# GROUP ART THERAPY FOR YOUNG-MID ADULTS WITH EPILEPSY: A PSYCHOSOCIAL INQUEST INTO MULTIPLE WAYS OF KNOWING

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#### **ABSTRACT**

# GROUP ART THERAPY FOR YOUNG-MID ADULTS WITH EPILEPSY: A PSYCHOSOCIAL INQUEST INTO MULTIPLE WAYS OF KNOWING

#### ELLEN SMALLWOOD

Purpose: This pilot study chronicled an 8-week group art therapy program at the Musée des Beaux Arts de Montréal art hive, exploring whether art therapy is an effective method to address the psychosocial component (e.g., self-esteem, quality of life, depression/anxiety) of epilepsy treatment in Canada. Situated within theories of psychosocial stigma, this study addressed systemic implications of living with chronic conditions and invisible disability. Methods: A mixed-methods (convergent, parallel) design examined the program's impact for six young-mid adults with epilepsy. Pre and post art therapy psychosocial questionnaires and interviews that followed Appleton's (2001) Art Therapy Trauma and Assessment Paradigm thematic clusters were compared.

Results: Numerical comparisons were made between two groups based on attendance (Attend = 4, No-attend = 2). After art therapy, the questionnaire data indicated that the attend group had substantially reduced scores on stress and depression questionnaires and increased scores on questionnaires assessing self-esteem and quality of life, compared to the no-attend group. The interviews revealed that art therapy increased the attend group's ability to talk about the impact of epilepsy, to express grief, and to make social connections. The interviews also showed that art therapy helped with daily emotional regulation, and for some, reduced the frequency of seizures and psychosomatic symptoms.

Conclusion: Group art therapy may address and improve the psychosocial treatment dimension of epilepsy while acknowledging systemic stigma and social barriers. Extending from Appleton's (2001) treatment paradigm, a cyclical model for chronic conditions, which can be validated with a future large-scale study, is presented.

*Keywords:* epilepsy, group art therapy, self-esteem, psychosocial, chronic conditions, invisible disability, art hive, stress, stigma, depression, anxiety, social isolation, medical trauma, wellness, quality of life, pilot study, mixed methods, museum, clinical, community

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#### List of Abbreviations

AATA- American Art Therapy Association

AMT- Autobiographical Memory Test

APA- American Psychological Association

AT- Art therapy

**BDI- Beck Depression Inventory** 

CATA- Canadian Art Therapy Association

DART- Description, Assessment, Response, Treatment

DSM-3- Diagnostic and Statistical Manual-3

DSM-5- Diagnostic and Statistical Manual-5

EEG- Electroencephalogram

ETC- Expressive Therapies Continuum

GAD- Generalized Anxiety Scale

MBAM- Musée des Beaux Arts de Montréal

PANAS- Positive and Negative Affect Schedule

PTSD- Post-Traumatic Stress Disorder

MDD- Major Depressive Disorder

PNES- Psychogenic non-epileptic seizures

QOLIE-10- Quality of Life Inventory for Epilepsy-10

QOLIE-31- Quality of Life Inventory for Epilepsy-31

RSES- Rosenberg Self-Esteem Scale

**RT-** Reaction times

SES- Social Economic Status

TC- Tonic-clonic seizure

TICS- Trier Inventory of Chronic Stress Scale

UHREC- University Human Research Ethics Committee

VEEG- Video electroencephalogram

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# **Chapter 1. Introduction**

A common statement in those undergoing treatment for epilepsy is that seizures are often only the tip of the ice-berg (Havlena & Stafstrom, 2012, p. 64). About one percent of the population have a formal epilepsy diagnosis, establishing it the fourth most common neurological disorder in the US, with over 40 different types of epilepsy and 20 different types of seizures (Epilepsy Foundation of Michigan, 2016). A diagnosis with epilepsy can bring negative changes in feelings of self-worth, as well as 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, depression, low self-esteem, social isolation, discrimination, and under-employment; in addition to the cognitive repercussions from taking anti-convulsants, which can include fatigue, reduced attention, and memory problems (Baker, 2002). As such, epilepsy is a condition that carries the weight of psychosocial stigma, as its effect on people's lives is multi-faceted, extending far beyond the seizures themselves (Havlena & Stafstrom, 2012; Baker, 2002).

Hermann and Jacoby (2009) assert 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). As Allen (1997) constitutes "art as a way of knowing", as an art therapy Master's student, I followed McNiff's (2018) mandate for arts-based research to tap into my own experiential knowledge in both arenas. McNiff asks "Where does your authentic expertise lie? What is it that you have done that others have not experienced with the same range and intensity?" (p. 39).

My own experience as someone that developed epilepsy at age 13 and lived with it until the removal of a benign brain tumor at age 25 (continuing to take medication for a few years after), has provided experiential knowledge, insight, and motivation, while injecting a degree of personal bias into the research process. I can attest to having experienced psychosocial stigma in my formative years (see Figure 1), with only a fictional character (*Caitlin*) on the television program *Degrassi Junior High* (Degrassi Wiki, 2017) as my epilepsy reference (see Figure 2). Not knowing any one else with the condition for most of my adolescent and young adult years, I learned that disclosure could mean exclusion and ostracization and found epilepsy very difficult to discuss. Once I understood that I needed psychosocial support, I realized that it was not widely offered within the epilepsy treatment model in Canada. Following my successful neurosurgery, I

began a self-directed creative healing process involving art, music, and writing in a project called *Teen Sleuth & the Freed Cyborg Choir* (see Figure 3). What began as independent healing work became a collaborative performance with a community of artists, which inspired me to become an art therapist (ten years later) and to specialize in working on the psychosocial dimension of epilepsy and other chronic conditions through this my Master's research.

With my experiential knowledge, I was eager to embark on the process of amplifying other voices who were currently facing varied psychosocial challenges of this spectrum condition. In this process, I acknowledge my privilege that I no longer have to deal with epilepsy on a daily basis and am no longer followed for the condition, however my experiences have inspired me to work toward positive social change for people who are living with epilepsy. As I began this pilot study in November 2018, as an artist, art therapy student, and instinctual researcher (McNiff, 2018), I drew a concept map for what I expected to find (see Figure 4).

It was my instinct (and own experience as a youth) that art therapy could provide a framework for healing and personal growth which can help with functions in daily-living for people with epilepsy. Malchiodi (2007) presents that image-based work can allow for greater self-expression and a realm to explore emotions and ideas that cannot always be easily put into words. I was invigorated by learning about Studio E, a national art therapy program through The Epilepsy Foundation of the United States that is currently taking place in 47 cities. Each program is facilitated by a registered art therapist operating in an open studio model. Goals of the program are listed as "artistic expression, building autonomy, art as empowerment, emotional stability, sense of self-worth, and connection with others" (Epilepsy Foundation, 2016). A recent 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 (Lowenberg, 2014). 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 abilities to perform daily tasks (Buelow, Vitko, & Gattone, 2014).

Inspired by Studio E, the goal of this pilot study was to begin a process of exploration and integration of art therapy into the psychosocial treatment dimension of epilepsy in Canada. This research investigates how group art therapy impacts the self-esteem, wellness, and overall quality of life for young-mid adults with epilepsy (aged 18-45 years old). It also assesses how group art therapy affects the psychosocial dimension of epilepsy though a variety of measures. As such,

this study used a mixed methods approach that employs a within-subjects design with a pseudo control group. Pre- and post-therapy standard tests of cognitive function, qualitative questionnaire and interview data were collected to chronicle the psychological and social implications of an 8-week group art therapy experience for six young-mid adults with epilepsy (aged 18-45 years old) at the Musée des Beaux Arts de Montréal (MBAM) art hive. Data was then analyzed as a group case study in order to test Appleton's (2001) psychosocial-oriented Art Therapy Trauma and Assessment Model that I have adapted to an epilepsy and chronic conditions context.

The overall objective of this study was to demonstrate the multiple ways of knowing how art therapy affects the experience of epilepsy by collecting personalized accounts of the participants' involvement with and change impact from art therapy in a clinical-community setting that is representative of society's culture. As people with disabilities have largely been excluded from academic and institutional research (Kitchin, 2000), I gladly moved forward with my experiential knowledge in this process as an empowered researcher, declaring that representation matters in research, clinical, and community environments, including art therapy.

# **Chapter 2. LITERATURE REVIEW**

This literature review will address the psychosocial dimension of epilepsy, origins and effects of stigma, and the ways it can affect self-esteem and social integration. Art therapy will be explored in a clinical setting for individuals and groups facing the psychosocial implications of the condition; as well as in an art hive setting as a portal to disassemble the hierarchies that have been enforced at a global level and re-enacted throughout our communities.

# Part I: Epilepsy

Hernmann and Whitman (1992) characterize the impact that epilepsy has on one's life by three dimensions: neuroepilepsy (which includes neurological diagnostic information and physical characteristics); medication (which covers the chemical interventions of anti-convulsants and their interactions with the body's chemistry); and psychosocial (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, social economic status, and the acceptance and adjustment to the condition) (p. 40).

Mondanaro (2008) emphasizes the 'symbiotic' affiliation between epilepsy and depression. In Canada, depression and anxiety affect 4.5 percent and 2.5-6.5 percent of the general population, respectively. However, for people with epilepsy the rates of depression are estimated at 9-22 percent in community settings and 27–58 percent in tertiary care epilepsy centers with anxiety in people with epilepsy at 15-25 percent (Macrodimitris, Wershler, Hat, Hamilton, Backsdermott, & Mothersill, 2011). Mondanaro (2008) contends 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 teenagers and young adults, which accounts for 50 percent of Sudden Unexpected Death from Epilepsy cases (p. 106).

# The Psychosocial Dimension

Lee (1970) emphasizes the importance of treating the psychosocial dimension of chronic illness and conditions in their pyramid model (see Figure 5), where medical and surgical treatment sit at the top of the pyramid, and psychosocial support at the bottom. Without an adequate foundation of psychosocial support to foster positive social-emotional conditions, the pyramid may come crumbling down, despite successful medical treatment. Lee (1970) points out that with psychosocial support, the family can represent and sustain courage, security, and hope. Where there is not adequate psychosocial support, the family may cultivate secrecy, shame and fear, fostering negative social-emotional conditions. Brofenbrenner (2005) highlights concerns that institutions are run on a deficit model where higher levels of individual failure garner higher levels of social support; however, by the time a crisis is reached, the road to recovery is more difficult. Macrodimitris et al. (2011) contend that the higher rates of depression and anxiety among people with epilepsy could represent a gap in care, with a significantly higher risk for suicide than the general population (Christensen, Vestergaard, Mortensen, Sidenius, & Agerbo, 2007; Tian, Cui, Zack, Kobau, Fowler, & Hesdorffer, 2016).

Origins of psychosocial stigma. According to Brofenbrenner's (2005) bioecological system's theory, there are interactive layers of environmental systems that influence a child's development (Paquette & Ryan, 2011; see Figure 6). A diagnosis with epilepsy can bring "negative changes in feelings of self-worth, as well as fragmentation in the sense of self, personal identity, and sense of control" (Bruckland, 2015, p. 175). A child's body (biological factors), emotional system, and cognitive abilities form the primary point of the microsystem,

which also includes immediate bodies of contact such as family, school, daycare, and neighborhood (Berk, 2000).

The micro level. Brofenbrenner (2005) asserts that interactions within all layers of this system are dynamic and subject to bi-directional influences, however these influences are stronger at the micro level, especially elements such as parent and child, and a child's school environment. This is reflected in Schore and Schore's (2008) modern attachment theory, describing attachment as "the product of the interactions of both nature and nurture, the strengths and weaknesses of the individual's genetically encoded biological predispositions (temperament) and the early dyadic relationships with caregivers embedded within a particular social environment (culture)" (p. 17).

The macro level. The mesosystem layer of this bioecological system encircles the microsystem, providing a realm for connection between different structures of a child's connections such as interactions between one's parent and one's school (Paquette & Ryan, 2011). The exosystem represents a larger social space, the community, and society-at-large, and impacts a child's development by influencing structures in the microsystem such as parents, school environments, or religious bodies (Berk, 2000). The exosystem is a place for connective influence with the outermost macrosystem, which encompasses cultural values, customs, and laws (Berk, 2000). According to Paquette and Ryan (2011), "the effects of larger principles defined by the macrosystem have a cascading influence throughout the interactions of all other layers" (p. 2). Conrad and Barker (2010) assert that it is our cultural values that determine what illnesses and conditions are stigmatizing, or which are acceptable. Sartorius (2007) asserts that people suffering from stigmatized conditions have "reduced value in the eyes of the community and the government" (p. 396).

Parental relationships. Lortie and Vanasse (2007) assert that parental reactions to a child's epilepsy, whether it is to withdraw or to become overprotective, can affect a child's social development in terms of relating to peers and their own levels of self-efficacy. As touchstones of adolescent development involve an intensified attention toward the self, an increased dependency on peer relationships, and a withdrawal from parental involvement to promote individuation (Blos, 1962), disruptions and negative influences in the microsystem could disrupt the development of ones' sense of self (Carr, 2014). Experiencing negative effects of stigma can impact a child or adolescent's sense of identity, family and interpersonal relations, participation

in recreational activities and travel, finding employment, post-secondary choices and comfort in public places (Lortie & Vanasse, 2007).

*Trauma*. Carr (2014) portrays that chronic illness can disrupt the development of a client's sense of self-identity. In a study assessing the relationship between trauma, Post-Traumatic Stress Disorder (PTSD), and chronic medical illnesses (including epilepsy), Sledjeski, Speisman, and Dierker (2008) found there to be a graded relationship between PTSD and frequency of traumas. In terms of chronic illness, cumulative trauma could build across a lifespan, which could include periods of time when seizures may not be under control. Edmondson (2014) puts forth the Enduring Somatic Threat model to distinguish between PTSD from enduring chronic illness versus PTSD from external trauma. The underlying fear of mortality sustains symptoms in both arenas, however "differences include the external versus internal/ somatic source of the threat, the past versus present/ future temporal focus of threatening cognitions, the different types and consequences of avoidance behavior, and the different character and consequences of hyperarousal" (Edmondson, 2014, p. 118).

Iseri, Ozten, and Aker (2006) found there to be a significant occurrence of PTSD and Major Depressive Disorder (MDD) in parents of children with epilepsy, suggesting that there could be a need for more clinical support regarding the psychosocial dimension for both parent and child. If there is a disruption in the child's body, such as an epilepsy diagnosis, and parents do not have the tools to support their child, as significant rates of PTSD and MDD among parents have suggested (Iseri et al., 2006), this could negatively impact a child's development and affect a child's ability to explore (Addison, 1992) and a parent's ability to attune. Schore and Schore (2008) describe a child's attachment outcome as a "personal trajectory of emotional growth, including the development of their unconscious, to be facilitated or inhibited by the context of their family and culture" (p. 17).

*Media portrayals.* Negative portrayals of people with epilepsy in the media reinforce stigma. In the 2018 Netflix film *The After Party*, a character is nicknamed Seizure Boy and many people make fun of him for having seizures. This led to a statement by Phillip Gattone (2018), president of the Epilepsy Foundation,

Making fun of someone having a seizure is bullying at its worse. When such responses are portrayed as acceptable behavior, even in movies, it is demeaning and hurtful to our epilepsy community and all of us. In fact, such treatment can put real people who have

seizures at increased risk of injury and death. If someone is ridiculed for a medical problem, such as seizures, they are more likely to hide their illness and less likely to seek medical care or the help of others (para 2).

Gattone issued a similar statement after an online video of a high school senior with epilepsy being mocked and taunted by another student went viral. While attempting a free-throw in a basketball game, the student was told to 'have another seizure' while another student imitated a seizure (Klausner, 2018). The school said it was investigating 'unsportsmanlike and disparaging' behavior by its students after the public humiliation (Parker, 2018). These are examples of a lack of dialogue and permissiveness of discrimination and stigma surrounding epilepsy that perpetuate social isolation.

Stigma of invisible disability. Hirschberger, Florian, and Mikulincer (2005) evoke Terror Management Theory to describe the social prejudice for people with disabilities (Greenberg, Pyszczynski, & Solomon, 1997), 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). The "surprise" factor (Lortie & Vanasse, 2007) comes when one previously passed as "normal" before disclosing epilepsy or having a seizure. Goffman (1963) describes how social stigmas can prevent social integration, noting that "an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us" (p. 14). Lortie and Vanasse (2007) contend that stigma promotes negative views of epilepsy as being unacceptable and disturbing and that these prejudices are often rooted in ignorance and fear, reinforced by the unpredictable, "surprise" nature of seizures, particularly tonic-clonic seizures where people's bodies convulse. Foucault (1980) posits that entering the era of biopolitics in the 18<sup>th</sup> and 19<sup>th</sup> centuries changed how humans related to their bodies which was integral to the formation of our modern institutions, the establishment of "social norms," and the need for our bodies to perform in a variety of institutional contexts and public spaces.

**Historical foundations.** The quest to feel like "a normal person" with epilepsy may be a complex road where the stigmatizing nature of the condition is a recurring theme. 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,

and the enacted stigma, which is the actual reactions of others, can be the manifestation of these fears. People living with epilepsy in developing countries are still subject to mass misconceptions of the causes of epilepsy (Baker, 2002), while many of these beliefs were still prevalent in developed countries less than a century ago, where people were regularly institutionalized for having epilepsy (Sampert, 2017). Historical misconceptions include notions of demonic possession, witchcraft, epilepsy as an infectious disease, as a sign of mental and moral weakness (Baker, 2002), and as a predictor of violent behavior and insanity (Sampert, 2017). According to Gregg (2015), even Freud believed that seizures were "manifestations of unexpressed rage and regression to a pre-birth state" (p. 188).

People living with epilepsy were subject to the eugenics movement of the first half of the 20<sup>th</sup> century. Leading up to World War II, between 1933 and 1939, 360 000 people suffering from conditions deemed 'unfit' to produce offspring (including many people with epilepsy, schizophrenia and people suffering from various mental illness and disabilities) were sterilized (Holocaust Memorial Day, 2016). When the Nazis began their mass killings they refined their tactics on this same group, with the first experimental gassing taking place at a killing centre set up in Bradenburg where thousands of disabled people were gassed in the showers. This technique was developed to speed up the previous use of medical-board approved euthanasia for people deemed unworthy of life due to a condition such as epilepsy (Holocaust Memorial Day, 2016). In Canada, people with epilepsy were sterilized up until 1972, under the Sexual Sterilization Act, which prevented the reproduction of people considered to be "mentally defective" by the government (Sampert, 2017).

It is well documented that people with epilepsy may face great challenges to be understood in our society, not only by their peers but by people in positions of authority such as health and education professionals (Havlena & Stafstrom, 2012; Baker, 2002) as well as police officers and prison officials, with a number of recent deaths related to arrests during a seizure (Sampert, 2017). Our culture plays a huge role in how an individual experiences illness (Conrad and Barker, 2010), and instances of discrimination in attempts to access education and professions (Baker, 2002) may lead to withdrawal. Social isolation is a huge problem for people with epilepsy (Havlena & Stafstrom, 2012) and creating multiple spaces to address psychosocial stigma via art therapy and community art studios aka art hives is key.

# **Self-Esteem and Epilepsy**

Rosenberg (1965) outlined self-esteem as "a favourable or unfavourable attitude toward oneself" (p. 15). Chew, Carpenter, and Haase (2019) describe three interconnected factors that relate to self-esteem for young adults with epilepsy as impairment effects, 'barriers to doing', and 'barriers to being'. Impairment effects describe how challenges of the condition (seizures, side effects of medication, functional issues, treatment stress, and condition-related demands) interfere with developmental trajectories involved with individuation (actions that involve independence, autonomy, and social growth). The severity of the impairment effects merge with systemic and social exclusion to create 'barriers to doing', causing emotional implications such as effects on self-esteem and sense of self, which formulate 'barriers to being'. 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).

Olthof, Ferguson, Bloemers, and Deij (2004) contend that stigma can cause shame, putting the self's core attributes at risk, and leading to feelings of unwanted identity, referencing Sabini, Garvey, and Hall's (2001) concept of shame as "public breaks with decorum that were uncontrollable, that were evidence of a serious mental disorder" (p. 113). Olthof et al. (2004) contend that this can cause doubts of the coherence of self, fearing that others may view them as inconsistent and lacking capability, viewing "the self as being unwilling or unable to authorize one of its manifestations to the outside world as originating from the self" (p. 401) which establishes an unwanted identity. Regarding shame-appraisals in the context of chronic conditions and invisible disabilities, the evoked unwanted identity "does not so much concern one's fear of being seen as a bad person, but one's fear of not being seen as a person at all" (Olthof et al., 2004, p. 401).

## Chronic Conditions, Self-Esteem, and Survivor's Guilt

Bogart and Hegelson (2000) note that for chronic conditions, the objective standard of well-being disappears, thus promoting social comparison to others as the threat is increased.

Ghaemian Oskouei (2016) citing Festinger (1954), notes that upward, downward, and lateral comparsions to others can occur, and that for people with epilepsy and chronic conditions, this can mean feelings of having it worse than others (loss of independence), having it better than others (less frequent and severe seizures), or identifying as having it relatively the same as

someone else. Depending on the source of identification, all comparison situations can have positive and negative effects on self-esteem. Ghaemian Oskouei's (2016) investigations into social comparison theory and epilepsy present new territory, however they assert that research on occurrences of social comparison among other types of chronic illness has been more established (Ghaemian Oskouei, 2016), such as upward and downward comparisons among cancer patients (Bogart & Hegelson, 2000; Bennenbroek, Buunk, Van Der Zee & Grol, 2002). The lack of certainty and concrete information offered for chronic conditions makes people more likely to engage in social comparison as a coping strategy to enhance well-being (Arigo, Suls, & Smyth, 2014). Due to the unpredictable nature of seizures, people with epilepsy may "feel ambiguous and uncertain about the future of their health standing, which results in a perceived threat to the person's self-construction. Perhaps a social comparison is more likely to happen as a consequence of uncertainty in living with epilepsy" (Ghaemian Oskouei, 2016, p. 54).

Vamos (1997) states that for patients facing chronic illness in group settings, there can be intentional emotional avoidance of others' plights, or intimate bonds formed that may share each others' illness trajectories. "The relationship created by ongoing proximity in the face of a common but uncontrolled threat is in many ways analogous to the comradeship forged in war" (p. 592). Vamos (1997) lists group identification as 'traumatized' and a feeling of lack of control over mortality and illness events as key formative factors to survivor's guilt. In mental processing of life-threatening stressors, "the death of some and the survival of others becomes magically linked. In this way, life becomes somehow contingent on death, and the survivor must justify continued existence in relation to those who died" (p. 593). Although the phenomenon was initially observed regarding one's survival of death over another, the term has expanded to social comparison scenarios, such as feelings of guilt one may experience for possessing a greater degree of health, wellness, and success (O'Connor, Berry, Weiss, Schweitzer, & Sevier, 2000).

Maxwell and Aldredge-Clanton (1994) note that survivor's guilt contains a spiritual dimension, highlighting its association with an existential search for meaning, as well as thought patterns of rationalization, restitution, and responsibility-seeking that are associated with cancer patients' psychosocial health. As a symptom of traumatic stress, survivor's guilt can be a predictor of depression and was listed as a diagnostic symptom of PTSD in the Diagnostic and Statistical Manual-3 (DSM-3) (Maxwell & Aldredge-Clanton, 1994). As stress-related disorders

were separated from anxiety disorders in the DSM-5 (American Psychiatric Association, 2013), it has been suggested that trauma and stress related diagnoses may exist on a complex spectrum as other psychiatric conditions (Friedman, Resick, Bryant, Strain, Horowitz, & Spiegel, 2011).

# **Group Therapy Processes**

Forsyth (2010) posits that getting to know one's self and valuing one's self may be equally associated to well-being, noting that "just as exclusion from a group can trigger a loss in self-esteem, so can inclusion in a group contribute to more positive feelings of self-worth" (p. 503). Groups can provide people with social identity, offer social support by validating that others experience similar challenges and feelings, provide a place to exchange information and help others, and offer a forum for social comparison (Forsyth, 2010). Festinger (1954) developed social comparison theory to understand how humans compare themselves to others (when lacking an objective standard for evaluation) as a means to promote self-enhancement.

Vinogradov and Yalom (1989) outline group process as being interdependent between both group members and leaders.

In group therapy both patient-patient interactions and patient-therapist interactions as they occur in the context of the group setting are used to effect changes in the maladaptive behaviors of the group members. The group itself, as well as the application of specific techniques and interventions, serves as a tool for change (p. 1).

In the spirit of genuineness when it comes to personal disclosure in a group setting, Yalom (2010) encourages therapists to share information from their own lives if it will benefit the client and their personal growth.

Clinician disability representation. Freeman (1994), in her practice as a psychotherapist with a hearing impairment, has open communication with her clients with disabilities regarding her disability and uses it as a metaphor to bolster the processes of psychotherapy. Freeman (1994) contends that identification with the therapist is important, and transference and countertransference processes often provide diagnostic clues in the first session regarding how a client feels about their situation (Asch & Rousso, 1986). Freeman (1994) emphasizes that "the issue of disability must be addressed directly in order to effectively establish the initial therapeutic relationship" (p. 81) and posits that this may be the first time that a female client with a disability has received help from "a disabled female role-model" (p. 82). As people with invisible disabilities may achieve social acceptance by "passing" as fulfilling a social norm

(Hahn, 1997; Palombi & Matteson Mundt, 2016), if appropriate for the therapist and client, being open regarding one's experience can establish disability as a shared social issue rather than an individual private struggle (Hershey, 2014).

*Peer identification.* Self-esteem has been shown to increase for groups of people that have been stigmatized when they have identified strongly with their group (Twenge & Crocker, 2002). In a clinical trial in Thailand, 60 people were offered an epilepsy support group as part of their neurology treatment services, while a control group of 60 people were offered regular services. Before the study, the treatment group's self-esteem (measured by the RSES) was significantly lower than the control group, however following the treatment, it was significantly higher than before the study, suggesting that group interventions relating to self-esteem should be integrated into the medical system to enhance the quality of life and self-esteem of patients (Sawangchareon, Pranboon, Tiamkao, & Sawanyawisuth 2013).

In a systematic review of qualitative studies on quality of life for young adults with epilepsy, Chew, Carpenter, and Haase (2017) call for strength-based social work interventions, citing that although many people had challenges and negative social experiences regarding epilepsy, there were also positive support experiences that could be bolstered by building resilience, coping strategies and psycho-education (Chew et al., 2017). When social support is offered to people living with epilepsy, this creates positive interactions with family, friends, and the community-at-large; establishing protective factors to enhance their self-esteem and social development as they navigate the chronic implications of the condition (Chew et al., 2019).

# Part II: Art Therapy

The American Art Therapy Association (AATA) defines art therapy as "an integrative mental health and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship" (AATA, 2017). Riley (2001) contends 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) states that "art therapy provides a way of working with illness-related experiences when words alone feel too challenging or painful" (p. 176). Whether this involves

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). Art-making acts as a mediator (Morgan, Knight, Bagwash, & Thompson, 2012), providing an "intermediate step that facilitates the externalization of somatic knowledge" (Czamanski-Cohen & Weihs, 2016, p. 65). In regards to epilepsy, art therapist Michel Ledoux refers to such experiences as 'body memories' (Jones, 2005, p. 23). Bruckland (2015) asserts 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 normalize 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 frustrations about 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) relays that relaxation techniques and body-sensing-imagery exercises can help patients visually address medical related trauma that they may not be ready to discuss.

Art therapy encourages meta-cognitive processes such as mentalizing, which is "the ability to understand actions by both other people and oneself in terms of thoughts, feelings, wishes, and desires" (Bateman & Fonagy, 2016, p. 3). In terms of navigating social norms and expectations, art therapy can address this "dilemma of connection" (Morgan et al., 2012) by becoming a platform for the client to reflect on communication (both with themselves and others), to engage in reflexive functioning (Czamanski-Cohen & Weihs, 2016) and to offer a container for intense emotions (Turner, Lovell, & Brooker, 2011). Research by Collie, Bottorff, and Long (2006) shows that in art therapy, even when emotions have been expressed in a negative context, often the patient will leave in a more positive context due to a sense of relief from expression. Havsteen-Franklin (2007) posits that artwork becomes "a map of the patient's internal space" (p. 60), can comfort as a 'transitional object' (Winnicott, 1988, p. 2), can enable projection as a 'scape-goat' (Schaverien, 1997, pp. 13–14) or represent 'a way of embodying feeling states and thinking' (Case & Dalley, 1992, p. 97).

**Mindfulness approaches.** The metacognitive process of mindfulness involves engagement, attention, reflection and non-judgmental curiosity. "Clients are taught to see thoughts, not as concrete reality, but just as thoughts, which come and go and therefore can be tolerated" (Czamanski-Cohen & Weihs, 2016, p. 67). During a pilot study examining sense of

mastery and self-efficacy for people with epilepsy, Michaelis, Niedermann, Reuber, Kuthe, and Berger (2018) employed mindfulness-based psychotherapy interventions for nine participants for a median of 13 sessions. These included one-on-one sessions with the therapist to teach mindfulness techniques, use of workbook 'Taking Control of Your Seizures', daily journaling, mindfulness-based relaxation exercises, and use of a seizure log (Michaelis et al, 2018). These interventions led to lower levels of self-stigmatization and changes in participants' attitudes regarding epilepsy. Participants became aware that "dysfunctional cognitions and behaviors had been transferred to seizures, and in turn, these dysfunctional cognitions and behaviors had been exacerbated by having seizures" (Michaelis et al, 2018, p. 158). This provided opportunities for participants to examine attentional bias and to reflect on aspects of self-care, which has been linked to seizure reduction (Tang, Poon, & Kwan, 2015).

Drass (2015) has developed mindfulness-based art therapy interventions such as mindfulness with watercolour where key concepts include 'staying in the moment', observing how the watercolour media interacts (while letting go of any formal expectations), followed by a group discussion of what the experience in doing so was like (Drass, 2015) which provides an opportunity to engage in real-life experiences via the safety of metaphor (Riley, 2001). Csikszentmihalyi (1997) asserts that "art-making may enable individuals to engage in the process of 'flow', which includes opportunities to challenge or stretch existing skills with clear goals that include feedback regarding progress" (Czamanski-Cohen & Weihs, 2016, p. 68). Hinz (2009) points out that engagement with various art media can promote mindfulness.

# **Key Art Therapy Assessments: Information Processing, Trauma, Epilepsy**

The Expressive Therapies Continuum. The Expressive Therapies Continuum (ETC) is an art therapy framework to organize art media engagement and experiential art-making through neurodevelopmental processes (Hinz, 2009). The first level is the Kinesthetic/ Sensory dimension which involves non-verbal information processing characterized by tactile and sensorial engagement and expressive movements. The second level may or may not involve words, and is the Perceptual/ Affective dimension which may focus on emotional expression, the recognition and creation of images or formal visual elements (Hinz, 2009). The third level is the Cognitive/ Symbolic dimension which often involves more complex information processing and verbal components to understand and express symbolic representations and cognitive planning (Hinz, 2009). The first three levels of the ETC correspond with the types of information

processing performed by left brain (Kinesthetic, Perceptual, Cognitive) and right brain hemispheres (Sensory, Affective, Symbolic) (Lusebrink, 2004; Hinz, 2009). The fourth dimension, the Creative component, is present throughout each level of the continuum. The Creative component has the ability to involve a single dimension or to incorporate all dimensions, representing integrative information processing of both hemispheres (Lusebrink, 1990; Hinz, 2009).

Hinz (2009) describes "optimal functioning" of an individual when they have access to all levels of information processing, however when there is unaddressed traumatic stress, there is dysregulation between the emotional and rational centres of the brain. This can have a polarizing effect, leading to either emotional overwhelm or emotional avoidance. The art-making process and use of materials can provide a pathway of assessment for the art therapist that can enhance their ability to guide a client to a more balanced functioning. An example is the use of clay to release anger. According to Hinz (2009), the healing function of Kinesthetic/Sensory dimension of the ETC has potential to discharge internal energy related to trauma (Hinz, 2009). Through sensorial and kinesthetic engagement, a client may gain more access to their affective processing, develop a narrative and through repetition, move toward a more cognitive realm to respond to stressful scenarios. Successful recovery from trauma involves working with all functions of the ETC (Hinz, 2009). Hinz (2009) suggests that working on the Symbolic component of the ETC can explore trauma at safe distance via metaphor, while working on the Perceptual/ Affective component can help understand emotions involved in relationships.

Art Therapy Trauma and Intervention Paradigm. Appleton (2001) utilized Lee's (1970) medical trauma stage model to create Art Therapy Trauma and Intervention Paradigm (see Figure 7) based on her work with burn victims. This model integrates goals based on art therapy's ability to address psychosocial elements at four stages of treatment. For each stage, psychosocial issues, themes, symbols, and graphic features are listed. The first stage is the Impact stage, where Appleton (2001) lists the art therapy goal of "creating continuity to address the psychosocial issues of trauma, denial, and shock" (p. 7), and includes illustrating the trauma event and the body as possible themes. Stage two is Retreat, with the goal of "building the therapeutic alliance to address psychosocial issues of regression, dependence, social withdrawal, and resistance of care" (p. 7), listing sunsets, fantasy, superheroes, and relaxation imagery as themes. Stage three is Acknowledgement, with the goal of "overcoming social isolation through

mastery to address psychosocial issues of mourning, social interactions, and resource examination" (p. 7), listing grief, psychological pain, social relationships as themes, as well as trees and mandalas as symbols. The final stage is Reconstruction with the goal of "fostering meaning to address psychosocial issues involving values and spiritual clarifications, mastery, independence, and concerns about the future" (p. 7). Reconstruction themes include illustration of hopes, fears, and future concerns, as well as imagery regarding home, work, and school (Appleton, 2001).

Art therapy seizure assessment. In a sculptural art therapy seizure assessment developed by Brown, Shella, and Pestana-Knight (2018), participants in an in-patient epilepsy diagnostic unit interpreted how a seizure felt in their body by creating a mask on a styrofoam mannequin head. Brown et al. (2018) note that often the patient placed the seizure "in a specific spot on the head, and included other physical effects from a seizure involving injury to the nose and tongue, or bitten tongue" (p. 9). This endeavour gave patients a way to represent their seizure experiences visually. Thematic patterns included presentation of electrical imagery such as lightning bolts, explosions, and zigzags, both organized and disorganized lines, fluctuating emotions, depictions of the ictal (post-seizure) state, and concepts of resilience, hope, and awareness (Brown et al., 2018).

It is the intent of Brown et al. (2018) that this assessment could potentially contribute an important component to the complex process of diagnostic clarification between epileptic seizures and psychogenic non-epileptic seizures (PNES). Psychogenic non-epileptic seizures are unconscious expressions of complex emotions that are often trauma-based and can be very difficult to distinguish from epileptic seizures, which can weigh both on the patient and the system (Brown et al., 2018). In this pilot study, although limited to a group of 5 people with PNES and 5 people with epilepsy, the thematic content of people with PNES suggested signs of trauma experiences outside of seizure-induced trauma, while the emotional content of people with epilepsy was more related to the limitations that seizures imposed on their life (Brown et al., 2018).

Art therapy can be beneficial to addressing psychosocial aspects of both disorders (Brown et al., 2018) and therapeutic treatment has led to reduction of symptoms for people with PNES (Russell, Abbass, Allder, Kisely, Pohlmann-Eden, & Town, 2016). It has been suggested that treating the psychosocial dimension for both epilepsy and PNES could decrease costs in the

medical system as diagnostic uncertainty often leads to multiple EEGs that may prove unnecessary (Brown et al., 2018, Russell et al., 2016), as well as there is a substantial rate of comorbidity for epilepsy and PNES (Vivas, Reitano, Waseem, Benbadis, & Vale, 2017).

A recent survey by the Canadian League Against Epilepsy noted that once a patient receives a sole diagnosis of PNES, they are often discharged from neurology without arrangements for follow-up care (Carter, Denton, Ladino, Hassan, Sawchuk, Snyder, & Group, 2018). As art therapy can be seen as a non-threatening, it allows clients to work through traumatic stress at their own pace (Riley, 2001), thus the integration of art therapy into a multi-disciplinary epilepsy treatment model could contribute to both a framework of assessment and a way to safely address psychosocial trauma of epilepsy and PNES.

# Working with Traumatic Stress and Memory through Art Therapy

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. xviii). In terms of epilepsy, this could represent threatening events and cognitions regarding the psychosocial, neurobiological, and chemical dimensions of the condition (Hermann & Whitman, 1992). Traumatic seizures involve the internal source of Enduring Somatic Threat (Edmondson, 2014), yet occur in an external social context (Hermann & Jacoby, 2009), instigating an internal psychosocial response (Chew et al., 2019). In art therapy, past traumatic events can manifest in art media, without being verbalized (Saltzman, Matic, & Marsden, 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).

Hinz (2009) asserts that in mood disorders, affective information processing can become unavailable or overly available, leading to dissociation or emotional outbursts. Neural plasticity suggests that art-making is key for self regulation and can help reintegrate memories and reorganize neural structures (King-West & Hass-Cohen, 2008). Moon (2016) emphasizes that due to the sensorial nature of art-making, even when a participant is depicting an event that happened in their past, they are engaging with it in the present through the somatic artistic

process. This promotes healing and a sense of mastery, emphasizing social integration when this process is witnessed in a group environment (Moon, 2016).

Cabannis, Cherry, Douglas, & Schwartz (2011) emphasize that coping strategies to stress can be either conscious or unconscious and are reactions to both internal stimulation (such as anxiety, developmental pressures) and external stimulation (such as academic, relational issues) (p. 297). Maladaptive defense mechanisms consist of compensatory behaviours that often occur to "relieve the internal stress load of having full relationships with others" (Cabannis et al., 2011, p. 298), leading to social avoidance and chronic loneliness. Yalom (2005) posits that human connection is imperative for human survival, thus creating in a group setting reduces social isolation, promotes personal and community empowerment, and fosters emotional risk-taking derived from group rituals that promote safety and psychological well-being (Moon, 2016). Rubin (2005) attests that art therapy's safe-space can allow a sense of mastery and rehearsal for the future.

Hass-Cohen (2016) notes that when working with autobiographical memories of complex trauma, it is important to avoid activation (by pairing with non-threatening information), to foster a sense of mastery for positive emotions (to minimize vulnerability), and to build social relationships (Hass-Cohen, 2016), including the therapeutic alliance. The combination of the non-threatening art making space and therapeutic alliance creates a powerful arena for emotional exploration. Czamanski-Cohen and Weihs (2016) emphasize that "once a safe enough attachment relationship is formed, the client engages with the art materials with relaxed exploratory arousal and is able to use the art-making process for self-expression and for the transition of emotional material from implicit to explicit arenas" (p. 65).

Schore (2003) emphasizes that there are two memory systems at play when it comes to repeated trauma events. The hippocampus recalls logistical and autobiographical details of the event and associated emotional reactions (conscious processes), while the amygdala manages physiological responses such as heart rate, blood pressure, and hormonal changes, which can trigger a panic state if not accessed safely (unconscious processes) (Schore in Timm-Bottos, 2006, p. 18). Lobban (2014) contends that the hippocampus, responsible for verbal declarative memory and memory modulation, becomes damaged by excessive exposure to the stress hormone cortisol and can shrink up to 26 percent with severe PTSD (Bremner, 2005). Lobban (2014) describes how the amygdala, acting as our body's danger alarm goes "on permanent red

alert, sensing threat everywhere, and so the PTSD becomes self-sustaining with every false alarm becoming a re-enforcement" (p. 5). This leads to avoidance of public places, crowds, and social withdrawal, which in turn causes anxiety and depression (Baker, 2002; Cabannis et al., 2011; Lobban, 2014). In high arousal states, survival is the focus, thus the brain's language centers close down and can result in "speechless terror" (Lobban, 2014, p. 5). This interferes with the ability to describe an experience verbally, both in the moment, as well as later impairing the ability to develop narratives to process events in words (Lobban, 2014). In neuro-imaging studies to the traumatic stress response, van der Kolk (1994) found less activity in left-brain areas involved in verbal processing, and increased activity in right-brain areas involved in emotions and visual imagery (Lobban, 2014).

Garland (2002) suggests that physiological and psychological responses during a traumatic stress response become overwhelmed by raw sensory information that is interpreted as if it is happening live. Interpreting through an attachment lens, Garland (2002) draws from Bion's (1967) containment theory, seeing a flashback as a loss of container for anxiety and a loss of emotional safety. As this affects an infant's ability to explore, a lack of containment affects a survivor's ability to engage in symbolic thinking, to embody 'as if' experiences and to convey these thoughts in words (Lobban, 2014). It is here that art therapy's ability to offer a container for intense emotions (Turner et al., 2011) is key.

Timm-Bottos (2006) contends that the safety of the community art studio provides a space where unconscious neural structures affected by trauma can be re-organized to promote healing and emotional regulation, "rebuilding the limbic system from the bottom-up" (Timm-Bottos, 2006, p. 18). Lobban (2014) signals that traumatic stress can lead to social isolation and feelings of abandonment, pointing to van der Kolk's (1987, p. 155) assertion that, "One of the most urgent tasks facing therapists of traumatized individuals is the re-creation of a sense of human interdependence and community" (Lobban, 2014). This provides a forum to repair attachment through art (Turner et al., 2011) promoting social integration (Moon, 2016).

# **Group Art Therapy**

Working with combat veterans who had multiple and prolonged exposures to traumatic stress, Lobban (2014) conducted a two-hour group art therapy program where the first hour was spent in open-studio art-making, and the second hour in a group discussion of artworks. This allowed a period of introspection, creative and sensorial engagement via art materials, and non-

verbal self-expression of unconscious emotional material in a safe setting where each individual could moderate the distance as needed from traumatic content. The second part of the session was spent as a group discussing, decoding, reflecting, witnessing, and connecting in a supportive environment. Engaging both right brain (emotional, intuitive) and left brain (verbal, analytical) functions, this experience provided a bridge to import traumatic memories (raw, sensorial, frozen, non-verbal) from the amygdala to the hippocampus (processed, verbal, fluid, autobiographical) through the construction of a verbal narrative and engagement of symbolic thinking in safe setting (container) (Lobban, 2014). Around the theme of 'Invisible Wound', the group identified concepts of disconnection, such as wanting to wear a mask to present a false self to the world in order to hide vulnerability, matters of control and avoidance, and feelings of being trapped in traumatic memories. Following their art making experience the participants described the group art therapy experience. They stated that they felt connected, spontaneous in the process, open to addressing emotional material and finding meaning, spontaneous in the process, and inspired by the ability to convey body sensations (stress responses) through art materials such as clay. This suggested that new neural pathways were being formed that allowed participants to gain mastery over their traumatic memories to form a verbal narrative to help promote structural reintegration (Lobban, 2014). Moon (2004) suggests that mastery of art materials in the open studio can promote feelings of independence, self esteem and a sense of success (Moon, 2004), all key elements in accepting a life with epilepsy. Such feelings, along with positive social interaction, are key to restoring the presence of an internal locus of control (Gardener, Cole, Berry, & Nowinski, 1983).

Moon (2016) contends that there is power in witnessing the healing of others, and that this can resonate in one's self. Both the problems and the solutions of others can stimulate genuine self-reflection and social interaction. Moon posits that "one of most beneficial qualities of artistic activity is its ability to integrate dichotomous forces" (pp. 6-7) citing McNiff's observation that "the poison becomes a remedy, and problems are transformed into doorways to new ways of living" (McNiff, 2003, p. 13). Gussak (2007) suggests that use of art media and symbolic interaction can "validate and reinforce new behaviours and identities" (p. 155). Allen (1997) posits that "art is a way of knowing", suggesting that engagement of symbolic imagery offers "signposts into the depths of yourself (Allen, 1997, p. 87). Gregg's (2015) work with young adults with epilepsy and intellectual disabilities found that identification with fantasy characters

(such as Dorothy from the Wizard of Oz) was prevalent in open studio art therapy sessions and this coping strategy was used by clients in order to boost their sense of self when complications of epilepsy would arise (Gregg, 2015).

Existing art therapy groups for individuals with epilepsy. Studio E is a community art studio that is dedicated to people with epilepsy, and for many participants, it may be the first time they have met another person with the condition. The rationale is to give participants a chance to explore their own creativity, meet others with similar conditions, and give a chance to open up about their epilepsy experience in a safe space (Epilepsy Foundation of Michigan, 2016). A typical program runs for 6-8 weeks, once a week for 3 hours, is free to participate in (funded by pharmaceutical companies), and can be specially catered to sub-groups such as children, adults, teens, and veterans (Epilepsy Foundation, 2016).

Another group art therapy treatment model for children and teenagers with epilepsy consisted of focus groups developed by Havlena and Stafstrom (2012). Over four weeks, participants would meet once a week for a directed session to explore themes relating to their epilepsy experience. Week one was a self-portrait of a box, with an inside and outside function, which encouraged participants to compartmentalize the elements of their lives that they deem public and private. Week two was a pastel and resist activity that was directed to convey an epilepsy memory. Again, drawing in pale colours could initially present the memory in a concealed and guarded manner, perhaps the way they may present their epilepsy in a social setting. Week three was meant to be a mandala of what was important to each individual and week four was a diorama that was meant to embody a dream or goal for the future (Havlena & Stafstrom, 2012). In particular, week two served as a conversation starter for participants to share their various traumas, as for many, it was the first time that they had ever met another person their age with epilepsy. Examining the drawings, researchers found that there was symptom-related graphic content that was consistently present. Recurring images included blurry landscapes, illuminated halos, and crying eyes, often accompanied by a smile or neutral expression (Havlena & Stafstrom, 2012). Participants linked these crying eyes with the overwhelming heartbreak they felt after experiencing a seizure, the embarrassment of crying in public, and the frustration regarding not only the lack of control of their body but their emotions as well. Following four weeks of art therapy focus groups, researchers observed a higher level of collective comfort and a more socially engaged group, which parents' observations also

confirmed. These groups were only the beginning, as researchers expressed a desire to extend these studies to involve a longer duration and specific types of epilepsy (Havlena & Stafstrom, 2012).

## **Creating Spaces to Address Psychosocial Stigma**

For people with epilepsy, art therapy can offer a portal to create community. Art hives are community art studios where there is an emphasis on social inclusion, engagement, integration and the creation of a safe space (Timm-Bottos, 2006).

Elmborg (2011) distinguishes Lefebrve's (2014) three-part framework of how people experience and consider space in contemporary society, as spatial practices, representations of space, and representational space, all of which can exist simultaneously. Spatial practices are how the body's senses resonate, move, connect and experience a space. Representations of space as dominated spaces are created by governing bodies and planners (through their lens) to implicitly shape 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 better meet their values, attribute their perspectives, and address their needs. Elmborg (2011) describes representational space as "individual, perceptual, intuitive, and symbolic" (p. 343).

Representational space 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 (Sampert, 2017; Baker, 2002). The potential to connect and explore through this arena is even more important as people with epilepsy experience cyclical disconnections on the avenue of spatial practices when having a seizure, which can mean losing consciousness, the ability to control one's body, and cognitive interruptions (Epilepsy Foundation, 2014), all which may affect their sense of time in a space.

Bhaba (1994) posits that there is a borderland between representations of space and representational space, calling this area Third Space (Bhaba as cited in Elmborg, 2011, p. 344). According to Elmborg (2011), Third Space occupies a framework where "people with less obvious social, political, or military power can still exert influence on space by resisting the represented structures of dominant cultures" (p. 345). Third spaces are transformative, where

lived experiences past, present, and future can intersect, create dialogue, and potentially deconstruct hierarchies (Timm-Bottos & Reilly, 2015).

The community art studio or art hive exists in Third Space as a public homeplace (Timm-Bottos, 2005; Timm-Bottos & Reilly, 2015). Public homeplaces (Belenky, 1996) are welcoming spaces where 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. Timm-Bottos and Reilly (2015) assert that "participants in public homeplaces develop self-respect, confidence, and a sense of agency through this process" (p. 104). Elmborg (2011) cites that the cultivation of third spaces in cultural institutions is a contribution to "the ongoing effort to create a 'more fair' and just world" (p. 349).

On a spatial level, a third space in a museum can engage the setting as a co-facilitator (Salom, 2008), offering stimulation such as artistic diversity, collectivity of images, architectural inspiration and a range of metaphors and narratives. These elements can model individuality and mirror Yalom'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) offer's Janson's (1971) metaphor, describing

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).

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, Rinehardt, Hine, Wilkinson, Tush, Mead & Fernandez, 2014), and to address various mental health and chronic conditions via art therapy for people of all ages (Bennington, Backos, Harrison, Reader, & Carolan, 2016; Thaler, Drapeau, Leclerc, Lajeunesse, Cottier, Kahan, & Steiger, 2017). Conrad and Barker (2010) assert that both culture and individual personality place a role in long-term illness via social construction. For some, it can "make 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, McGivern, & Kerins, 2016, para. 2). For people with disabilities and chronic conditions, particularly those with an invisible nature, art hives may offer the chance to embody the slogan of the International League Against Epilepsy by inviting people to come "out of the shadows" (WHO, 1997).

# **Chapter 3. METHODOLOGY**

### **Research Question**

How can group art therapy impact the self-esteem, wellness, and overall quality of life for young-mid adults with epilepsy (aged 18-45 years old)? In what ways can group art therapy address the psychosocial dimension of treatment?

## **Methodological Rationale and Design**

A pilot study was conducted to "to evaluate the feasibility of recruitment, randomization, retention, assessment procedures, new methods, and implementation of the novel intervention" (Leon, Davis and Kraemer, 2011, p. 626). 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). As mixed methods provide an opportunity to explore outcomes through various lenses, it is conducive to the multi-faceted complexities that exist within the field of art therapy (Kapitan, 2017).

## **Mixed Methods Approaches**

Greene (2007) describes mixed methods as "actively inviting us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished" (p. 20). By design, mixed methods can embody a non-hierarchal perspective as it does not prioritize quantitative or qualitative data (unless it is by conscious design). It offers a more expansive view, contributing to a fuller understanding of "what is truly happening in a situation and why" (Kapitan, 2017, p. 103).

Mixed methods research can allow us to both explore a realm (in a qualitative sense), and then to test the knowledge gained (in a quantitative sense) (Creswell & Plano-Clark, 2011). The essence of a mixed methods research methodology goes beyond merely collecting both quantitative and qualitative data, it is embodied by how these data sets are collected, brought

together and compared. Data sets can be collected concurrently or sequentially. Concurrent data sets may be more time efficient as the data is collected at the same time, however sequential designs allow two datasets to build off of each other, with research designs being either fixed or emergent (Bradt, Burns, & Creswell, 2013).

Fixed design allows the researcher to plan in advance data integration, enabling them to consider aspects such as timing. Emergent design allows for a more holistic approach, as aspects (such as timing to merge data) may reveal themselves in the process. It is recommended that emergent designs be conducted by more experienced researchers, however, this design allows for the collection of rich and complex data (Bradt et al., 2013).

Creswell and Plano-Clark (2011) outline four common mixed methods designs that could be pertinent to research designs for the creative arts therapies: convergent parallel design, exploratory sequential design, and embedded design. Designs vary in terms of timing and order of data collection, data hierarchy options, and the fluidity of data to influence and transform one phase to another. The researcher is empowered with such design potential as it can truly be shaped by the research question (Bradt et al., 2013).

## **Data Collection**

For this project, a convergent parallel design was employed, which involves collecting both datasets simultaneously with an equal emphasis on the quantitative and qualitative data. Integration of the data is fixed, thus only happens at the data interpretation level after each set of data is analyzed independently (Bradt et al., 2013). Bradt et al. (2013) describe this final step as the time where "the researcher examines in what ways the two datasets converge, diverge, or simply relate to each other... the purpose of this design is to collect complimentary data on a given phenomenon" (p. 134). If datasets contradict or diverge, it may be necessary to reexamine data, analysis methods, collect additional data, or to review quantitative constructs and qualitative themes (Bradt et al., 2013). Data will be presented with a side-by-side approach, first reporting quantitative results and then qualitative, making an interpretation comparison within a discussion format, and finally presenting a visual display that represents both forms of data (Creswell, 2014).

### **Ethical Considerations and Recruitment**

As this study involves human participants, it is of the upmost importance to adhere to research codes of ethics of the Canadian Art Therapy Association (CATA), American Psychological Association (APA), and of the University Human Research Ethics Committee (UHREC) at Concordia University. These guidelines are in place to protect participants from harm and include rules to ensure that respect is maintained both throughout the study and with the data presentation following. Informed consent forms outlining all aspects of the study must be explained and signed before participants provide data and it must be made clear that participation is voluntary (Creswell, 2014).

Upon ethics board approval, clinicians at two Montreal epilepsy clinics were provided with a script to describe the study to patients whom they felt would meet participation criteria and benefit from participating in the study. Ethically, it is integral to emphasize that participation is voluntary and would not affect their care at the clinic. Potential participants would fall between the age group of 18-45 years old. Patients with co-morbid psychosis and intellectual disabilities (that would diverge greatly from the group's general cognitive abilities) were screened out. Interested participants signed a consent-to-referral form and received a follow-up from the researcher (either by telephone, email, or in-person at clinic) to explain more information on the study, to answer any questions, and to gather additional information regarding factors such as availability. Points for sample selection included recommendations by a physician, availability, levels of social engagement, perceived limits of quality of life due to epilepsy, number of years living with the condition, perceived severity of the condition, and a desire to participate in the program. Additionally, a poster was placed at the clinics, in community spaces, and in online epilepsy support groups.

## **Participants**

Participants were recruited by neurologists and neuropsychologists at two city hospitals, and via a poster in both French and English on social media support groups. Six participants completed the pre-test and post-test, while one participant withdrew following the pre-test and first art therapy session. Another participant completed the pre-test, but cited too much anxiety to be able to attend the art therapy sessions and after trying for three weeks unsuccessfully, they did not communicate further. The participant group was diverse, varying in demographics such as

the type of epilepsy, seizure frequency and severity, age of onset, how many years living with epilepsy, various levels of social isolation and functioning, and whether they had experienced discrimination, bullying, or psychosocial or medical trauma related to the disorder. For the limitations of this paper, six participants (assigned pseudonyms by the researcher) were profiled who completed the pre-test and post-test sessions, noting where this information was sourced. Protective factors were assessed by the researcher during the interview, and the following information is from the pre-test interview and survey (see Figure 8).

### **Procedure**

Under the mentorship of Dr. Signy Sheldon, tests were administered by the researcher and research assistant, and numerical analysis was conducted by Dr. Sheldon and her research team. Data merging of quantitative and qualitative data was conducted by the researcher, with consultation of Dr. Sheldon for integration of numerical data analysis.

Prior to testing, the researcher met individually with selected participants to clarify the study procedure and to attain informed consent. It was re-emphasized that participation is voluntary, that participants may leave the study as they wish, and that their identities in the study will be kept confidential. It was explained that study participation means granting the researcher rights to use and publish photographs of their artwork (with anonymity, while participants retain ownership to decisions such as exhibition of works) and to record audio from the sessions. Raw data would be stored on an encrypted device with no ties to participants' identity for 25 years. All original artwork would belong to the participant and they were able to bring it home following the end of the study. Additionally, a peer group confidentiality contract was explained and signed, which means that no session material shared in the group would be discussed outside of the group between participants. Finally, limits of confidentiality in accordance with the Canadian Art Therapy Association's legal and professional ethical requirements regarding confidentiality were explained and would be respected, including the need to break confidentiality if it was deemed that a participant is at risk to commit suicide or to harm someone else (CATA, ND).

## Pre-therapy and post-therapy test battery

Participants were then tested at the Sheldon Memory Lab at McGill University with a.) questionnaires assessment dimensions of social cognition, memory, self-esteem, quality of life b.)

a measure of autobiographical memory and c.) standard neuropsychological assessment of cognition (see Appendix A for full testing list that are beyond the scope of this paper).

- a.) The questionnaire data included the Rosenberg Self-Esteem Scale (RSES) (1965) and the Quality of Life Inventory for Epilepsy-31 (QOLIE-31). Both tests were administered by Buelow et al. (2014), although a more brief version in the QOLIE-10. It is recommended when possible to use the extended QOLIE-31 (containing 31 questions regarding emotional well-being, social functioning, cognitive functioning, energy and fatigue, seizure worry, medication effects, and overall quality of life), as it provides a more in-depth reading than the ten questions of the QOLIE-10) (Devinksy & Cramer, 1993). We also included tests to collect self-report mood levels of the individual, which included the Beck Depression Inventory (BDI) (Beck, Steer, & Brown, 1996), the Generalized Anxiety Scale (GAD) (Spitzer, Kroenke, Williams, & Löwe, 2006), and the Trier Inventory of Chronic Stress Scales (TICS) (Schulz, Schlotz, & Becker, 2004) which contain measures related to stress and mood factors. For the scope of this paper, quantitative questionnaire analysis will include the BDI, TICS, RSES, QOLIE-31, and GAD.
- b.) The Autobiographical Memory Test (AMT) was added to examine how the therapy affects the ability accessing emotional experiences from one's own life since memory is key for identity, social cognition, and self-esteem (Wilson & Ross, 2013). Here, participants are presented with positive, negative and neutral cue words (joy, amazed, awful, upset, concentrate, busy) and asked to use it to retrieve a past personal memory. The reaction time to access this memory is recorded.

Finally, participants completed a qualitative survey and interview designed and conducted by the researcher (see Appendix B). This consisted of open-ended, close-ended, and multiple choice questions to determine the epilepsy history, quality of life, levels of disclosure, and levels of social engagement of each individual prior to the study, as well as potential accounts of discrimination or their perceptions of the ways that epilepsy may limit their life. Audio data from interviews was recorded, transcribed and scored for qualitative themes relating to epilepsy impact on wellness, self-esteem and quality of life. Quantitative psychological tests were examined with numerical analysis (descriptive statistics due to low sample size) to compare pretest and post-test data collected from the within-subjects experimental design to assess whether

the treatment (art therapy) made a difference (Creswell, 2014). Quantitative data was then integrated with qualitative data to paint a fuller picture (Kapitan, 2017).

# Art therapy intervention

The next phase involved an 8-week group art therapy program which occurred for 3 hours per week, on Saturdays from 10 am to 1 pm (June 9<sup>th</sup> to July 28<sup>th</sup>, 2018) in a clinical-community art setting (Musée des Beaux Arts art hive). Sessions consisted of open studio time with suggested themes and bi-weekly visits to incorporate elements of the museum's collection that could serve as inspiration for creative exploration. Themes were chosen to promote exploration, resiliency, and community building while examining identity, social comfort 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 own creative vision. The diversity 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 approximately 30 minutes was set aside toward the end of each session for participants to share work as desired.

Each week began with a check-in, which provided participants a space for peer support, to share stressors related to the week, as well as an opportunity to share positive events and get feedback and information from the group as needed regarding challenges. A theme would be introduced, and on a bi-weekly basis, the group would embark on a museum visit for approximately 30 minutes. This tour would be facilitated by a trained museum guide, who presented pieces that related to the theme that were chosen by the museum's team of art education facilitators and staff art therapist. Upon return to the art studio, participants would have a brief discussion of their perception of the theme, how it related to the art they saw, and embark on approximately 1.5 hours of art making. On weeks where there was not a tour, participants had 2 hours to make art.

The themes of the first seven weeks were as follows: (1) *Introducing Yourself in Art/ Identity;* (2) *Emotion* (featuring a guided visit); (3) *Body Memory*, (4) *Social Isolation* (featuring a guided visit); (5) *Group Brainstorm* for a theme, with ideas introduced such as the Hero's Journey, finding a voice later in life, finding humanity in the system, dignity, and why apologize after a seizure?; (6) *Body: Control, Joy, Resilience* (featuring a guided visit); and (7) *Community and Resilience* (featuring a guided visit). In week eight, we introduced a group intervention

entitled *Making a Piece of the Collective Pie* to commemorate the community in the group, continued on the pieces from the week prior, as well as conducting a group artwork review and closing activity.

The researcher/ art therapy facilitator conducted these sessions in English and French with a co-facilitator to help with translation and to ensure that the group facilitation was fully bilingual. The co-facilitator was a music therapy Master's student and aided the researcher in data collection.

Qualitative data would consist of field observations by the art therapy facilitator, recorded in a DART (Description, Assessment, Response, Treatment) clinical progress note for each participant and reinforced with audio recordings. Sessions were transcribed and data was scored for thematic and meaning clusters. Artwork was photographed following each session and the researcher reviewed the images for thematic clusters or common symbols, comparing to Appleton's (2001) Art Therapy Trauma and Assessment Paradigm in a theoretical sense. Braun and Clarke (2006) describe the process of thematic analysis as "familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report" (p. 87). Creswell (2014) emphasizes 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. A contextual thematic analysis of this data was performed, which Braun and Clarke (2006) assert "acknowledges the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality'" (p. 81).

After completing the 8-week program, qualitative and quantitative materials were merged and reviewed in a group case study format by the researcher. Each week included a Positive and Negative Affect Schedule (PANAS) test to measure affect pre and post intervention, which has been shown to be a valid and reliable measure of affect in various large-scale samples, and as well to have the ability to distinguish between anxiety and depression in clinical samples (Crawford & Henry, 2004). Due to the small sample size, the PANAS was administered as an exploratory measure and data will not be integrated in this preliminary analysis.

Following the ending of therapy sessions, post-testing of the same test batteries occurred with a brief Exit Interview (See Appendix C) by the researcher for each participant, as well as

adding the Museum Survey (See Appendix D). Pre and post quantitative and qualitative datasets were compared, analyzed, and merged into visuals for interpretation.

# Role of Therapist/ Researcher

Kitchin (2000) citing Oliver (1992) takes issue with "the widespread exclusion of disabled people from disability discourse and calls for the adoption of research strategies that are both emancipatory (seeking 'positive' change) and empowering (seeking 'positive' individual change) through participation" (pp. 25-26). Yalom's (2010) assertions that a therapist should disclose genuinely what could benefit a client, motivated the researcher to respond in kind when participants inquired about the motivation to conduct such a study. Thus, when participants inquired about the researcher/ art therapy facilitator's motivation to conduct this study, it was shared with them that I had experienced epilepsy in young adulthood however I had received neurosurgery, and after taking medication for 15 years, I no longer required it. This minimal disclosure seemed to provide a base of trust to establish the therapeutic alliance, with some participants commenting that they had participated in many types of research, although it was usually clinical trials for medication and having a psychosocial dimension to the research was rare.

### **Chapter 4. RESULTS**

### **Attendance and Data Analysis**

Demographic aspects such as types of epilepsy, seizure frequency and severity, age of onset, years living with the condition, levels of treatment stress, and whether research participants had experienced discrimination or bullying, would play a role in attendance, sense of belonging in the group, responsiveness to art therapy treatment and results on psychometric tests (See Figure 9). This allows data analysis not only as within-subjects, but by creating a pseudocontrol group based on the level of session attendance. For our analysis, the data of four participants will be classified as "Attend Group", having attended between 6-8 sessions each (Camille, Luc, Nicole, and Ben) and completing both the pre-test and post-test interviews. Two participants (Lauren and Joe) attended 1-2 sessions while completing the pre-test and post-test interviews, and will thus be classified as "No Attend Group".

With the challenges and complexities of these variations in participants, who all have a form of epilepsy, mixed methods bring insight to both an individual's data and situation. For the

Attend Group, this presents an opportunity to compare effects of art therapy intervention relatively early in an individual's epilepsy experience. For example, Ben (see Figure 10), who had already gone through individuation prior to his diagnosis (as measured by the researcher regarding his completion of post-secondary education, enactment of career choice and professional experience), however he now faces stressors related to his treatment (surgical intervention) and how it will affect his life and capabilities moving forward. These include changes in self-image, as his sense of efficacy and independence as a young parent are affected; increases in negative thoughts, stress, and worry propensity that manifest as nightly anxiety before bed; and overall anxiety regarding his future cognitive and functional abilities if he has neurosurgery. All other participants received a childhood or adolescent diagnosis (preindividuation), had many more years of epilepsy and often higher levels of psychosocial trauma relating to discrimination and social isolation. Figure 11 shows the life changes from epilepsy for the pre-individuation onset in the Attend Group, with reports of impact on education, social economic status (SES), career and social development (affected by bullying, discrimination, learning, and energy depletion), as well as reports of lack of understanding of invisible disability (leading to social isolation and effects on self esteem), and a lack of trust in the medical system to treat the whole person (to recognize the psychosocial dimension of the condition).

Following Session 1, Lauren said that her employment work schedule had changed and it would affect her participation in the group. We told Lauren that she was welcome to return at any point and she said she looked forward to coming and thanked facilitators for "making such a safe space for the group" (via email). Lauren did not attend any further art therapy sessions but accepted the invite to participate in the post-interview. At this stage, Lauren revealed that since she had not had seizures for two years, she feared that other participants in the group would dislike her and that her presence in the group would cause others pain. Lauren had the lowest level of disclosure regarding her epilepsy, had the highest level of education and professional achievement, and had experienced discrimination at both educational and professional levels on the rare occasions that she has disclosed in these settings. This is an example of how enacted stigma (described as the concrete negative reactions of others to the condition and the manifestations of fears), can fuel perceived stigma (people's fear regarding how others may react) (Baker, 2002), and how Lauren's resiliency in society may have involved her burying epilepsy as deep as possible as a means of both survival and success. This may have been

Lauren's 'way of knowing', and going from talking about epilepsy as little as possible and never meeting anyone else with the condition to being in a room where everyone had a form of epilepsy and there was an eagerness to discuss it, may have been an overwhelming experience that Lauren was not ready to address. Although Lauren did not choose to attend further sessions, she did inquire about participating again in a future group in the post-test, feeling that she may be "more ready".

### Results

Quantitative questionnaires, qualitative interviews, and session material were assembled by the researcher in a non-hierarchal manner following a separate analysis of both datasets to create a visual (Creswell, 2014), which took shape as a concept map to interpret the results. Following the presentation of each dataset, this will be presented as *Figure 53*.

#### **Quantitative**

*Mood questionnaires.* Questionnaire results collected during the pre and post therapy tests sessions were compared between the participants who attended the art therapy sessions regularly (more than 6 out of 8 sessions, N = 4) versus those who did not attend the sessions (fewer than 2 sessions, N = 2). Given the small sample size and the exploratory nature of this study, only numerical comparisons are made rather than statistical comparisons.

First, the change scores (post-pre test scores) from questionnaires that reflect well-being were compared between these groups (see Figures 12 and 13). Numerically, those who attended art therapy sessions had an increase in self esteem on the RSES (M = 1.75, SE = 1.89) and those who did not attend showed a decrease in self esteem (M = -3.0, SE = 3.0). Those who attended art therapy had a higher increase on the QOLIE-31 quality of life dimension (M = 10.3, SE = 0.786) and those that did not attend had a slight increase (M = 2.50, SE = 15.0). The Overall QOLIE-31 score had a slight increase for those who attended art therapy (M = 1.80, SE = 5.14) compared to a slight decrease for those that did not attend (M = -1.43, SE = 0.760). Participants that attended art therapy had substantially lower levels of stress (see Figure 14) (post-pre test scores) on the TICS (M = -8.25, SE = 2.50) compared to stress levels of those who did not attend (M = 11.5, SE = 2.50). Participants that attended art therapy had lower levels of depression according to the BDI (M = -3.50, SE = 1.85) than those who did not attend (M = -1.00, SE = 2.00). Participants that attended art therapy had higher levels of self-disclosure of epilepsy (see

Figure 18b), as measured by the Survey Interview Guide (See Appendix A) (M = 1.5, SE = -0.224) than those who did not attend (M = -0.5, SE = -0.5).

Second, the change scores (post-pre test scores) from questionnaires were compared for those that attended art therapy (see Figures 15 and 16), with participants showing increases in self-esteem on the RSES (M = 1.80, SE = -0.5) and increases on overall quality of life ratings on QOLIE-31 (M = 10.3. SE = 0.33). Participants showed lower levels of depression on the BDI following art therapy (M = -3.5, SE = 0.55) and substantially lower stress levels (M = -8.25, SE = -0.08). For participants that attended art therapy, on the AMT there was a substantial decrease in the reaction time (RTs) for positively valenced memory cues at Post-Art Therapy (see Figure 17), suggesting that positive memories are more readily available (M = -7, SE = -0.77).

When it comes to museum experience (with 4 representing a maximum positive experience), participants who attended six or more sessions gave a more positive rating of their experience overall (M = 3.75, SE = 0.189), with extremely positive dimensions of expressivity (M = 4.0, SE = 0.00) and interesting social contact (M = 3.5. SE = 0.250) (see Figures 19 and 20). For those who did not attend more than 2 sessions, their overall museum experience was less positive (M = 2.50, SE = 0.100), with less positive range of expressivity (M = 2.50, SE = 0.500) and less interesting social contacts in group (M = 1.00, SE = 1.00). *Figure 21* shows the relationship between museum experience and lower levels of stress (according to TICS), based on attendance, with participants who attended more sessions having lower levels of stress and more positive experiences. *Figure 22* outlines a table of quantitative results.

## **Qualitative**

Art sessions and post-interviews. In the first session, introducing one's self through art was the theme, and it was emphasized to participants that they had complete agency over what they chose to include or disclose in both artwork or verbal processing (which was also optional). In the verbal check-in, people introduced themselves and included diagnostic information about their type of seizures, how long they have had epilepsy, how long since their last seizure, any upcoming treatment plans, and what types of medications they take or have taken in the past, including side effects. People also included information such as their employment or studies, whether they have partners or children, shared resources such as online coping groups and travel resources, and various coping strategies they have tried such as yoga. People touched on the

ways that they felt epilepsy had limited their life which included social isolation, loss of independence, lack of driver's license, and the invisibility of the condition.

Artwork was examined between Appleton's (2001) Art Therapy Trauma Intervention and Assessment paradigm, and scored for particular stages due to psychosocial issues and art themes (see Figure 23). Due to the cyclical nature of epilepsy and other chronic conditions, there seemed to be more overlap between the impact, retreat, and acknowledgment stages, and this seemed to relate to the level of control of the condition (seizure frequency and severity) as well as the current treatment situation (how much treatment stress) and age of onset (types of grief). This amounts to more dynamic exchanges between the impact, retreat, and acknowledgment stages, as one's work moves toward the reconstruction stage. Although there was some alignment on Appleton's graphic features, participants' work and artistic process conveyed a wide spectrum of the ETC and more diverse use of media (3-D work, sculpture). A future analysis will further investigate more extensive interactions between art process and product and how each individual's work varied from stage to stage of the model.

# Early-Mid stages: Group art trends in case study

In early sessions, it was more prevalent for participants to depict a specific seizure story or traumatic seizure event, as well as the psychological pain they were experiencing from the condition. Tonic-clonic seizures were represented through elemental symbols such as lightning bolts, volcanoes, electrical shots or storms, tornados, and whirlpools, often attacking the head of the participant. This was done both as a means to introduce themselves and their situation to the group, as well as a gateway to explore implicated emotions, such as confusion, grief over the loss of control, time, and independence; anxiety regarding treatment; and resulting psychosocial factors such as the impact on social relationships, limits on work and education, and stressors such as navigation of the healthcare system and side effects of medication.

Ben. In Session 1, Ben introduced himself by portraying a self-portrait of himself receiving a shot to the head, with eyes hidden under glasses and his mouth covered by his beard (see Figure 24). As Ben contemplated the implications of possible neurosurgery and possible effects on his memory and cognition, he said he wanted "to symbolise the drama and the changes coming... I wanted it to be a bit violent... like electric but also like a gun shot." When asked how it felt to put his situation in art, Ben said "It's difficult to say... as soon as I express these feelings they stop so I think it will be good. But it's also just embarrassing, I felt lame drawing myself a

bit (laughs)", showing vulnerability in both artistic skills and sharing emotional material in a group setting, as most participants made comments regarding their lack of artistic skill in early sessions. When Camille asked Ben why there was no mouth, Ben alluded to the somewhat invisibility of his condition in the social sphere and the containment of intense emotions, anxiety and stress. "I'm lucky enough that my seizures are when I go to bed, I'm lucky that when I go out I'm confident. It stresses me sometimes, having little auras... if I do too much work, or if I do a long shift I can be uncomfortable at the end. But in general, it's internal. It's a neutral face, but there's something explosive going on inside."

Camille. Camille introduced herself by making a backpack out of paper (see Figure 25) to mark the one year since what she described as her worst seizure of her life. In Camille's seizure story, she describes how she sustained many injuries including a broken collar bone, a cerebral concussion, a black eye, sprained ankle and stitches, and how she feels that she has been in 'survival mode' since. Camille relays both the trauma of this experience, as well as the resulting psychosocial implications she experiences as she carries these memories, the anxiety that it may happen again, and how it has affected her education and work opportunities (having had to discontinue classes and take time off from her university studies), as well as the impact on her social spheres (tired of explaining to friends and feeling that they pity her). Camille relays her story through symbols of a volcano, an electrified brain, a whirlpool, and medication, writing "1 year, day by day, I haul my backpack." Camille describes the anxiety, stress and social isolation of her situation as "Very, very heavy, my back hurts. I look forward to resting. I can't wait to get out of the house and tell myself, it's going to go well, I'm not going to have a seizure ... I'm looking forward to saying that. To not be afraid to leave my home...that's the first thing. Not to have social exclusion." Camille describes what she sees as an ever present seizure threat with epilepsy as "a whirlwind because it's kind of always swirling in my brain." Camille indicates that if she had more time, she may have crumpled up papers and magazine images to put in her backpack to reference different dimensions of her situation such as school and work.

At this stage, Lauren, (a participant who has been seizure-free for two years), asks Camille "Do you think that if there were flowers, like your favorite flowers, do you think that you would put them in the bag, in this backpack which symbolizes a year...a flower or something like that, are you going to put something ...?" Camille finishes Lauren's sentence with "Happy?" "Yes, Lauren responds, "Are you thinking of putting something like that in your backpack?" Camille

answers "It's sad to say so, but for a year I haven't had any good memories. And I was a floral designer for 5 years, I have a lot of flowers. But in a year, I have had no good memories. Really, nothing. It's really sad to say it like that, but I cannot find any." Camille's work introduces her situation and aligns with Appleton's (2001) Stage 1, Impact stage by illustrating a trauma event, as well as Stage 3, Acknowledgement of her grief over her loss of agency, as well as the psychological pain that discontinuing her studies and social isolation has caused. Appleton's Stage 2, Retreat stage is verbally referenced via social withdrawal, as a maladaptive coping mechanism to avoid further traumatic injuries by staying home.

Lauren. For Lauren, her introductory work consisted of relaxation imagery (plants) and experimenting with watercolour crayons (see Figure 26). Addressing the group, after everyone had showed their work, Lauren said, "First I'll say I'm happy to see the art here, you have really explored your identity. And me too, I tried to do something very happy but it's probably because I try to be happy with the fact that yes, I have epilepsy. Six years ago, I started having a lot of seizures (again). The Tegretol I was taking was no longer working. I started having seizures once a month and it became every two weeks and it would always be accompanied by nasty things that you know you're just embarrassed about. Many doctors were experimenting with many different medications but they weren't working. So no one advised me, it's me who told myself that, 'You have to try something else, because you do not try yoga, because you do not do anything else.' And I was always thinking it was because doctors never offered anything outside meds. So I started with yoga, nothing too complicated. I have to see beyond epilepsy. It's just to calm me, to say 'Listen, yes, you do not drive, yes, you have no independence. But here you have to see beyond this.'"

Lauren goes onto to compare her creative process with art materials to how doctors experiment with trying different medications, her experimentation involving the addition of drops of water to her page. "We try meds, we try other therapies to see if they will work. The two drawings for me represent something, yes it's also personal, but at the same time, trying to be someone who is happy to not have seizures for two years. It's like I think about epilepsy but at the same time I think it's because the color is very lively. At the same time, you must always stay in your head and survive. We never know if the meds will work 10 years in the future. As I started with Tegretol, 15 years ago, I imagine that my body got used to it. I needed more than that, so I started taking more meds." Lauren's work gravitates between the Acknowledgment

and Retreat stages, referencing dependence and social withdrawal with the mourning of agency and periods of greater security where she had less seizures, while examining resources in recognition that medication may not always be effective as a sole treatment.

These worries may drive anxiety that motivates Lauren to avoid focusing on negative emotions relating to epilepsy, as her reaction to Camille's piece is a wish for her to add something positive (flowers) into a piece that is chronicling Camille's feelings of loss and despair. Lauren alludes to a process of maintaining a discrepancy between her internal emotions and what she may share with the world. "I've had epilepsy for the last 25 years and the first time it (a seizure) happened I was a teenager so, its a time of life when you're very closed in, you start to develop your own personality, so I've not shared that I've experienced seizures with many people in my life, but over the years I've started to try to be more open about it because people want to help you. If something happens they want to help you, they want to make sure that they know how to take care of you. So this is the first time I'm actually meeting someone like you guys who also share the same condition and it's very exciting for me because you just are in your own little vacuum and everyone's very happy but no one shares what's inside, you know?" Having referenced serious instances of discrimination in both work and educational settings according to her pre-test interview, as well as the lowest level of disclosure among the sample (2/10), Lauren may gravitate towards exhibiting a higher level of mastery over her condition in a group setting, perhaps as a coping mechanism to deal with anxiety that may be evoked by hearing other people's negative emotions regarding their epilepsy experience. Ultimately, Lauren chose not to attend the group, and acknowledged in post-interview that she may not have been ready to deal with deeply buried emotions regarding epilepsy, and hoped that she could participate in a future edition of the group.

*Nicole*. Nicole introduced herself to the group by depicting an arch set on green grass against a blue sky (see Figure 27), saying "I put myself in the sky because I thought that I was invincible". Being seizure-free for many years, Nicole reflected that she had good memories of travelling, and that she had almost forgot that she had epilepsy as a child. With the return of a tonic-clonic seizure this year and some partial absences, Nicole is now processing the loss of her freedom, of her independence, her right to drive, and feeling that epilepsy has narrowed her choices. "Now if I wanted to go somewhere alone, my spouse follows me so we can leave together. But for me travelling is like liberty, and I did my travelling alone. I had my trips alone,

I was happy, but now I can't leave alone as I have no more license, I'm not approved, I don't have freedom. For me (artwork) it's a good memory, an adventure. But I can't wait to start (travelling) again, not always having to have someone else to drive, to be able to go alone." Nicole simultaneously evokes a memory she finds positive and relaxing, while alluding to feelings of dependence in social relationships, congruent with Appleton's (2001) Stage 2 of Retreat, as well as moving verbally into Stage 3, Acknowledgement of grief. She also says she associates the colour blue with not being able to remember what happens with a seizure.

Partial seizures or absence seizures were further represented through colours as symbols, such as blue clouds or a head under the ocean. This is emphasized in Nicole's next work (Figure 28) where she portrays herself among what she describes as two realities, with a neutral expression and two speech bubbles. In the first bubble, there is a blue whirlpool, which represents the helplessness she feels following a seizure, saying that "people can tell you what you just did, but we do not remember anything." In the second bubble, "I was telling myself all the restrictions, after a seizure you don't have the right to do many things", illustrated by a ban symbol and accentuated by a lightning bolt parallel to Nicole's head, which represents a tonic-clonic seizure.

Joe. An absence seizure is portrayed by Joe in his introduction to the group (Figure 29) as he portrays a head covered by water, with the body visible from the neck down. "What I remember very much is the loss of consciousness, that's what affected me, to be in the dark, feeling without sensation." Although Joe has lost control and consciousness in the moment, he is supported by a series of hands in the air which he says represent supportive co-workers among his confusion. "I didn't know why I was on the ground. Lots of people were there to help, and the hands are work friends." These works are more firmly in Appleton's (2001) Impact stage by depicting a seizure event, while exhibiting dependence and a forced social withdrawal caused by a seizure event (which may be indicative of the Retreat stage). The Acknowledgement stage is evoked, with references to grief over the loss of control and consciousness and with depictions of social interactions, referenced in either neutral or positive ways (social support).

Ben's depiction of his view of watching himself having a seizure on the video electroencephalogram (VEEG) monitoring unit (see Figure 30) provided a unique opportunity to explore the emotions involved with the loss of control, feelings associated with not remembering something, (yet seeing yourself on video doing it), and somatic sensations involved. Embarking

on our first museum tour and seeing portraits inspired Ben to portray this image he said he had in his head for awhile. "One time I could watch the videos of my EEG. I even asked for a copy of the video but they told me it's just the nurses who can have it, I can't keep it but I had the chance to see it. 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. It's weird to see but I don't know, I want to see it (laughs). So I decided, when I saw this on the doctor's computer, I drew the little Windows logo as I love comics, so I tried to do that style. The sound I made in the video was really striking ... as soon as I put the sound on, the doctor closed the speakers. Especially since 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."

This provided an opportunity for the group to discuss the VEEG experience, how bizarre it can be to actively want to have seizures while in the unit (to shorten the stay), and how frustrating it can be to go off your medication and then not have seizures in the hospital. As this was Session 2, it gave the group an opportunity to discuss experiences in treatment, witness diverse experiences, and offer peer support for vulnerability. For most of the group, being the first time they had met other people with epilepsy, this was an important aspect in solidifying the group alliance.

Loss of control and the seizure cycle were also represented in an overview of epilepsy as like the weather, where the emphasis was on the unpredictable nature of seizures and the way that this could consume the participants plans, desires, and daily activities, as well as the aftermath of the storm and resulting emotional wreckage (symbolic of the psychosocial impact and an externalized locus of control). In Session 3, Camille depicts a rainbow with googly eyes that is being attacked by a lightning bolt (see Figure 31), saying "We're supposed to be alive, to be happy, to be joyful, to be all right, but us, our brains, our neurons are not filled with a rainbow like a person in good health. The rainbow represents a little joy, a good mood, all that we are supposed to have in life. And the cloud that comes blowing into our life, a rupture that makes us have a seizure, it attacks us in the brain and it makes lightning." Also in Session 3, Nicole made two pieces consisting of storm imagery (tornados) and a calm aftermath (sun and rainbows) (see

Figure 32) using watercolour, tempura paint, and sparkles. These symbols represent her feelings regarding before and after states, both in terms of having a seizure and coming back to herself, as well her experience with not having a neurologist since childhood, and how recently acquiring one has made her feel more positive about her situation now that epilepsy is part of her life again. In both cases, this imagery seems to cycle between the Impact stage (depicting a traumatic event), to Acknowledgement (grief regarding loss of control, psychological pain) as well as Retreat (alluding to issues of dependence and social withdrawal; imagery featuring suns, relaxation themes, and exploration of new materials in a regressive style) (Appleton, 2001).

The seizure cycle was also represented as a response to having less seizures, recognizing the positive emotions that this could bring, as well as a way to examine the emotional impact of the cycle. In Session 2, Camille portrayed a memory from previous Sunday afternoon (the day after Session 1, see Figure 33) "Last Sunday I spent the day with friends who have a big pool (with a deck) and everything. I don't know how many years it's been, if it's because of the week that I had, is this because of the art therapy on Saturday or because I spent a super nice day on Sunday, I swam, I tanned myself and everything. But on Sunday I had no absences! So that's it, I'm very proud. It's the only day of my life since I don't know how many years." Camille described that she recreated the scene, choosing to engage the deck as means to represent her seizures, calling it her "epilepsy deck", citing that wood is "hard like seizures". Camille constructed four columns by gluing small sticks side-by-side to represent her perception of seizures. The first two rows where crooked, representing having one absence seizure after another. The third row is more crooked and collapsing with holes to account for the memory loss after a seizure, contradictory reports from witnesses, and emotional impact. The final row has straight sticks representing her experience Sunday, and her hope for future seizure-free days, with positive emotions relating to increases toward her sense of mastery and independence. "It's so rare that I can swim alone, well not alone but with everyone. So it was a great day. I essentially wanted to present my feelings, my emotions deep down... that's my epilepsy deck in a sense, what was happening and after I wanted to illustrate a positive feeling that I've never had in relation to my epilepsy, not having a seizure... It's been 28 years that I've had seizures every day, absences too. And the absences, I don't remember when I've not had one. And the sun was so beautiful."

Somatic experiences with positive associations were translated by a use of sensorial materials such as blue sand for the pool (encased in pipe cleaner), feathers and cotton balls for the blue sky and clouds, with copper glitter to represent the sun and a kinesthetic depiction of grass as scribbled oil pastel. This piece was a shift toward mindfulness, and a shift to acknowledging positive emotions in the present, and stress reduction with positive social experiences. Camille continued to report less absence seizures, with Sundays (the day after the group) seizure-free for seven weeks, which resulted in positive peer-support experiences and group solidarity (with members inquiring about her Sundays in subsequent sessions). This work encompasses both the Retreat stages (examining dependence, relaxation imagery, abstractions) as well as the Acknowledgment stages (positive social interactions, loss of control, psychological pain, resources examined, and exploration of diverse collage media (Appleton, 2001).

Depictions of before and after states of seizures illustrated relational interactions and the impact on social and familial spheres, both in recent times and in childhood. In Session 3, Ben, who is navigating epilepsy onset as a young parent, depicted a seizure story from earlier in the year (which involved both his wife and children witnessing his seizure) (see Figure 34). "It can happen while I have my seizures or in my postictal state that I get really violent. I had plans for three boxes of me with seizures and my son who sees me, paramedics who arrived to intubate, and me at the hospital being violent with the employees. But, I did it on the back because it wasn't me, I don't remember it so I left empty boxes. I fall and after that I don't remember, I blank out and hours and hours later I wake up at the hospital. So it's not really a memory, it's the other way around. I put some lines around me because I feel pretty bad when I wake up at the hospital afterwards. Like a hangover, a headache and all that." Having embraced comics as his method of expression allowed Ben to acknowledge complex emotions such as guilt at upsetting his family with a seizure, scaring his children and wife, assaulting medical staff (when his conscious self is a non-violent person), juxtaposed with frustration, confusion, and sadness as he mourned the loss of control of his body, agency, consciousness, and time (consistent with Appleton's (2001) Stage 1 and 3, Impact and Acknowledgement)

In Session 4, Nicole relayed a story involving childhood bullying (see Figure 35). "When I was in school I had a lot of friends and when I started to have epilepsy...there was a lot of isolation, people rolled away. I separated them between happy and after it's like... I had acquaintances but not friends like I had before." In this image, 'happy' is pre-epilepsy and 'after'

is post-epilepsy. Nicole painted a scene putting herself with two friends next to a house with smiling faces to represent her social life before seizures against a warm background. Encapsulated to the side, is a figure with a frown on top of her smile that is all alone and represents her after she started having seizures and experienced cruel jokes. This is set against a darker background, with frenzied strokes to represent the seizure and to separate the figures. Up top, she is represented as an adult, still alone but with a smaller smile as she indicates that when she was older she made friends, but did not open up about having epilepsy. "I don't share, I keep it for myself." Nicole and Camille feel that this can be an act of prevention. "People don't understand...here it's good, you know people, you know about epilepsy, but for someone who doesn't know, it's banal." This represented increased trust in the group as Nicole did not disclose bullying in her pre-interview, however she later indicated that the visibility of her epilepsy medic-alert bracelet increased bullying incidents. There is an exaggeration in the size of the hands of the isolated figures in Nicole's work, with the largest being her adult self, perhaps representing increased needs to connect which is what brought her to this group. Witnessing by the group and therapist may have enabled Nicole to express challenging emotional material. Disclosures by Camille and also the therapist, that epilepsy-related bullying had indeed happened in their childhood as well, may have validated Nicole's experiences and supported her first depiction of a negative emotion in her artwork (prior facial expressions had remained neutral). This may be an example of enacted stigma's role (via bullying) in fueling perceived stigma (fear of disclosure) in Nicole's internal working model, which may have contributed to social isolation. As the experience of bullying related to a disability constitutes psychosocial trauma and a seizure story is represented, this work evokes Appleton's (2001) Impact stage, as well as Retreat (with issues of social withdrawal and dependence), as well as Acknowledgement of psychological pain, loss of control and social relationships.

As Nicole's confidence grows, she brings forth the question 'Why apologize after a seizure', examining her automatic reaction to excuse herself for having a seizure, despite the fact that she says knows it is not her fault. Depicting a seizure event and her husband's reaction during and after, Nicole works symbolically (see Figure 36) to represent a feeling that she describes as "the loss of control, and I cannot remember doing anything about it because I am not conscious of it." Nicole uses marker and colours to represent her emotions during the event timeline, depicting herself during the absence experience as a figure encapsulated in white, with

a neutral face and whirlpools in her eyes to represent what she describes as the beginning "dizzy feeling". She is then surrounded by greyish blue clouds which represent further seizure activity, attached to a blue barrier where her husband is reaching through but cannot get to her. Depiction of after-the-seizure consists of her apologizing via speech bubbles, set against a backdrop of purple and blue which represent her sadness and confusion. Above her, there are clouds of red and orange, which indicate her frustration and embarrassment, while her husband, although still separated from her, is reassuring her and is set against what she describes as a soothing pink, as he is calm, and she feels gratitude for his positive reaction. When asked why the after-depiction of the husband's hands are white, Nicole at first says she could not find beige, however when Camille wonders if unconsciously she made the hands white to represent her spouse's confusion, fear, and feelings of being unable to protect her, Nicole agrees that maybe she did. This aligns with Appleton's (2001) Impact stage by illustrating the trauma event, the Retreat stage of dependence, and the Acknowledgement stage of difficult social interactions.

Luc. Luc described his introductory piece (see Figure 37) to the group as guided by his intuition, emphasizing the importance of movement in making an interactive paper sculpture rolled up with scribbles of pastel and text written on the inside, stating, "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." This was both an exercise in mindfulness, as well a container for intense emotions that came up on his reflection of his near life-long experience with epilepsy, receiving the diagnosis as a 7 month old, as well as a diagnosis of PNES in his 20s. As the only group member present who had ever met another person with epilepsy before (partnered with a history of social advocacy in this area), Luc's creative process 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 others) in terms of both communication and coping strategies regarding psychosocial stigma.

Explaining his artwork, Luc shares, "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 in order to share our experiences in how to communicate about epilepsy and how to raise the subject to establish dialogue about our lives and our emotions that are collectively not always pleasant to share. It is through this journey, (examining) an obstacle in communicating interpersonally. So it's the universality of this intuition a bit. I then took the decision 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's a difference, for me 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 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 colors."

This reflection engaged Luc on the Acknowledgment (Appelton, 2001) stage as he explored and examined social barriers that he experienced over decades with the condition, alluded to negative emotions, and shared his attempts to construct and reframe a personal narrative that is based on resiliency and available resources. His communication regarding dependency and the indication of communication obstacles that promote social withdrawal or alienation also engage on the Retreat stage (Appleton, 2001). Luc's work continued to engage in a somatic-driven process, working on sensorial and kinesthetic dimensions of the ETC as he worked toward mastery of being in the present moment with epilepsy and PNES.

The tendency to compare one's self to others in the group, and the notion of survivor's guilt came into the group, as participants attempted to address their psychological pain, while feeling guilty to complain in comparison with other people who they felt may have it worse. Participants felt that this concept was further complicated due to the invisible dimension of epilepsy. Ben illustrated this conflict in his comic art (see Figure 38) depicting himself saying "I asked them for a service dog but with my seizures being so rare and infrequent..." and holding a bowl with "a spaced-out goldfish" in it. To describe his piece, Ben said, "It's maybe more about all the sessions here. It's like at the hospital downstairs, it's odd to see someone in front of me who has it much harder than me, I can't compare myself to everyone but maybe a little between the two... I'm lucky that I do not have seizures more often, but in the end, it's 'Oh no, you're ok, take your pills you'll be fine.' But no, I have pretty intense situations and there were no services

for someone at my level. I can't take all the services for people who need more than me so it's up to me...to regulate or I don't know?"

Lack of treatment for the psychosocial dimension was a theme, with reactions to stress examined as possibly increasing perceptions of seizure activity. Ben sharing that his neurosurgeon posited that the smaller seizures he had been experiencing nightly before bed may have been psychosomatic and related to PTSD, recommending Ben seek psychiatric consultation as Ben had experienced traumatic stress throughout his diagnostic experience (thinking he had a malignant brain tumor and may die while his wife was pregnant). Although not a malignant tumor, Ben's stress continued to be amplified as treatment options were discussed, with different professionals giving different insights on whether Ben should have neurosurgery, debating whether the potential effects on his memory and cognition could be worth the potential of seizure prevention especially since perhaps his seizures may only be happening twice a year (if the nightly events were in fact PTSD-related) and perhaps treatment for Ben could be a combination of medication, stress management, and psychosocial care. Regardless of the scenario, Ben felt stressed that he should be asking more questions, feeling overwhelmed with different treatment options and the anxiety of future side effects and how this would impact his life and family. Ben said that having a place to talk this out, with people that understand, was important to him, and felt that the group was an important support resource in his process. This work involves the Retreat stage (issues of dependence and fantasy, with Ben's injection of surrealism and humor to navigate challenging information, indicative of social withdrawal), and Acknowledgement stage (psychological pain, grief, social interactions, and resources examined) are represented.

Both the art process and product acted as a container for Luc to express anger and frustration that he had experienced over his decades of experience with epilepsy and PNES, whether it involved side effects of Tegretol, a lack of focus on the psychosocial dimension, and issues of treatment alliance with his various neurology care teams, including the feeling that PNES was not explained to him adequately when he received his diagnosis in his twenties. Feeling that he was only ever offered medication (and invitations to participate in medication-based research), Luc felt that there was a lack of dialogue regarding his quality of life, citing that at one point he was in a wheelchair to cope with side effects of medication and psychological stress. This was exacerbated by a recent visit to the emergency room due to a panic attack he experienced as he was directed to increase his dosage of Keppra. For multiple sessions, Luc was

processing a lot of anger regarding his perceived lack of communication (that he felt increased the trauma of that event), and this was put into artwork. Luc engaged in sensorial, kinesthetic and perceptual ways to externalize his somatic stress, creating pieces that acknowledged his psychological pain, challenging social interactions regarding his care, and feelings of dependence.

In Session 3, he worked with fragments of tissue paper, pastel scribbles, and watercolour paint (see Figure 39), while in Session 5 he began to experiment with clay and 3-D objects, engaging with sculpture in symbolic, kinesthetic, and sensorial ways. In Session 5, Luc's checkin (prior to art-making) focused on his frustrations in treatment, wishing for a more "human" approach beyond medication, comparing the medical authority of doctors to the dominant influence of priests in Quebec in 1960s, citing that the lack of explanation of PNES and medication side effects make him feel like "an observer in his diagnosis". Luc wishes for a community foundation in neurology as he has seen develop in oncology over the years, with more emphasis on what he refers to as the "whole person" and "human dignity". Luc expresses that he is "convinced that art therapy brings benefits. I have seen it since the beginning of the process. I mean, it allows me to extract my emotions and express them. So it is a tool, for determining an inner balance toward oneself and then toward our inner peace. Basically, that's how I feel, I am in a great moment of realization. There are messages, then reflections and then awareness that raises my openness to asking questions, while maintaining my conviction of all of my pride in my journey". As Luc processes intense emotions through art-making, he is witnessed by the group, and he finds both resiliency and empowerment that helps him ask questions to himself and the system, in more constructive ways. Making three pieces this session, his first is similar to his work prior, resembling a vortex of stark lines (see Figure 40), while he then engages somatically with clay (See Figure 41), to create pieces with more kinesthetic flow, integrating words and symbols. Describing his art, Luc says "It's the feeling of internal peace, of the present moment of feeling. It responds to the community and having things in common and solitudes elsewhere and then afterwards, with my intuition I say 'I'm going to go for color'... malleability, the 3-dimensions, intuition, the present moment, I found it interesting to explore, it's a space of liberation, of modeling the energy. It's the journey, it's calm, it's the music. It's the sea too, I do not know. It's full of things. A tree that stands out as a sort of 'thanks'. An abstract vision and a concrete vision, the tree has always had a path, even a very long time ago. I wrote

on the back about the moment of sharing we had before, and I tell myself that these moments of sharing that I have here well, I mean, they bind, and can link my artistic and therapeutic journey to words. The memory is a faculty that sometimes forgets, this moment of sharing between the conscious observer and the reflection for the activation of the global well-being. It is valuing movement with mindfulness."

A lack of support services, invisibility of the condition, and social understanding is also depicted by Camille in her Session 4 illustration (see Figure 42) of her talking to her neuropsychologist about the psychosocial implications of her seizures. Writing 'university, friends, practicum, money and epilepsy' by her thought bubbles, she crosses out the neuropsychologist's ears and writes "I listen but I do not hear." With emotion, Camille says that "Since January, I had a lot of epileptic seizures and I was hiding, I was isolating myself in my apartment. There were several seizures that I had never told my friends that I had because... You know I'm tired of telling it to my friends, when it's not obvious, when I don't have any bruises, I'm tired of telling my friends that I have had a seizure again and they say 'Poor you, aww. Awww!' I'm tired of being pitied. You know it's my life, and it's an illness. I don't often say it. You know, one time I told my nurse. I told her my feelings and she said 'At some point you have to get it out, you have to talk, you have to say it.""

The following session, Camille reflected that she feels that she used to cry more after having seizures when she was younger, but now feels that she is looking more for ways to move forward and to deal with stress, which she defines as one of her triggers. In Camille's next work, (see Figure 43), she depicts a tornado in the centre (surrounded by sun), to not only represent the seizure cycle, but as well as a spiral of epilepsy-related negative mental health challenges that she experiences. In front of the tornado, there is a woman in contemplation, positioned on a purple path (her favourite colour), surrounded by trees (nature as her "happy place"). On the left side of the tornado, Camille portrays "not something that happened in our lives, but what we wanted, what we could have had". With collage, Camille communicates grief and loss of autonomy by representing driving, dependence (being on social assistance due to inability to work), memory, and cognition with words and symbols such as a brain. On the right side, Camille depicts "a bit of a dream I was pursuing and I'm still pursuing" with representation of her school and career goals (working with domestic abuse survivors), a love of flowers (lavender to represent serenity and self-care), financial independence, and travelling. "I just loved my little

woman I made because she's thinking about where she's going. Does she choose the tornado or does she go on the path you know that will continue her life, which will go toward her dreams, not the dark ideas, but the best ideas that she could have to continue her life and to do the best for others too. So, she looks more over there. Actually, she will go for scent first. So, the smell is first, she'll smell it with lavender. Actually, she's going to go towards it, it is her main cause which is domestic violence against women. For me it's really my main cause... So, I only put 'Bionic Woman' up top just because I want to harness my tornado, I do not want anything to come out on top. In fact, I do not want epilepsy or my seizures to be stronger than me. In fact, it's a little bit like that. I want to fight them. I will succeed in fighting them, for sure they are very strong. But I will succeed. I will succeed. How? I do not know, but I will succeed."

After five weeks of the artwork portraying the impact of epilepsy and containing Camille's psychosocial pain, while still acknowledging it, she is also empowered with increased agency in her situation, suggesting a shift in attentional bias, a shift toward a more internalized locus of control, and the reintegration of traumatic memories to reconstruct her personal narrative as a means of moving forward. Using the metaphor of a super-human who is engaged in mentalization, Camille examines her thought patterns and choices, suggesting such implementations of coping strategies for Camille as she works toward an increased sense of mastery over her life with epilepsy. Stage 3 is implicated with themes of grief, loss, psychological pain, trees, and resources examined, focusing on the psychosocial impact of the seizure cycle. Stage 2 is evoked with super-human imagery, relaxation images, sun and themes of dependence. Stage 4 is formulated with concerns of future, work, school images, values and spiritual clarifications as she describes meaningful connections with clients at her internship and how she wants to make a difference in their lives and mental health. Her declaration of her political advocacy for women who face domestic violence shows Camille embracing her full potential (Appleton, 2001).

In the check-in of Session 6, Camille shared that she had had a tonic-clonic seizure during the week at a bus stop, which caused her to have 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 that she would use to repaint her apartment "for her new life", representing positive shifts in her mood and resiliency to current and upcoming challenges. Inspired by the museum tour, Camille said "I wanted to do like the sculpture we saw upstairs on emotions, on the person,

on the behaviors and all, but, it's because this week because I had a lot of stress, I think it is connected to my seizure finally. I ended a friendship that was filled with negative energy. So, I wrote 'To live extraordinary power,' I wrote, 'To take back my listening,' 'A glimmer of hope to free body and soul,' 'Make your own luck' and I wrote 'Your best at 40.' She is 43 but it's me who is 40. So that's when I saw the sculpture upstairs, it seems to me it represents me, although it is crooked, at the same time, it is filled with great emotions, it's sentimental. In any case, there were lots of things that spoke to me. So, so that's it... I think it's the stress, (the loss of) negativity will probably liberate me, and not always having to be on guard, of... I do not know. Well, to have, well seizures too. I'm going to finish it next week.... And I want to talk about epilepsy, what it will bring me regarding stress, less stress, for my studies too...I tried, I tried too much. I tried too much in the end. Then I reached my limit, I finally hit it, and I explained too many times... I need to protect myself so that I don't have more seizures, I am ... no longer able." With support of group, Camille was able to identify that communicating with her ex-partner that week had caused her a lot of stress, and felt that she had the confidence to set boundaries to discontinue their communication and to focus on self-care and stress reduction for her health and well-being.

Luc continues to employ mindfulness and engages with mentalization in his creative process as he works in kinesthetic and symbolic ways with watercolour, pastels, and words (see Figure 44). He relies on "intuition but also to be in the present moment. So, I started with the doors that open the doors of memory and hope in the space. That is the thought of the moment after the (museum) visit, and then, it's as abstract as it is concrete. It reminds me a little of the bad feeling that I could feel throughout the years, with the loss of control in public and then what is released by energy as well as by emotions. It reveals the loss of control then also the feeling of being desperate thereafter for things, to gather yourself, to refocus and then continue to walk. So, there is a person on the exterior, then on the interior of the second. So, it's always intuitive as a movement. There is, we, I have still defined a body through certain shapes and then the little colors create a movement."

# Final Stages: Reconstruction, Resiliency, Community

Moving into the final two sessions, participants had touched on themes that worked through Appleton's (2001) first three stages, addressing the impact and psychosocial trauma of seizure events (Impact), examining issues of dependence, of treatment alliance, and social

withdrawal of the Retreat stage, and exploring the psychological pain of the seizure cycle, loss of control, treatment stress, and grief associated with stigma and social isolation that can accompany epilepsy. Leading into the final sessions, participants began to work towards the reconstruction stage by pairing coping strategies with goal-oriented imagery, mindfulness, and values and spiritual clarifications. Challenges were still addressed, but within a framework that seemed to restore agency, re-aligning locus of control, and involving both positive and negative emotional material. As triggers such as stress were identified by the group, strategies of self-care were put forward and participants became more empowered to take agency in their own lives.

As Ben navigated treatment stress, he also reflected that he had support, describing his piece (see Figure 45) as "It's my brother showing my son how to put the little fish on the hook...We talked about community and it's my brother who shows him things that I can't...it's like to say thank you for showing him how to fish." Although the depiction of the fish has what Ben refers to as a "violent" association (putting the hook through its head), as he faced a lot of treatment uncertainty (whether he would have neurosurgery), Ben became better able to able to voice his needs for support and feel comfortable in his situation, referencing increased comfort in discussing epilepsy with family, friends, and co-workers, and recent relief from the suggestion that what he had thought were smaller seizures may have been psychosomatic episodes related to PTSD. "I thought every time I was alone or when I was going to bed, I was scared to have a seizure but my doctor said to me 'Well, calm down, you don't have them that often.' I feel lucky for that so I can enjoy this afternoon because I know that it's ok. It's like even if I stay late, I took my pills, I'm in good shape, I'm not too stressed. That's why I should not have any. Even if I do, I found people who understand, so I am glad that I can relax all this afternoon." In the final session, Ben alludes 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 practice. 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."

Luc continued his reflections by employing mindfulness in art-making, employing a multisensory process and using the artwork as a container for intense emotions. These explorations continued to feature diverse media such as clay, collage, and pastel (see Figure 46). Using his art process as metaphor (covering and uncovering the clay with tissue to preserve malleability), Luc commented on his journey over the years, and how he felt that art therapy has brought him a sense of clarity. "Sometimes we cover up our emotions and sometimes we discover them. Well there is the space, the community, resilience and the vibrations the community has in its exchange."

For Luc's final pieces (see Figure 47), he reflected on his journey in both art therapy and epilepsy, finding meaning in his experiences in both the past and present, as well as expressing more confidence in himself to meet challenges moving forward. "I have intentionally worked through abstraction of my movements to let go, in terms of... the words and the process which was an exploration too, so there is a release... you can see the presence of openness to the world and the absences are like the representation of the moments of unconsciousness that epilepsy can deliver. And the sharing, the listening, the comprehension of different ways to live our challenges, well for me lightens my load in everything I talked about, moments of discovery every Saturday."

Camille's final piece (see Figure 48), made over the last two sessions, was continued from Session 6. In this process, Camille transformed from processing her grief (regarding ending a stressful friendship where she felt forced into a role of caretaker), to applying more energy to nurturing herself. She ended up with a vision board for daily emotional regulation at home, created with collage words such as 'Confidence is a privilege', 'A good story' 'It's never too late to change', 'Thank you', 'Magnetism', 'Well-being', 'Discovery', 'Live at full force', 'Being happy', 'Sharing', surrounding the drawing of the sculpture she identified with on Week 6. Regarding this piece, Camille remembers her process in the post-session interview, "I began to glue things...like all positive things. What touches me really is what am I looking for...where I want my path to bring me...That one's my favorite. I even hung it on my door...I look at it all the time, I read it." Camille indicated that she planned to add dried flowers and continue to add words to it as part of her process.

For Ben's final piece (see Figure 49), he made four panels that could be rearranged as a coping strategy to foster resiliency and reconstruct his personal narrative in the face of recurring challenges. "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 sort of to show that I feel good now at the end of it all, but I have to keep that attitude at the same time. To say don't relax too much, that's the concept of the Inner Hero in a way. It takes care of you, like the Bionic

Woman who is the hero of life to protect on the hard days, to encourage. I think I'll put them on my desk on a little hook or something!" When reviewing his collection of art, Ben shared with the group that he felt the process helped him with "being more open and to talk about emotions." He was pleased with his work, yet still looked at the comic art with hints of perfectionism, noting technical improvements as he reviewed it. He also noticed that his work became less epilepsy specific, musing "Maybe because I haven't had it as long and it's less severe ... but I think it's good sign that I had already released what I wanted to release."

Nicole portrayed positive social interactions in portraying a scene of her husband camping in nature (see Figure 50) and emphasized how she felt that art therapy had helped her become more comfortable in talking about the psychosocial dimension of epilepsy and self-expression (see Figure 51). For a final group work, "Making a Piece of the Collective Pie" (see Figure 52), participants were encouraged to reflect on the idea of the group, their experience, and anything they felt relevant to share. Both Nicole and Ben referenced the social and supportive dimensions of the group, emphasizing the significance of the discussion and witnessing of other group members. Ben showed 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. It made me feel like drawing...So that's it, I wanted to show the discussion and all the things I talked about." Nicole illustrated the group's creative process by showing six seats at the table and a collective speech bubble that said "Epilepsy". On reflecting on her piece, Nicole said "Well, I find art expresses our feelings in our lives. That's why I left bits of crayon to say that we shared what we lived." When asked how she felt about her collection of art, Nicole said "It's happy. I loved the courses and all that, and I liked the visits to the museum as much as here. For sure at the beginning we draw what we can but after we do emotions, that's when they take shape." For Luc's group piece, he referenced community, self, spirituality, and mindfulness, writing "Art comes with self-transcendence", and emphasizing verbally, that it means "Surpassing yourself, hope opens, words carry levity, spirit, lightness, art pieces, colours, words, roots, flowers, connectedness. This is a summary of the process, as well as cultivating a dynamic listening stance to be open to other people's opinions and experiences." Reflecting on his experience in the group, and his own journey in art therapy, Luc described that it "helped me to articulate, and I tell you, it's to put on paper the conscious emotions of your unconscious, I mean, and then the work to transmit a balanced interior. Yes. And then it is to let intuition be expressed then sometimes to follow your intuition to develop

your projects (in life) that... it's what calls for confidence in oneself in terms of, acquired knowledge."

For Camille, she used her group piece as a reflection on her pieces that made her journey in art therapy and to show gratitude. "Me, what I wanted to do first was, well, say thank you, in the end, it is like a summary of all the art that I made. It's my flight. That's when I was able to enjoy my days or when I didn't have seizures. That's when I confided in my psychologist and that, well... I don't even remember... (Nicole: The rainbow?) Yes, the rainbow ... you know, that's it, I could have put lightning but in the end I wanted to make it a little more positive... You have to invent stories in life and then believe them."

When reviewing her work in the process, Camille said that she could see that her work became more positive as she went on. Seeing her backpack again seemed to take Camille by surprise, "Oh, wow it's been a long time, I didn't remember anymore. Wow, it's true, it was a year to the day that I had all that. Oh boy, it's been a long time. With the whirlpool, the pills, ha! My God. Actually, wow! It's really more positive than when I arrived, actually yes. If I were to come back for the first time I will probably not make the same one, I probably wouldn't do it the same way, but you know, it's definitely a volcano, it's red but... uh I don't know, I would not, I would not do the same. From one week to the next is full of things. 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. No, I don't even want to take it. 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. This suggests shifts in attentional bias, movements toward a more internal locus of control, and the reconstruction of her personal narrative. That Camille can revisit this incident (her worst seizure) and say that she would not tell the story the same, and that she would not introduce herself to the group that way, suggests the formation of new neural pathways and the reintegration of traumatic memories (Lobban, 2014).

Both the researcher and assistant made a piece of the pie as well, and to close the group, each member gave a word as they lifted their piece from the pie. Ben's word was 'support', Camille's was 'sharing', Nicole's was 'thank you', and Luc's 'harmony'. The researcher's was 'gratitude' and the assistant's was 'exchange'.

### **Chapter 5. DISCUSSION**

## **Qualitative and Quantitative Integration and Interpretation**

The integration of qualitative data, collected from pre and post interviews and surveys, art therapy sessions (audio transcripts, progress notes, and artwork), and quantitative mood questionnaires was assembled in a flow chart and assigned a stage of Appleton's Art Therapy Trauma and Assessment Paradigm (see Figure 53). Quantitative and qualitative data are integrated in a non-hierarchal sense (Creswell, 2014), and links and overlaps of stages are accommodated to indicate the complex processes of art therapy that mixed methods has the ability to capture (Kapitan, 2017). Although themes were open and content optional, even in the context of introducing one's self to the group in art, many participants chose to do something epilepsy centric. As the majority of group members had not met another person with epilepsy, and perhaps with the knowledge that this group would run for 8 weeks only, it was common for the participants to begin by depicting a traumatic seizure event, as well as grief over loss of control and independence as a way to introduce themselves and their situation to the group. This was more common for participants that were undergoing treatment for stress such as changes in medication or contemplating neurosurgery, and for participants that were having a higher frequency and severity of seizures. The tendency to compare oneself to others in the group was high, despite statements regarding the spectrum of epilepsy and the emphasis on diverse experiences. This is consistent with assertions that chronic conditions increase social comparisons (Bennenbroek et al., 2002; Bogart & Hegelson, 2000) as a coping mechanism for the ambiguity of chronic conditions (Arigo et al., 2014) and verifies Ghaemian Oskouei's (2016) preliminary investigations into social comparison and epilepsy.

This social comparison presented the phenomenon of survivor's guilt in chronic conditions (Vamos, 1997), with members feeling that perhaps they "had it easier" than others (O'Connor et al., 2000; Ghaemian Oskouei, 2016), however they still faced extremely challenging diagnostic and treatment situations and the psychosocial implications that ensued. For Lauren, her perception that her peers would dislike her for not having had seizures for two years was an example of enacted stigma (Baker, 2002), as group members remarked that they missed her presence, however she suffered costs of disclosure in the past that may have altered her social cognition. Lauren's wish to avoid discussing the emotional context of her epilepsy, and wish for

Camille to censor her own negative feelings regarding her own epilepsy experience, may have been a defense mechanism (Cabaniss et al., 2011) that was a necessary means to social survival. By Session 5, Lauren's wish for Camille to integrate flowers actually came to pass.

For Ben, he felt lucky not to have seizures during the day, comparing himself to Camille. He was able to explore this in art, and his painful experience was validated by others, including Camille, evoking the power of witnessing (Moon, 2014) and sharing painful memories in a group setting (Lobban, 2014) to gain further mastery over them. The power of the group as a place of social rehearsal was imperative, as connections formed (Yalom, 2005; Vinogradov & Yalom, 1989) that enabled a sense of community (integral to treating chronic traumatic stress) (van der Kolk, 1987), safety (Rubin, 2005), support and witnessing (Moon, 2016) that created a portal to processing and healing psychosocial stigma that seemed to extend beyond the group (as indicated by higher levels of disclosure and reports of more ease talking about epilepsy with others).

Ben alluded to the element of social rehearsal and the importance of the discussion section of the group, in addition to the art-making. Having time to contemplate one's work and engage in sensorial processes facilitated the externalization of somatic knowledge (Czamanski-Cohen & Weihs, 2016), allowing participants to explore and engage somatically (Moon, 2016) with challenging emotional material that they many had previously never verbalized, including medical and psychosocial trauma (Keller, 2001; Saltzman et al., 2013). Traumatic memories became more accessible as participants engaged in the safety of a group setting with art process as the container (Lobban, 2014; Turner et al., 2011), and the art product as the mediator (Morgan et al., 2012) to enhance group communication (Riley, 2001). Engagement with art materials in the safety of the community studio, as well as embarking on museum tours, qualified as the pairing of non-threatening information with challenging emotional material, that was necessary to work toward the reintegration of painful memories without activation (Timm-Bottos, 2006; King-West & Hass-Cohen, 2008). The decreases in chronic stress for the Attend group, as measured by the TICS, combined with the increases in levels of disclosure and decreases in level of seizure worry (self-report), reinforce that neuroplasticity may have been occurring (King-West & Hass-Cohen, 2008), with less damage to the hippocampus from the overproduction of the stress hormone cortisol (Schore, 2003), and thus increased access to verbal and autobiographical memories (Lobban, 2014), allowing the reconstruction of personal narratives.

The intensity of seizures and unpredictable nature of the seizure cycle was often explored via the safety of symbols (Hinz, 2009) and metaphor (Riley, 2001), often translating into weather, elemental or electrical imagery, and zig-zag lines which is consistent with previous explorations of art therapy and epilepsy (Brown et al., 2018). Art was used to visually depict the feeling of the seizure, including loss of consciousness and postictal state (Brown et al., 2018) as well as emotions associated with loss of control (Havlena & Stratsrom, 2012) and time, as well as psychosocial impact on identity (Bruckland, 2015). For Camille, a traumatic memory (her worst seizure) was presented in the first session by her backpack, and by the last session, she declared that she would not tell the 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 as a means to introduce herself to the group, and identified feelings of greater agency in her life. This was embodied by Camille's report in the post-interview that she had hung her final art as a vision board for daily reminders of her goals, self-care and emotional regulation, with effects of the art process continuing beyond the group (Gregg, 2015; Bruckland, 2015). Before Camille could get to that point, acknowledging her immense grief was integral, and metacognitive processes such as mindfulness and mentalization through art played a key role in restoring agency and bolstering toward a more internalized locus of control (Gardner et al., 1983). Symbolic interactions (Gussak, 2007) gave Camille an opportunity to formulate and test out new visions of her identity, exploring her journey through her art process, validating art as a way of knowing (Allen, 1997). Revisiting her first piece in the final session, she was not emotionally activated as she had been when she first showed it to the group, crying with her hands shaking. Now, she looks at it with a sense of mastery, suggesting engagement of right and left brain functions and the formulation of neural pathways to gain mastery over trauma (Lobban, 2014).

Shifts in attentional biases relating to depression are corroborated by lower scores of on the BDI for the Attend group, as well as lower reaction times on the AMT to positive cue words, suggesting that positive memories are now more available and that shifts have occurred regarding negative attentional biases associated with depression. 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 was depicted visually by Camille as the concept of having more choices in terms of her emotional reactions to epilepsy, as she depicted a tornado to not only represent the seizures, but also the choice she felt she was

presented to pursue "dark thoughts" or to move toward self-care. As she examined her choices, employing mindfulness as a tool, shifts in attentional biases in terms of epilepsy (Michaelis et al., 2018) seemed to arise, resulting in more self-care, less stress, and less absence seizures, which has been associated with seizure reduction (Tang et al., 2015). Mindfulness and sensorial engagement, helped the group stay in the moment, where the discussion section allowed application to real-life experiences (Drass, 2015). As the group transitioned from exploring psychosocial trauma to more positive material such as coping strategies and future goals, this recall's McNiff's (2003) assertion of the importance of "exploring the poison in the remedy", confirming that the expression of negative material can lead to positive effects and greater well-being (Moon, 2016; Collie & Bortoff, 2006).

For Nicole, she did not indicate that she had experienced bullying related to epilepsy in the pre-interview, however by the mid-point of the sessions, she was able to explore such as a painful childhood memory and examine how it had caused her to avoid social connection as a defense (Cabaniss et al., 2011), with enacted stigma fueling perceived stigma and resulting in social withdrawal as Baker (2002) suggests. Her final artwork, emphasizing that art therapy helped her find the words and explore emotions regarding epilepsy and psychosocial trauma, is a testament to the power of witnessing in terms of risk-taking (Moon, 2016) and social connection in personal development (Yalom, 2005), as she would become more confident in later sessions, often volunteering to share her work first. The connection in the art therapy space, both to the therapist and the group, created an opportunity to repair attachment through art (Turner et al., 2011), providing support, validation, and emotional attunement that may not have been available through parental, familial, and social networks for participants diagnosed in childhood or adolesence, such as Nicole and Camille. Freeman (1994) posits that, in particular, identifying with a female therapist with disability experience may provide transference potential to work on childhood trauma and repair attachment for clients with disabilities where there previously may not have been the parental resources available.

Sensorial engagement with art materials such as clay, provided a portal to explore body memories (Lobban, 2014; Jones, 2005; Hinz, 2009) which may have led to decreases in traumatic stress and increases in verbalization (Czamanski-Cohen & Weihs, 2016). Substantial engagement and movement on all levels of the ETC suggested integration of both right and left brain hemispheres in the art-making and witnessing process which is essential in work 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 (Camille, Luc) or perception of seizures in psychosomatic episodes (Ben). Having a space to discuss treatment stress and loss of control, alleviated anxiety regarding the need to present a false-self to the world as a means to protect oneself against vulnerability (Lobban, 2014). The growth between Ben's introductory piece (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 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, GAD, and TICS, stating that he worried less, and "even if he did have one, he had found people who understood." Ben reported putting a sign up at his work in his cubicle about halfway through the group, and had increased levels of disclosure regarding epilepsy. Additionally, he no longer had nightly reports of anxiety before bed and what were posited (by neurosurgeon) to be psychosomatic episodes. Ben's final piece would be adaptive to his needs on a particular week, as he would place this 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 (Moon, 2016).

Luc explored his journey with epilepsy through his art process, using clay, watercolour, and kinesthetic movement to explore emotions via scribble drawings with pastels. Luc was able to convey treatment stress (hospitalization for panic associated with increased medication dosage) as well as mentalize feelings of emotional dysregulation regarding invisible disability, experiences of discrimination, and feelings of dehumanization in the system via a variety sensorial art processes (Bateman & Fonagy, 2016; Drass, 2015; Lobban, 2014). Luc found that exploring his emotions through art therapy was a tool to greater self-understanding (Allen, 1997), working on the Perceptual/ Affective component helped him identify and comprehend his emotions with himself and others (Czamanski-Cohen & Weihs, 2016; Hinz, 2009; Morgan et al., 2012), especially key for his well-being with his co-morbidity of PNES.

As participants moved through the group, social integration occurred (Moon, 2016), and witnessing of each others' stories in the safety of the community studio helped in bolstering

connections (Timm-Bottos, 2006), repairing attachment via art (Turner et al., 2011), finding personal meaning (Allen, 1997), and greater clarity moving forward (Lobban, 2014). Group identification (Forsyth, 2010) occurred as participants realized the similarities in challenges they faced (Freeman, 1996), leading to peer support statements as a means to deal with treatment stress, suggesting increases in self-esteem and quality of life (Chew et al., 2017; Chew et al., 2019; Twenge & Crocker, 2002) which are consistent with Sawangchareon et al.'s (2013) study of support groups. Greater feelings of self-efficacy and self-expression translated into higher readings of self-esteem on the RSES and higher readings of overall quality of life on the QOLIE-31, consistent with research by Buelow et al. (2014) on Studio E. Decreases in depression and chronic stress according to self-report, BDI, and TICS suggest that the pairing of art materials and safety of the community studio helped "rebuild the limbic system from the bottom up" (Timm-Bottos, 2006), reconstructing each participant's personal narrative, and increasing resiliency through social support (Chew et al., 2019). The Reconstruction phase at the bottom of the graphic, combines the majority of qualitative and quantitative data, which is indicated on the graphic (See Figure 53).

Based on these theoretical and field observations, the researcher has adjusted Appleton's (2001) Art Therapy Trauma Intervention and Assessment Paradigm into a more cyclical model to apply to group art therapy for epilepsy and other chronic conditions, in order to address cyclical psychosocial implications. A Treatment model is pictured in *Figure 54* and an Assessment model is featured in *Figure 55*. As there was more interaction on the first three stages of Impact, Retreat, and Acknowledgment, there is more dynamic movement and overlap on these stages. As participants approached the Reconstruction stage, more positive treatment results were attained and confirmed by qualitative and quantitative measures. Due to the chronic nature of epilepsy, it is theoretically posited that once one reaches the Reconstruction stage, a treatment setback or further psychosocial trauma may occur. It is then possible to cycle back up through the first three stages, however, due to the integration of coping strategies and the formulation of new neural pathways, it is posited that this process may occur more quickly and with less resistance. The bottleneck design (with cyclical arrows) is to accommodate treatment complications, periods of higher stress, and psychosocial setbacks, with the idea being that once Reconstruction stage has been reached, with adequate psychosocial support, it may be easier for

a participant to cycle back to a higher state of wellness on a more regular basis. This model will require future testing and validation at a clinical level with a larger sample size.

## **Implications**

There are multiple ways that art therapy can impact psychosocial dimension of treatment for epilepsy, and mixed methods was key to capture the diversity of lived experiences, particularly in combining qualitative and quantitative data. Although a small sample size, participants who developed epilepsy in childhood or adolescence (pre-individuation) had experienced more effects from psychosocial stigma (discrimination, bullying) that impacted their quality of life, self-esteem and well-being, particularly in regards to social development, education, and professional settings. For those with a later onset (post-individuation), if they had not experienced it directly, they indicated that they worried about it, and limited who they discussed epilepsy with, causing increases in stress and depression. This is consistent with Hermann and Jacoby's (2009) assertion that epilepsy exists in a social context and qualifies as "a way of knowing", determining people's navigation in the world and Chew et al.'s (2019) analysis that for young adults, impairment effects from epilepsy establish 'barriers to doing' (concerning social participation) and 'barriers to being' (concerning self-esteem). Luc's thoughts on invisible disability and that it destabilizes people to witness someone having a seizure are consistent with Hirschberger et al.'s (2005) account of Terror Management Theory (Greenberg et al., 1997) regarding social exclusion. This evokes Sabini et al.'s (2001) account that witnessing such a break from social norms can establish feelings of unwanted identity as a defense to not being seen as a person, which diminishes self-esteem (Olthof et al., 2004).

For Ben, having had a later onset of epilepsy (post-individuation), it had not affected his post-secondary education, career, or social partnerships; however, it did cause significant traumatic stress, depression, anxiety and negative implications on his quality of life (as measured both quantitatively and qualitatively). For Ben, he felt that he had "expressed what he needed to" regarding epilepsy, and felt readier to leave the group. Although not having directly experienced psychosocial trauma, Ben had a high degree of traumatic treatment stress regarding his epilepsy, causing him to acknowledge that stigma had been a worry for him. In terms of the quantitative testing, Ben had the highest improvements, particularly on the QOLIE-31, having the least years of epilepsy, yet more substantial levels of treatment stress. For Camille, who was diagnosed pre-individuation (having 28 years of epilepsy), she had indicated that epilepsy had

"changed her dreams and life plans", and described a high level of experience of psychosocial stigma. For Camille, the qualitative data was most positive (her interviews and discussion of artwork) regarding her improvements in emotional regulation, quality of life, and epilepsy attitudes, and she expressed substantial stress and sadness regarding losing the group, particularly as her school semester would begin soon. When it came to quantitative questionnaires, particularly more epilepsy-specific dimensions of the QOLIE-31 (such as medication, cognitive abilities), there were less improvements, and in some cases, an increase in worry was indicated, bringing down the overall QOLIE-31 score, however not translating on GAD, suggesting that anxiety was epilepsy specific. For participants that had more years of epilepsy, it seemed that the TICS score was the most substantial improvement, suggesting that reductions of stress may preclude improvements to QOLIE-31, as perhaps with many years of epilepsy, negative biases and cognitions may have solidified as Michaelis et al. (2018) have suggested. Comparing Ben and Camille (see Figure 56), supports the importance of early intervention with art therapy in treatment, as more years without psychosocial support may have substantial negative effects on quality of life.

As people with epilepsy have been "othered" in society on many levels, both historically and systematically, residual prejudice, ignorance, and fear may resonate throughout many layers of society and may determine one's code of conduct in response. Experiencing discrimination in the realms of work and education may create complex psychosocial effects that echo long after the experience, often putting one's self-worth into question, and may be considered psychosocial trauma, causing the individual to develop compensatory emotional and social behavior strategies (such as social withdrawal) to defend against further injury. As the goal of this study was to examine group art therapy's role in treating the psychosocial dimension of epilepsy, it became important to examine how the layers of psychosocial stigma can impact social realms, thus establishing epilepsy as a way of knowing.

In *Figure 57*, Brofenbrenner's bio-ecological systems theory (2005) was applied to the historical and psychosocial context involved with epilepsy to examine the complexities that may fuel enacted and perceived stigma (Baker, 2002). This may translate as government enforced sterilization, extermination, or institutionalization from the macrosystem (History, Global, Government) through to the exosystem (Culture, Media, Laws), where dehumanizing portrayals in the media may condone discrimination and exclusion in academic or professional settings

(Sampert, 2017; Baker, 2002). This stigma trickles down to the mesosystem, where a child may experience bullying at school, teachers who may lack understanding of the disorder, and the parents may not have the emotional support to process layers of stigma (Iseri et al., 2006). This may impact their attachment and parenting style, cultivating anxiety that may result in emotional withdrawal or overprotection which could hinder their child's exploration (Lortie & Vanasse, 2007) and individuation from the microsystem. Negative social experiences of enacted social stigma, such as Nicole's account of childhood bullying, led her to withdraw socially, causing her to be less open and outgoing with her peers, due to the risks of perceived stigma (Baker, 2002). Lauren's experience of discrimination in both professional and educational fields led to her knowing that disclosures of epilepsy could come at a painful social cost, affecting her confidence and ability to talk about negative aspects of epilepsy which affected her attendance of the group. Luc and Camille's experience of invisible disability and social exclusion evoke terror management theory (Greenberg et al., 1997; Hirschberger et al., 2005), and both internal and external factors that affect emotional regulation, such as the pressure to perform in society (Foucault, 1980); 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).

As psychosocial stigma has been historically and systemically installed and perpetuated by institutions of the government and church, perhaps the modern notion of "an institution" could be used to dismantle the effects of psychosocial stigma. In *Figure 57*, representational space (Elmborg, 2011; Lefebrve, 2014) exudes from the microsystem, providing a navigational pathway to deconstruct the systemic hierarchies that have been enforced to the detriment of people with epilepsy. By fostering third spaces in institutions such as art hives (Elmborg, 2011; Timm-Bottos, 2006), we provide a portal to healing and addressing elements of psychosocial stigma that were bred in dominant spaces. Historically, museums have been institutions that are representative of society's 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 healthcare (hospital, clinical) and culture (museum, community).

An integrative clinical-community art therapy treatment model is adapted from Lee's (1970) pyramid in *Figure 58* to address the complexities of psychosocial dimension of treatment, to normalize talking about the emotions related to epilepsy treatment, and to meet patients where they are at. This model extends across clinical inpatient, outpatient, and community art therapy realms, with potential benefits across the board, for both patients and institutions. Individual art therapy interventions in VEEG inpatient wards at epilepsy tertiary centres (hospitals) could be crucial to manage potential PTSD, psychosomatic symptoms, anxiety about treatment, and to offer a container for intense emotions relating to treatment stress (as well as to screen for candidates who may benefit from a closed group art therapy program such as this one). This need was demonstrated in Ben's case, where he initially felt that he was having small seizures nightly before bed, however his neurosurgeon posited that these may have been psychosomatic expressions of stress. Not having a place to process emotional responses to treatment (with plans often discussed with patients in VEEG wards), may increase stress, depression and anxiety, as well as psychosomatic symptoms that may be perceived as seizures. Ben emphasized that the discussion portion of the group was crucial to his description of the group as social rehearsal. This approach corroborates the efficacy of closed groups for people dealing with traumatic stress, such as Lobban's (2014) PTSD group, with significant portions of the group devoted to art-making and witnessing discussions.

The integration of art therapy on a multi-disciplinary team could additionally be a valuable component to address PNES co-morbidities with epilepsy and decrease costs in the system that could translate in additional MRIs, VEEGs, and diagnostic testing, as Brown et al. (2018) suggested and was demonstrated in terms of decrease of stress-related events for Ben. As was the case with Luc and Camille, art therapy led to seizure reduction and provided a place to contain treatment stress, whether it be communication ruptures with their care team over medication side effects (Luc), or the feeling of being listened to but not heard (Camille). The treatment of the psychosocial aspect could lead to improved communication relationships between patients and neurology care teams, as it was a common sentiment that participants felt that they were only offered medication. Having an art hive in the epilepsy clinic, where 50

patients may come per weekly clinic, could install a feeling of human connection where there is treatment stress, as participants would be able to come and go as they please, installing a sense of agency in a situation where there is a sense of lack of control. This relates to Luc's wish for a community foundation for neurology to provide psychosocial services, as he has seen develop in oncology.

Additionally, for patients who may not have experienced psychosocial trauma relating to epilepsy, a 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 as part of their epilepsy experience, it may not be helpful for them to attend a closed group where traumatic stress of the group may become the focus. For participants who may not be ready to explore past psychosocial trauma, such as Lauren, an art hive in the epilepsy clinic or neurological hospital could slowly integrate patients from a place of social isolation and emotional avoidance, to where they may feel more comfortable to explore their emotions regarding epilepsy as needed. For participants with severe side effects and high seizure frequencies, having an art hive in the clinic provides a chance to pair neurology appointments with self-care and stress reduction, when it may be too challenging in terms of transportation and social overload to commit to attending a closed group regularly. The clinic art hive and closed group in the museum would then be linked to the art hive network, where partnerships and special events could encourage participants to eventually frequent hives that are not associated with the hospital, but with the community at large, promoting social integration.

## **Delimitations: Validity and Future Research**

It is my goal for this pilot study to lay the groundwork and to assess research methodology to create a future study that would have both a larger number of participants (to address validity) and a refined qualitative method. Due to a small sample size and the use of a pseudo-control group as opposed to a true control group (established from the beginning), it is not possible to conduct statistical analysis. Adding additional psychological tests to address components of self-esteem and quality of life (such as memory and mood), as well as employing a mixed methods design, is gradually building on Buelow et al.'s (2014) research in a way that can hopefully give insight to why and how self-esteem and quality of life were shown to increase, and can hopefully lay the groundwork for a study with a higher number of participants to increase validity. The results of this pilot study would be used to apply for funding in order to manage the logistical

requirements of this endeavor and would go through an evaluation process with an external auditor, as recommended by Creswell (2014) to increase validity in qualitative aspects of studies and develop a standardized program that could withstand clinical trials. A future study would additionally have credentialed art therapists that were not also serving as the researchers, as this opens the window to potential bias.

Additionally, working in closer collaboration with neurology departments could bring insight to the clinical dimensions of each individual's case and bring further insight to what was largely self-report of seizures, which could be prone to negative bias and cognitions (Michaelis et al., 2018). Comparing self-report before and after would account for changes in seizure perception, although it may not reveal the discrepancy between attentional bias and seizure symptoms from a neurology perspective. Using an established scale of seizure severity classification could help to understand this phenomenon, as a classification scheme was developed for comparison by the researcher and is prone to subjectivity and influence of a participant's biases in self-report. Also, at the time of the study, the research database at the hospital was not available, making it harder to reach potential participants who had agreed to participate in research, thus recruitment was impacted by who may have had appointments scheduled during this period, which often led to older participants. A closer collaboration with neurology, could also allow eventual investigation into different age groups (such as children and adolescents), which could be imperative to life-long well-being as psychosocial trauma was reported by older participants as having occurred largely during those years.

In future tests, the researcher would separate further from the quantitative testing, as it is possible that the presence of the researcher and therapy facilitator could have skewed tests in either a negative or positive way. Additionally, testing a model where the cost of termination is not a factor, (either with the program continuing, or running longer, perhaps testing at the midpoint, could eliminate effects of termination from the results). More extensive collaboration on the analysis of quantitative data, as well as the use of content analysis software to compare emotional tone in the pre-test and post-test interviews (qualitative) would be desirable. This would also allow the research team to better address neuropsychological batteries and PANAS data that was collected and is in need of integration. Finally, the researcher would collaborate more closely in the selection of the pieces viewed in the museum tours based on the feedback of participants in this study.

## **Chapter 6. CONCLUSION**

When addressing a chronic condition such as epilepsy, that may include experiences of psychosocial stigma or trauma in treatment, the employment of mixed methods is important, as if we were only looking at quantitative data, we may underestimate the impact of art therapy more easily (Kapitan, 2017) (due to varied dimensions of QOLIE-31, complexities of trauma, and traits of perfectionism that may translate to RSES). Although there are slight improvements on quality of life on QOLIE-31 and self-esteem on RSES for the Attend group, qualitative data shows key instances of art therapy's positive influence on emotional regulation, social engagement, sense-of-self, sense of mastery, and overall wellness.

The ability to reconstruct personal narratives surrounding traumatic seizure situations and psychosocial impact suggests the reintegration of traumatic memories, as supported by better access to positive memories on the AMT, and less depression on the BDI. This is supported by a substantial decrease in chronic stress for the Attend group, which would be significant in a larger sample size, as measured by the TICS. This is corroborated qualitatively as participants used art therapy as a container for intense emotions, to process complex grief and treatment stress, and to develop a sense of connection to self and others to foster resiliency and self-care in the face of a chronic condition. Art therapy was found to be a successful way to treat the psychosocial implications for epilepsy, with participants improving self-esteem, wellness, and quality of life on both quantitative and qualitative measures. Appleton's (2001) Art Therapy Assessment and Treatment Paradigm for Psychosocial Trauma was adapted into two parts: a cyclical treatment model for epilepsy, developed to a more process-oriented way of working (integrating art therapy and neuroscience literature) in order to better approach ongoing treatment stress for chronic conditions. Part two was an assessment model that was epilepsy specific, and both models will require further testing and corroboration.

Finally, an adaptation of Brofenbrenner's (2005) bio-ecological systems theory was fused with representations of space to enable clinicians to better approach the complex weight of stigma and how it can resonate across many layers of a person's life. Understanding the complexities of these dynamic, systemic interactions gives an opportunity to engage and reclaim space by honoring and empowering the lived experience of people with epilepsy and others who live with invisible disabilities. As representational space dialogues with hierarchies of these systems in the third space of an art hive (Elmborg, 2011; Timm-Botto, 2006), opportunities for

healing the institution by changing the institution are provided. As society attempts to reconcile ostracizing people with disabilities past, present, and future, it can be argued that it is the obligation of governmental institutions who may have established and perpetuated psychosocial stigma, to now collaborate with those impacted most by it towards healing in order to move past it.

The proposal of a clinical-community model of art therapy empowers people with epilepsy to gravitate toward the avenue that best suits their needs, whether it is inpatient individual art therapy in the VEEG setting, an 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. The integration of this model allows people to move at their own pace, to navigate comparison to others, and to have a community support structure in place for termination of closed treatment groups. The juxtaposition of clinical-community setting is a key factor to address the complexities of psychosocial stigma, as well as the fluctuations in both physical and emotional wellness that accompany chronic conditions. The integration of art therapy to treat the psychosocial dimension of epilepsy could take the weight off the neurology department by giving patients more verbal tools to represent their seizure experiences and their emotions, and this could potentially decrease use of expensive diagnostic testing when symptoms may be 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. This pilot study was intended to be a stepping stone toward this direction, a small grain of representation in research and clinical settings for people with invisible disability experience, to amplify the voices of people who are currently experiencing implications of epilepsy and to bring insight on the integral importance of treating the psychosocial dimension toward overall wellness and quality of life.

Having 15 years of epilepsy experience was integral to my journey to become an art therapist, as creativity had been a component of my personal healing from the experience of psychosocial stigma of epilepsy. When I learned about Studio E, it was incredibly promising and I felt compelled to research the integration of a similar program in Canada, feeling that perhaps for people with epilepsy, art therapy can offer a portal to create community and perhaps

this can develop through the art hives network. My 'way of knowing' that this could have helped me personally as an adolescent and young adult, led me to prevail past challenges in recruitment and to push through the learning curve on my first exploration into mixed methods research.

This project is meant to be a starting point. My long-term goal is to contribute to a body of research, treatment centres, and social advocacy projects regarding art therapy's ability to address the psychosocial dimensions of epilepsy. I see a future where neurologists and creative arts therapists regularly collaborate to benefit the total health of the patient. Although we can work towards a general population that is more educated regarding epilepsy, we cannot ensure that people will not face enacted stigma and discrimination. What we can aim to address, however, is the self-perception, self-esteem and self-worth of people with epilepsy, and art therapy has proven itself as a highly effective therapeutic process in this regard. Building a network of communities to tackle social isolation could continue to improve the quality of life for participants who attended art therapy initiatives. The concept of a group treatment that is free and accessible, like this pilot project or Studio E, could impact health and well-being for people with epilepsy across the board, and could additionally ease the weight on the system regarding neuroepilepsy treatment aspects. As the social media platform continues to evolve, there is huge potential to take initiatives like Studio E and offer them as online communities for people living in isolated areas. This could include chatrooms, online galleries, skill-shares and forums as key components. I remain passionate to pursue such art therapy initiatives to intervene with the psychosocial challenges of epilepsy and feel that this pilot study is a key starting point for my future research and aspirations in this field.

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## **Appendices**

## Appendix A

## Pre and post test session list

## To be administered by researcher with Sheldon Memory Lab.

- 1. Neuropsychological Test Battery to assess cognitive function Memory
  - a. Logical Memory Test- Participants learn and remember a short story. This test assesses verbal memory
  - b. Rey-O Complex Figure Participants learn and remember a complex visual image this assesses visual memory
  - c. AMT- Autobiographical Memory Test participants are given cue words and asked to recall specific memories for their past.

### II. Executive Function

- a. Trails A/B a measure in which people connect numbers and letters in a short time period
  - b. SART This measure assesses attentional capacity
  - c. Digit span
- 2. Questionnaire Data to assess Quality of Life and Social Cognition
  - a. RSES Rosenberg Self Esteem Scale
  - b. QOLIE-31 Quality of Life Inventory for Epilepsy
  - c. PANAS Positive and Negative Affect Scale
- 3. Questionnaire Data to assess Mood- 45 min
  - a. BDI Beck Depression Inventory
  - b. GAD Generalized Anxiety Scale
  - c. TICS Trier Inventory of Chronic Stress

## Pre and Post each art therapy session:

PANAS scale to be administered by researcher/ art therapy facilitator

## Appendix B

## **Survey and Interview Guide**

To be administered by researcher pre and post-intervention.

The following questions will be administered to participants in written and oral sections.

- 1. Does having epilepsy affect your social life?
- 1 2 3 4 5 6 7

Completely Neutral

Not at all

- 2. In what ways does epilepsy affect your social life? If you answered NOT AT ALL to Question 1, please describe if there is a scenario that you could imagine would affect you?
- 3. What types of seizures do you have and at what frequency in a typical month? How long have you had your diagnosis?
- 4. Prior to this group, did you know anyone else that had a diagnosis of epilepsy?
  - 5. YES NO
  - Have you ever experienced discrimination related to having epilepsy?
     YES NO
  - 7. If applicable, how did this experience affect your life?
- 8. With whom do you talk about your experiences with epilepsy? Please circle all that apply- A. Doctor and associated medical contacts. B. Your parents. C. Your siblings. D. Your partner/extended family/children. E. Your close friends. F. Your professors and teachers G. Your acquaintances. H. Your professional contacts. I. Whenever it comes up. J. Whenever I meet someone new. K. No one.
  - 9. How has your diagnosis with epilepsy changed your life?
- 10. Does your epilepsy affect your post-secondary or vocational career choice? Please give one example.
- 11. Have you ever done art before? Please briefly describe your past artistic experience.

## Appendix C

## **Exit Interview**

- 1. Looking back at your artwork (review on computer), what comes up for you? How did you find this experience?
- 2. How was your quality of life these last 8 weeks? How were your epilepsy symptoms (frequency of seizures)? Anxiety levels?
- 3. Did this experience impact your social, professional, familial or medical relationship? If yes, how?
- 4. Do you see yourself continuing to use art as an outlet?
- 5. How did you find being in the group? Would you like to see this community continue? In what way?

# Appendix D

# **Museum Survey**

## Rated 0 to 4 (Maximum Positive)

At the Musée des Beaux Art de Montreal: I,

- 1. Established contact with other Participants
- 2. Experimented new practices or new ways of expressing yourself.
- 3. Acquired more confidence in your creative potential.
- 4. Are interested in new things.
- 5. Are happier, more positive.

Source: Musée des Beaux Art de Montreal

Figures



Figure 1. Art Therapist Process Art from Child and Adolescent Class at beginning of research process (October 2018) exploring childhood bullying relating to epilepsy.



Figure 2. Caitlin from Degrassi Junior High in epilepsy episode in EEG originally airing in 1988 (Degrassi Wiki, 2017).



Figure 3. Teen Sleuth & the Freed Cyborg Choir examining my neurosurgery, epilepsy and rehabilitation experience through art. Live performance shot from Pop Montreal 2009. Photo credit Marwan Taliani and Cindy Lopez.



Figure 4. Art Therapy Researcher Concept Map at beginning of research process.

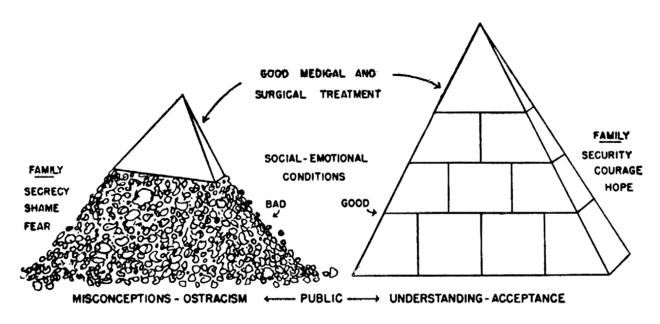
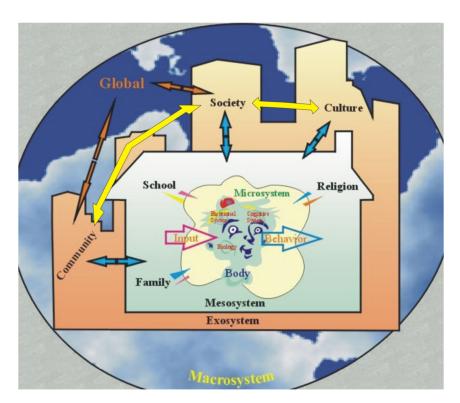


Figure 5. Lee's (1970) model of psychosocial dimension of healthcare, featuring four stages of psychosocial transition from trauma.



*Figure 6.* Brofennbrenner's (2005) bio-ecological systems theory illustrated by Paquette and Ryan (2011).

Stages* & Goals	Psychosocial Issues	Art Themes	Graphic Features	
Stage I, Impact				
Art Therapy Goal: • Creating continuity	<ul><li>Trauma</li><li>Denial</li><li>Shock</li></ul>	<ul><li>Trauma event</li><li>Burns &amp; body</li><li>Burn story</li><li>Accident maps</li></ul>	<ul><li>Spatial disorientation</li><li>Regressive line use</li><li>Symbolic color</li><li>Limited use of media</li></ul>	
Stage II, Retreat  Art Therapy Goal:  • Building therapeutic alliance	<ul><li>Regression</li><li>Dependence</li><li>Social withdrawal</li><li>Resisting care</li></ul>	<ul><li>Fantasy</li><li>Sunsets</li><li>Super-humans</li><li>Heroes</li><li>Relaxation images</li></ul>	<ul><li> Unfinished pictures</li><li> Abstractions</li><li> Color use increases</li><li> Exploration of media</li></ul>	
Stage III, Acknowledgment				
Art Therapy Goal:  • Overcoming social stigma and isolation through mastery	Mourning     Social interactions     Resources examined	<ul><li>Psychological pain</li><li>Grief &amp; loss</li><li>Social relationships</li><li>Trees</li><li>Mandalas</li></ul>	<ul> <li>Developmentally regressive schema</li> <li>Line and colors used to communicate emotion</li> <li>Exploration of diverse media: collage</li> </ul>	
Stage IV, Reconstruction Art Therapy Goal:	Values & spiritual	Home images	Completed pictures	
Fostering meaning	clarifications  • Mastery  • Independence  • Concerns about future	<ul><li>Work images</li><li>School images</li><li>Future issues</li><li>Hopes &amp; fears</li></ul>	(gestalts)  • Colors as symbols  • Exploration of challenging media, oil & acrylic painting	

Figure 7. Appleton's (2001) art therapy trauma intervention and assessment paradigm, adapted from Lee's (1970) four stages of psychosocial transition from trauma.

Pt	Current Age/ Age of Onset	Years of Epilepsy	Types of Seizures	Seizure Frequency	Effect on Work/ Education	Discrimination or Bullying	Treatment Stress	Protective Factors
Ben	33/ 30 yrs old	3	Tonic Clonic (nocturnal) & partial (before bed), benign brain tumor.	4 TC/ year Partial= 1/ week.	No. (Dx post- university). Works in media.	No (but is a worry).	Possible Neurosurgery, Weighing potential costs loss of memory.	Father of two young children, supportive partner.
Luc	45/ 7 mos old	44	Tonic Clonic (Dx 7 mos), PNES (Dx early 20s).	3/ month "90% PNES Seizures".	Yes. Discrimination at Post-Secondary level affected him finishing; feels that chemical effects of meds on energy and lack of focus on therapeutic dimension of treatment has jeopardized his rehabilitation.	Yes, "I always had to fight prejudice about epilepsy. It makes people uncomfortable to see someone lose consciousness in a group. It psychologically destabilizes them, I understand it."	Feels there is lack of dialogue with neurology care team, recent ER visit for panic associated with medication change. Feels that PNES was not properly explained to him.	Partner, friends, philosophi cal interest, travel and yoga interest, disability advocacy.
Camille	40/ 12 yrs old	28	Tonic Clonic, Partial Absence.	3-4 TC/ month, 10 absences/ day.	Yes. "It destroyed my life plan to join army, and get college education paid for to be psychologist." Had to discontinue semester at school, currently avoiding social contact due to fear of seizures	Yes, "it was more intimidation than discrimination because discrimination is more a particular thing and bullying is moreof a stigma. People didn't know about it. So it's like "she's in the moon, you can mess with her" because she's fragile. Psychological violence."	Waiting for Vagus Nerve Stimulator, has medication resistant epilepsy.	Some close friends, interest in social justice, education.
Nicole	40/ 7 yrs old	33	Tonic Clonic, Partial Absence.	1 TC last Sept, prior no TC since childhood, Partial absences every few months in past year.	Pre-test: "No, because I always worked anyway, I always studied. I didn't stop." Post-test: Yes "A lot for studies, already I had a hard time passing. " Chose "easier" career.	No, (but later described bullying "but it wasn't to do with the epilepsy, but it's part of it because when you're young and you have a bracelet, everyone sees you have epilepsy.")	Dealing with return of seizures after many years of being seizure-free, trying to find a neurologist and treatment plan.	Partner support.
Joe	36/ 18 yrs old	18	Partial Absence	1/ month since last Sept (last surgery).	Yes. "I had to choose job where it would not be problem to always have to relearn things". Had to discontinue first choice of school due to memory problems.	No.	Has had neurosurgery 3 times, has short- term memory issues	Supportive family, supportive workplace (2 other people have epilepsy,) religion.
Lauren	37/ 15 yrs old	17	Tonic Clonic	No TC for 2 years.	Professional Career. Experienced discrimination at university and career level, which now impacts her disclosure.	Yes, at university level she was not allowed to retake an exam when she had a seizure during it. Was also passed up for a job, seen to interfere with her work ability.	No seizures for 2 years, still seizure worry as job has long hours, stress and travelling.	Supportive partner, passionate about social justice, career, friendship s.

Figure 8. Participant Chart

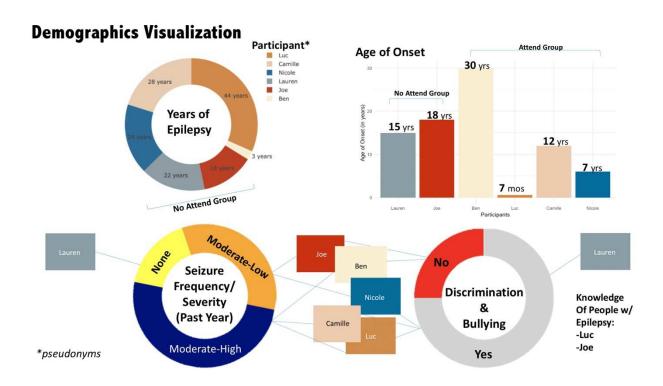
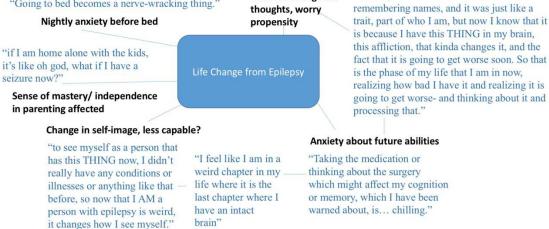


Figure 9. Participant Demographics featuring years of epilepsy, age of onset, seizure frequency and severity in the past year, and experiences of discrimination or bullying for Attend and No Attend group; as well as knowledge of people with epilepsy (2 of 6 people).

# Ben: Has Epilepsy Changed your Life? How... (Later onset) Pre-test "Going to bed becomes a nerve-wracking thing." Nightly anxiety before bed Increase in negative thoughts, worry propensity prop



*Figure 10.* How has epilepsy changed your life: Young-Mid Adulthood Onset: Ben (Interview conducted in Pre-test-Survey Guide).

# Has Epilepsy Changed your Life? How? (Child/Adolescent Onset)

# Educational or Vocational choices (lower SES)

#### Camille: "It changed my dreams"

Nicole: "I already had a hard time passing, and it affected my memory a lot. For that reason, I chose an easier field career-wise.

Luc- "I didn't have access to choice... at the moment I am on social assistance."

#### **Energy depletion from meds**

« ..l couldn't finish my training because I am on too much Tegretol and.. It's Tegretol that affects my energy and productivity. »

#### Impact on social development → isolation

Camille: "I don't want to go out of my apartment now because I am afraid I will have a seizure. My epilepsy is making me hide in my apartment.

« It's frustrating to disengage when you get to that point, that it changes how you feel and you don't want to go out, it's not necessarily the medication or the epilepsy that is making you sad, but more the social isolation »

#### Lack of trust in medical system

"It has an enormous psychological effect on me and it saddens me to think that we are in this model now in Quebec."

# Lack of understanding / invisible disability

- "I find there is a lot of loneliness and little understanding"
- « When you are not in a wheelchair, but you are disabled, it is difficult to exercise your rights and access services. »

#### Discrimination/Bullying

« There is a stigma that the world does not understand. They think 'oh she's on the moon, she's fragile, you can mess with her. This is even at school. »

Figure 11. How has epilepsy changed your life: Childhood/ Adolescent Diagnosis for Attend Group (Interview conducted in Pre-test- Survey Guide).

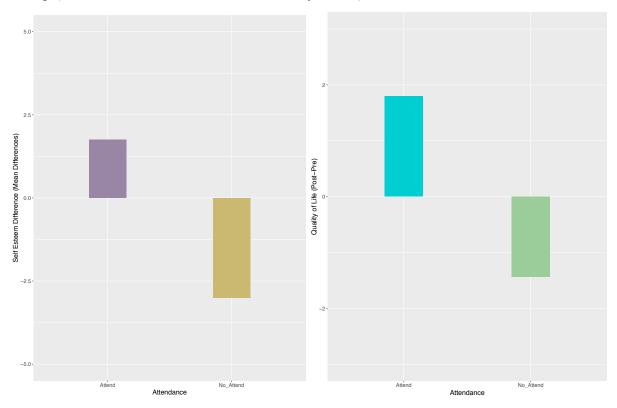


Figure 12. Group questionnaire results comparing means differences (Post- Pre) for Attend and No Attend groups on self esteem (RSES) and quality of life (QOLIE-31). Higher scores are more positive.

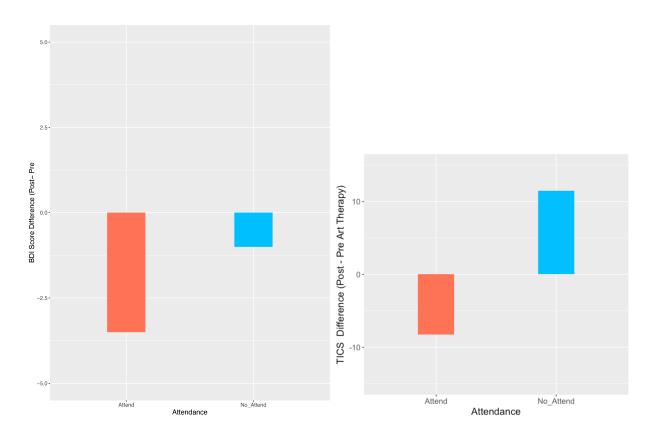
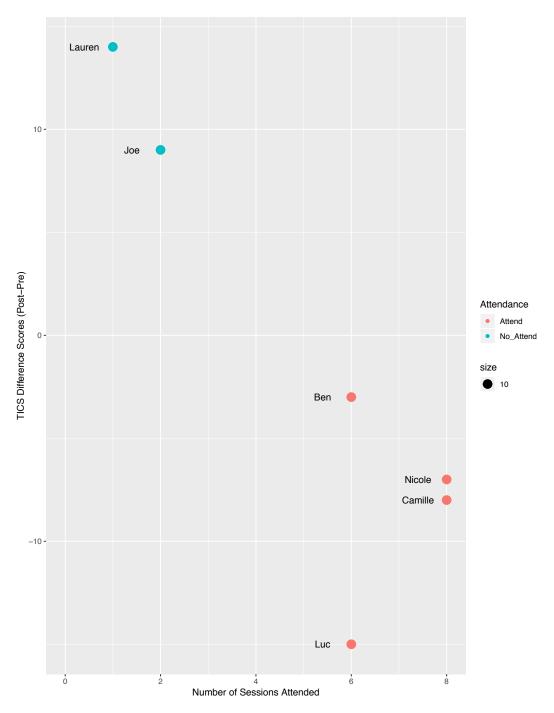


Figure 13. Group questionnaire results comparing means differences (Post-Pre) for Attend and No Attend groups on depression (BDI) and chronic stress (TICS). Lower scores are more positive, representing lower depression and lower chronic stress ratings.



*Figure 14.* Chronic Stress (Mean differences Post-Pre) as a function of number of sessions attended for Attend and No Attend Group. Lower scores represent less stress thus we see the benefit in participants who attended 6 or more sessions.

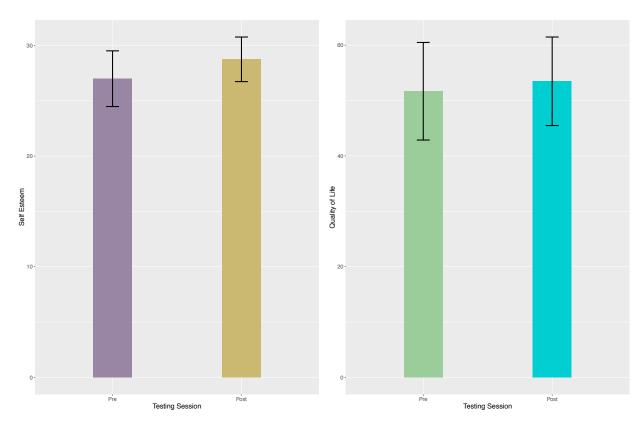


Figure 15. Group questionnaire results comparing means for Attend group on self esteem (RSES) and quality of life (QOLIE-31) as measured in the pre-test and post-test period. Higher scores are more positive, representing higher quality of life and self- esteem.

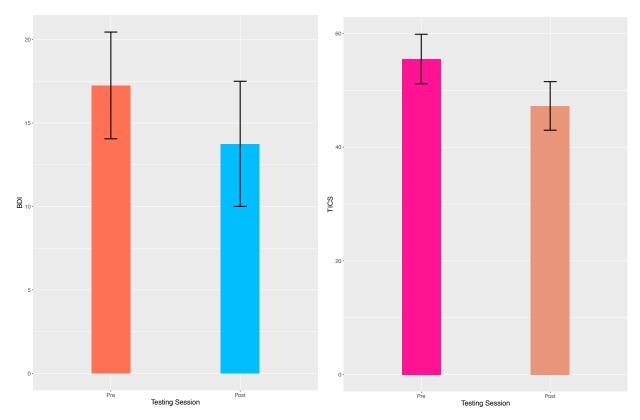


Figure 16. Group questionnaire results comparing means for Attend group on depression (BDI) and chronic stress (TICS) as measured in the pre-test and post-test period. Lower scores are more positive, representing lower depression and lower chronic stress.

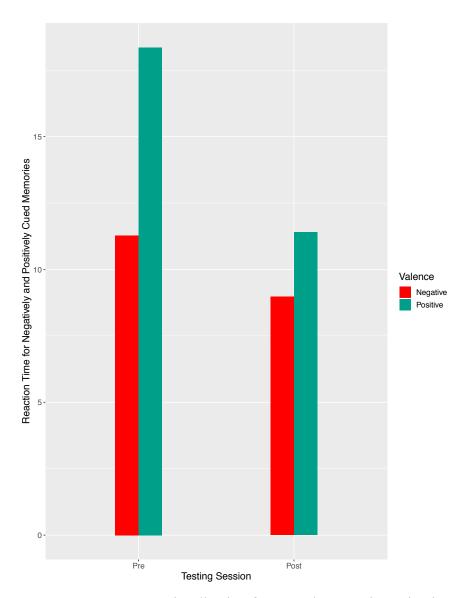
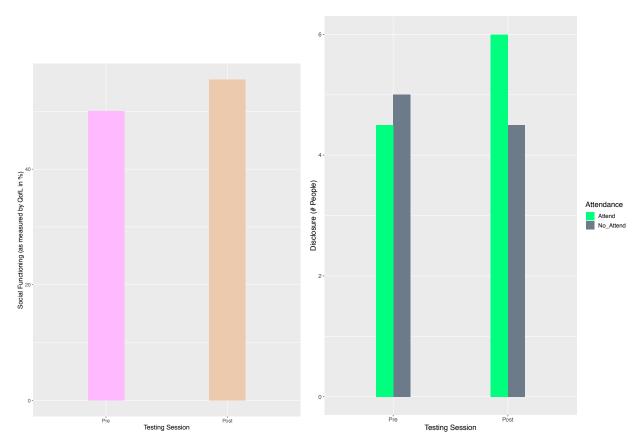
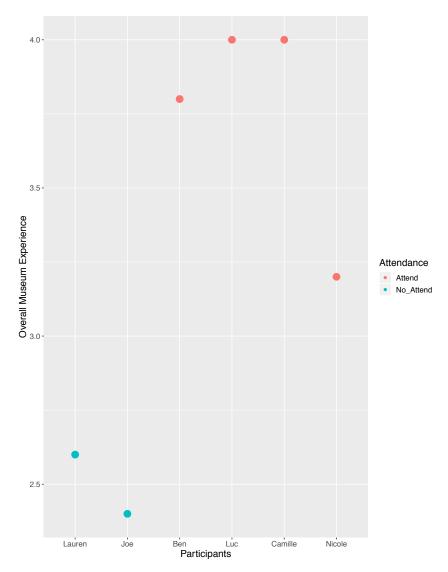


Figure 17. AMT Data Visualization for Attend Group, investigating reaction time to come up with memories in response to Negative and Positive cues for Attend Group as compared in the Pre-test and Post-test sessions.



*Figure 18.* Social Functioning for Attend (measured by a subscale of QOLIE-31 in percentile) and Levels of Disclosure (measured by number of people from Survey Guide) for Attend and No Attend.



*Figure 19.* Overall Museum Experience (means) as measured from the MBAM survey administered in post-test, with a range of 0-4 (negative to positive) available for participants to rate their experience, comparing Attend and No Attend groups.

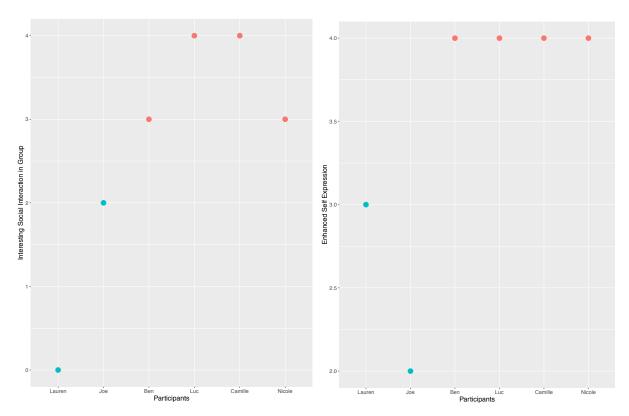


Figure 20. Selected dimensions from the MBAM survey administered in post-test: Interesting Social Interaction in Group and Enhanced Self-Expression. Higher scores represent a more positive experience with a range of 0-4 (negative to positive) available.

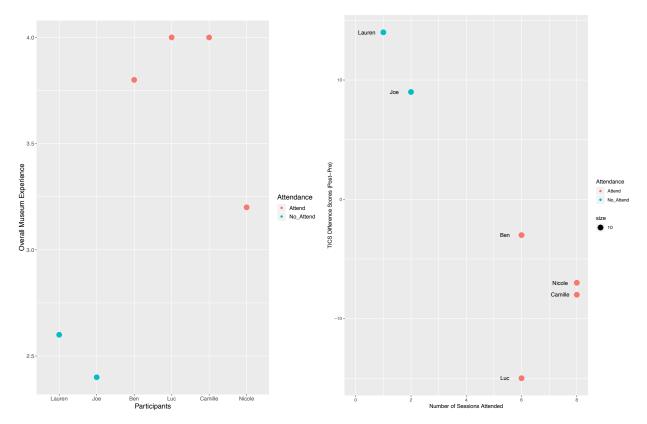


Figure 21. Overall Museum Experience (Means) comparing Attend and No Attend groups (higher scores represent a more positive experience) compared with Chronic Stress and sessions attended (lower TICS scores represent less stress).

## Descriptives: Mood Between Attend and No Attend.

	Attendance	RSES	QofL_Overall Subscale (QOLIE-31)	OVERALL QofL Score (QOLIE-31)	BDI	TICS
Mean	Attend	1.75	10.3	1.80	-3.50	-8.25
	No_Attend	-3.00	2.50	-1.43	-1.00	11.5
Std.						
error	Attend	1.89	0.786	5.14	1.85	2.50
mean						

Attendance	RSES	QofL_Overall Subscale (QOLIE-31)	OVERALL QofL Score (QOLIE-31)	BDI	TICS
No_Attend	3.00	15.0	0.760	2.00	2.50

Figure 22. Quantitative Results- Mood scores between groups.

Chronological Review of Artwork via Art Therapy Trauma Treatment and Assessment Paradigm for Psychosocial Issues and Art Themes (Appleton, 2001).

	<b>S1</b>	S2	<b>S3</b>	<b>S4</b>	<b>S</b> 5	<b>S6</b>	<b>S7</b>	<b>S8</b>
Ben	3 <b>,1</b>	<b>1,</b> 3	<b>1,</b> 3	х	х	2,3	4, 2, 3	4
Luc	3,2	х	2,3	х	2,3,4	3,4	3,4	4
Camille	<b>1,</b> 3	2,3,1	3,1,2	2,3,1	2,3,4	2,3,4	3,4	4
Nicole	2,3	1,2,3	1,2,3	3,2,1	<b>1,2,3</b>	<b>1,</b> 3	4	4
Joe	х	1,2,3	х	х	х	2,1,3	х	х
Lauren	2,3	х	х	х	х	х	х	х

<sup>1 =</sup> Impact Stage, 2 = Retreat Stage, 3 = Acknowledgment Stage, 4 = Reconstruction Stage. \*Coded by most prevalent stage listed first. x = no attendance

*Figure 23.* Analysis of Artwork using Appleton's Art Therapy Trauma Intervention and Assessment Paradigm- table.



*Figure 24.* Ben's first work showing Stage 3, Acknowledgment (psychological pain), and Stage 1 (seizure as trauma event; Appleton, 2001).



Figure 25. Triptych view of Camille's first work showing Stage 1 (impact of trauma event), Stage 3 Acknowledgment (psychological pain and grief), Stage 2 Retreat (social withdrawal, dependence; Appleton, 2001).



*Figure 26.* Lauren's work in Session 1, gravitating between Stage 3 Acknowledgment (psychological pain, grief, resources examined), Stage 2 Retreat (dependence, relaxation imagery; Appleton, 2001).



Figure 27. Nicole's first work spanning between Stage 3 Acknowledgment (psychological pain, grief, loss, resources examined), Stage 2 Retreat (dependence, social withdrawal, relaxation imagery; Appleton, 2001).



*Figure 28.* Nicole's work in Session 2, showing Stage 1 (impact of trauma event), Stage 3 Acknowledgment (psychological pain and loss of control, consciousness, social interactions), Stage 2 Retreat (dependence, social withdrawal; Appleton, 2001).



Figure 29. Joe's first work (Session 2) showing Stage 1 (impact of trauma event), Stage 3 Acknowledgment (psychological pain and loss of control, consciousness, social interactions), Stage 2 Retreat (dependence; Appleton, 2001).



*Figure 30.* Ben's second work (Session 2) showing Stage 1 (impact of trauma event), Stage 3 Acknowledgment (psychological pain and loss of control, consciousness, social interactions), Stage 2 Retreat (dependence; Appleton, 2001).



*Figure 31.* Camille's work in Session 3, showing Stage 1 Impact (of trauma event) in seizure cycle, Stage 3 Acknowledgment (psychological pain, loss of control, grief), Stage 2 Retreat (social withdrawal, dependence; Appleton, 2001).



Figure 32. Nicole's work in Session 3, showing Stage 1 Impact (of trauma event) in seizure cycle, Stage 3 Acknowledgment (psychological pain, loss of control, grief), Stage 2 Retreat (social withdrawal, dependence, relaxation imagery, suns) (Appleton, 2001).



*Figure 33.* Camille's work in Session 2, showing Stage 2 Retreat (social withdrawal, dependence, relaxation imagery, suns), Stage 3 Acknowledgment (psychological pain, loss of control, grief, social interactions, resources examined), Stage 1 Impact (of trauma event) in seizure cycle (Appleton, 2001).



Figure 34. Ben's work in Session 3, showing Stage 1 Impact (of trauma event) in seizure cycle, Stage 3 Acknowledgment (psychological pain, social relationships, loss of control and consciousness, grief), and Stage 2 Retreat (dependence) (Appleton, 2001).



*Figure 35.* Nicole's work in Session 4, showing Stage 3 Acknowledgment (psychological pain, social interactions, loss of control, grief), Stage 2 Retreat (social withdrawal, dependence,), and Stage 1 Impact (of trauma event) (Appleton, 2001).



*Figure 36.* Nicole's work in Session 5, showing Stage 3 Acknowledgment (social interactions, loss of control and consciousness, psychological pain, resources examined), Stage 2 Retreat (social withdrawal, dependence), and Stage 1 Impact (of trauma event) (Appleton, 2001).



Figure 37. Luc's first work showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 (dependence, social withdrawal) (Appleton, 2001).



*Figure 38.* Ben's work in Session 6, showing Stage 2 Retreat (social withdrawal, dependence, fantasy), Stage 3 Acknowledgment (psychological pain, loss of control, grief, social interactions, resources examined (Appleton, 2001).



*Figure 39.* Luc's second works in Session 3, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 (dependence, social withdrawal) (Appleton, 2001).



*Figure 40.* Luc's works in Session 5, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 4 (reconstruction, spiritual values) (Appleton, 2001).



*Figure 41*. Luc's second works in Session 5, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 (dependence, social withdrawal) (Appleton, 2001).



Figure 42. Camille's work in Session 4, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 (dependence, social withdrawal) (Appleton, 2001).



Figure 43. Camille's work in Session 4, Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 (dependence, social withdrawal) (Appleton, 2001).



Figure 44. Luc's work in Session 6, Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 4 (reconstruction, spiritual clarification) (Appleton, 2001).

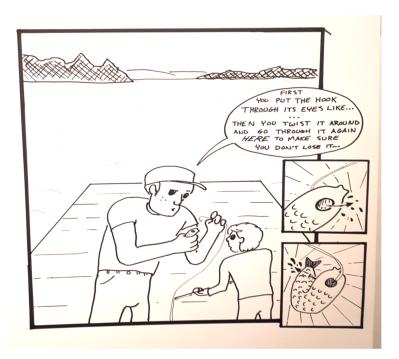


Figure 45. Ben's work in Session 6 and 7, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 2 Retreat (dependence, social withdrawal), Stage 4, Reconstruction (images of home, family, social interactions) (Appleton, 2001).



*Figure 46.* Luc's work in Session 7, showing Stage 3, Acknowledgment (psychological pain, resources examined, grief), Stage 4, Reconstruction (values and spiritual clarifications, social interactions) (Appleton, 2001).



*Figure 47.* Luc's work in Session 8, showing Stage 4, Reconstruction (values and spiritual clarifications, social interactions (Appleton, 2001).



Figure 48. Camille's work in Sessions 6-8, a process beginning in Stage 2, Retreat (dependence, social withdrawal) and Stage 3, Acknowledgment (psychological pain, resources examined, grief), and shifting by Session 8 to Stage 4, Reconstruction (values and spiritual clarifications, social interactions) (Appleton, 2001).



Figure 49. Ben's work in Session 8, showing Stage 4, Reconstruction (values and spiritual clarifications, social interactions, coping strategy, mastery for future concerns) (Appleton, 2001).



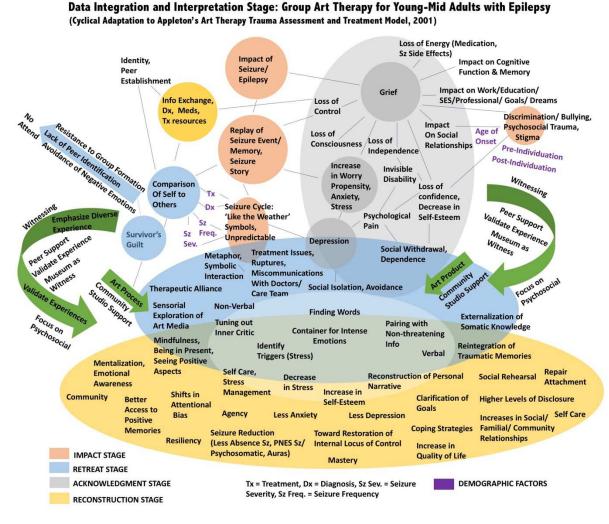
*Figure 50.* Nicole's work in Session 7, showing Stage 4, Reconstruction (social interactions, home, family images) (Appleton, 2001).



*Figure 51*. Nicole's work in Session 8, showing Stage 4, Reconstruction (values and spiritual clarifications, social interactions, future issues) (Appleton, 2001).



Figure 52. Group work "Making a Piece of the Collective Pie" in Session 8- Top right comic art: Ben; "Merci": Camille; Bottom Centre: Luc "Art helps you transcend your self"; Nicole "Epilepsy"; art therapy facilitator, and art therapy facilitation assistant.



*Figure 53.* Data Integration and Interpretation Stage for Qualitative and Quantitative Data in a non-hierarchal sense.

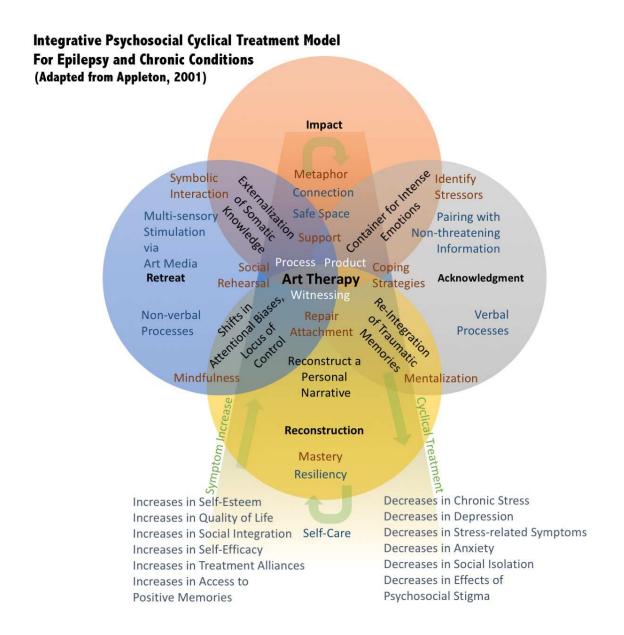


Figure 54. Integrative Psychosocial Cyclical Treatment Model for Epilepsy and Chronic Conditions- Adapted from Appleton (2001). Based on qualitative and quantitative data from Figure 53, integrating art therapy, neurobiology and psychology theories (Bateman & Fonagy, 2016; Carr, 2014; Czamanski-Cohen & Weihs, 2016; Drass, 2015; Gussak, 2007; Gardner et al., 1983; Keller, 2001; King-West & Hass-Cohen, 2008; van der Kolk, 1994; Lee, 1970; Lobban, 2014; Macrodimitris et al., 2011; Malchiodi, 2007; McNiff, 2003; Michaelis et al., 2018; Moon, 2016; Morgan et al., 2012; Riley, 2001; Rubin, 2005; Saltzman et al., 2013; Schore & Schore,

2008; Tang et al., 2015; Timm-Bottos, 2006; Turner et al., 2011; Wilson & Ross, 2013; Yalom, 2005).

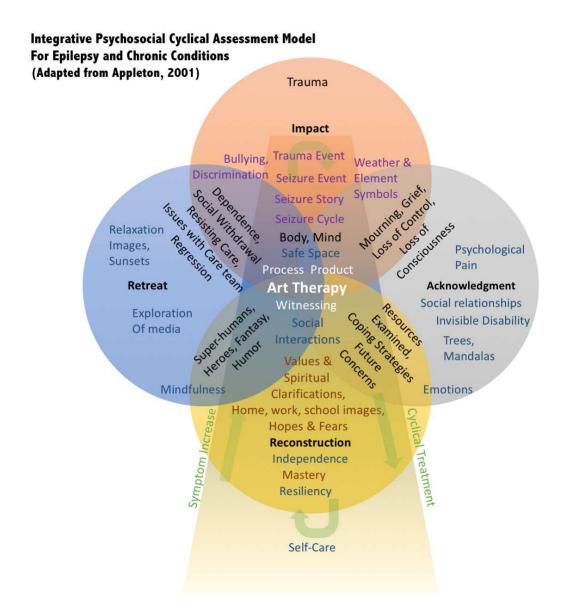
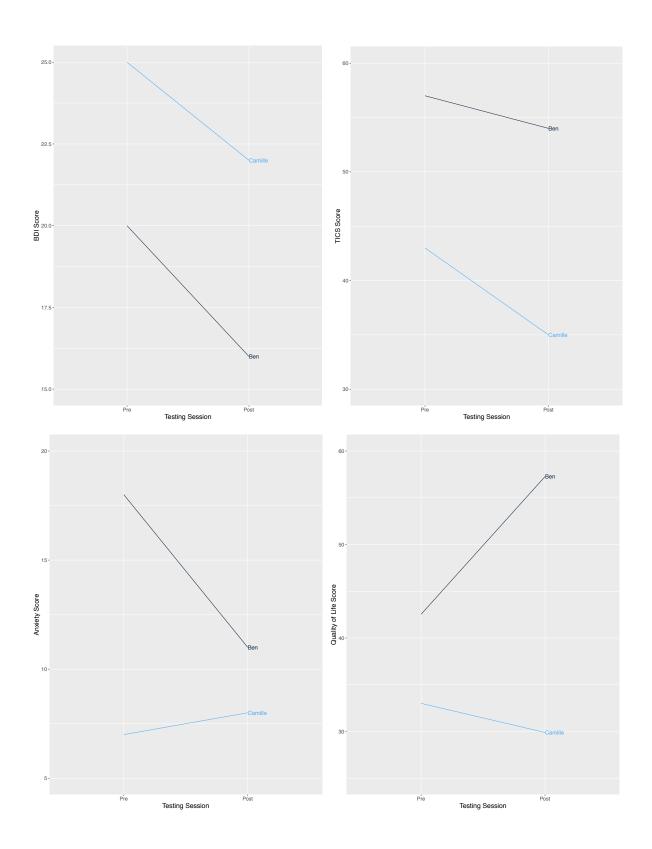
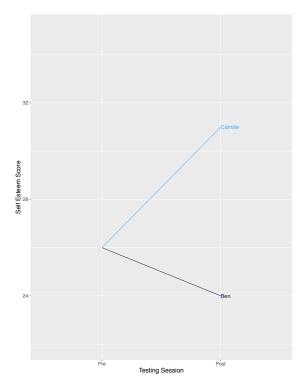


Figure 55. Integrative Psychosocial Cyclical Assessment Model for Epilepsy and Chronic Conditions- Adapted from Appleton (2001). Based on qualitative data from Figure 53 (Baker, 2002; Bruckland, 2015; Brown et al., 2018; Carr, 2014; Czamanski-Cohen & Weihs, 2016; Gregg, 2015; Havlena & Strofstrom, 2012; Jones, 2005; Keller, 2001; Lee, 1970; Macrodimitris et al., 2011; Michaelis et al., 2018; Moon, 2016; Morgan et al., 2012; Riley, 2001; Rubin, 2005; Saltzman et al., 2013; Schore & Schore, 2008; Tang et al., 2015; Timm-Bottos, 2006; Turner et al., 2011; Yalom, 2005).





*Figure 56.* Comparison of Ben (Later Onset, 3 years of epilepsy) to Camille (Childhood Onset, 28 years of epilepsy) on quantitative measures such as BDI, TICS, and GAD where lower scores represent less depression, less chronic stress, and less anxiety, respectively. Also pictured are comparisons on QOLIE-31 and RSES, where higher scores represent a higher quality of life and higher self-esteem.

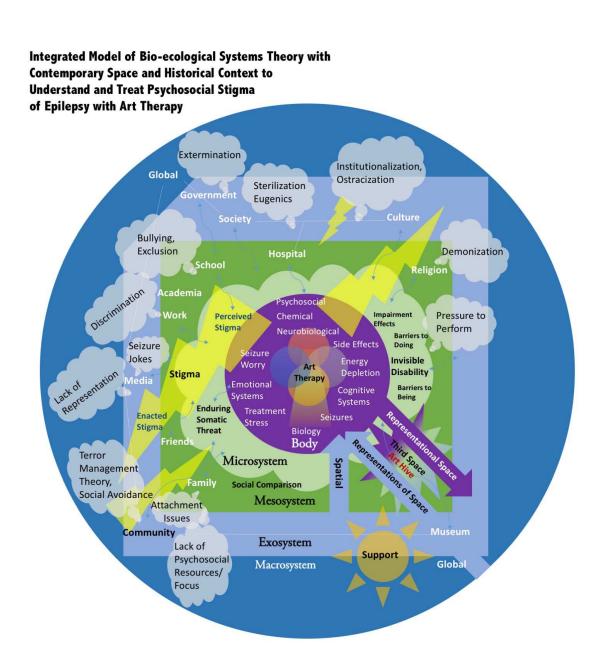


Figure 57. Integrated Model of Bio-ecological Systems Theory with Contemporary Space and Historical Context to Understand and Treat Psychosocial Stigma of Epilepsy with Art Therapy. Integrating historical and theoretical frameworks (Addison, 1992; Baker, 2002; Bhaba, 1994; Bion, 1967; Blos, 1962; Brofennbrenner, 2005; Chew et al., 2019; Edmondson, 2014; Elmborg, 2011; Festinger, 1954; Figley, 1986; Focault, 1980; Forsyth, 2010; Garland, 2002; Gattone,

2018; Ghaemian Oskouei, 2016; Goffman, 1963; Greenberg et al., 1997; Hermann & Whitman, 1992; Hermann & Jacoby, 2009; Hirschberger et al., 2007; Holocaust Memorial Day Trust, 2016; Iseri et al., 2006; Klausner, 2018; Lee, 1970; Lefebvre, 2014; Lortie & Vanasse, 2007; Mondanaro, 2008; Parker, 2018; Paquette & Ryan, 2011; Sampert, 2017; Salom, 2008; Salom, 2011; Sartorious, 2007; Sledjeski et al., 2008; Timm-Bottos, 2006)

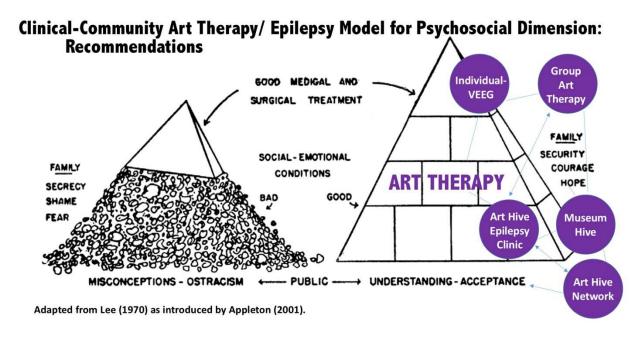


Figure 58. An Integrative Clinical and Community Treatment Model for the Psychosocial Dimension of Epilepsy (and other chronic conditions), based on Lee's (1970) model of psychosocial dimension of healthcare to transition from trauma (Brown et al., 2018; Elmborg, 2011; Salom, 2008; Timm-Bottos, 2006).