stress was identified as a trigger for some people's seizures, a reduction in stress could contribute to a reduction in seizure frequency.

The integration of art therapy to treat the psychosocial dimension of epilepsy could reduce the stress on neurology departments by giving patients more verbal tools to represent their seizure experiences and their emotions, and this could decrease the use of expensive diagnostic testing (e.g., in the case of symptoms being psychosomatic reactions to stress). Representations of people with epilepsy within a clinical-community model of art therapy, both as art therapists and as participant mentors in art hives, would serve to normalize the experience of people with invisible disabilities, to dismantle hierarchies in ableism, and to redefine institutions as more representative of a diverse society.

Limitations

Due to the small sample size and to the dual role of the clinician/researcher, these findings will require further corroboration in clinical trials, with the integration of a control group, and a thematic assessment of artworks and transcripts by an external reviewer. Additionally, clinical and diagnostic data were collected as self-report; thus, closer collaborations with neurology and psychiatry departments would be imperative.

Conclusion

Group art therapy may address and improve the psychosocial treatment dimension of epilepsy while highlighting and targeting systemic stigma and social barriers. Mixed methods were essential to investigate participants' diverse experiences, varying conditions, and complex nuances of stress. In this research, participants who attended benefitted on the psychosocial dimension, reporting decreased depression and chronic stress as well as increased quality of life and self-esteem. As this study was an initial exploration, further mixed-methods research is needed with a larger sample size and closer collaboration with neurology and psychiatric departments.

As society attempts to address the ostracization of people with disabilities past, present, and future, it can be argued that it is the responsibility of government institutions that may have established and perpetuated psychosocial stigma to collaborate now with those impacted most by oppressive systemic factors. Working with an open-studio approach may allow individuals with diverse experiences to address various levels of treatment stress, psychosocial stress, or traumatic stress in a group setting by moving at their own pace. Given that such a treatment program may be situated in a museum, multiple threads may be woven to extend across education, culture, health care, and community settings, shifting systemic patterns while increasing agency and fostering resilience, all of which could be key steps toward integrative wellness for people with chronic conditions.

This initial study was intended to be a stepping stone in the psychosocial direction, a small grain of representation in research and clinical settings for people with invisible disability experience. The goal was to amplify the voices of people who are currently experiencing repercussions of stigma, social barriers, and chronic stress that may surround epilepsy and to highlight the integral importance of treating the psychosocial dimension. Art therapy may provide an ideal modality to dialogue with the psychosocial complexities of epilepsy.

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