

Art In The Face Of Death: Art Therapy with a Family

Lindsay Joy Hamilton

Kutenai Art Therapy Institute, Nelson, BC

APPROVAL

Name: Lindsay Joy Hamilton

Degree: D.K.A.T.I.

Title of Thesis: Art in the Face of Death: Art Therapy with a Family

A THESIS SUBMITTED IN PARTIAL FULFILMENT
OF THE REQUIREMENTS
FOR THE
DIPLOMA KUTENAI ART THERAPY INSTITUTE.
D.K.A.T.I.

Approved by:

Monica Carpendale B.F.A., D.V.A.T.I., R.C.A.T., B.C.A.T.R.
Executive Director of the Kutenai Art Therapy Institute

Nicole LeBihan B.A., D.K.A.T.I., R.C.A.T.
Thesis Advisor

Date Approved

ABSTRACT

This thesis explores the nature of practicing art therapy with a family facing the terminal illness of one of the members; and seeks to discover where in lies the meaning and value of making and sharing art during intense moments of losing a loved one. The thesis will offer a literature review of terminal illness, the impact on child development, specific approaches to families in crisis and relative bereavement theory for the clinical and research approaches employed. The family will be introduced followed by five art therapy session descriptions accompanied by client artwork. As a form of data collection, analysis, and as a method to enhance meaning a/r/tography was utilized in the form of a retrospective case study art exhibition. Art works and poetry written in response to the practicum experience have been included as part of the data. The a/r/tography inquiry was validated by the response art of colleagues which is part of the data collection. Through applying a wholistic approach to thematic analysis of all the data collected, three themes emerge; the universal and existential experience of death and dying; the impulse to be in relationship with another; and art as an indestructible container for suffering.

ACKNOWLEDGEMENTS

I would like to acknowledge Grandpa and Grandma Mills, Grandpa and Grandma Hamilton, Doug Reedhead, Auntie Lorna, Katy VanDrunen and Cristin Mills; your lives have brought such love and meaning into my life. Without you I would not have been called to this profession. I miss each of you every day.

I would also like to thank Monica Carpendale, Nicole LeBihan, Juanita Kiff and Millie Cumming for the rich mentorship and guidance throughout my time as a student at the Kutenai Art Therapy Institute. Thank you for guiding me to my vocation.

I would like to thank my parents and family members for their unwavering support and belief in my abilities while I pursued my dreams. I cannot forget my partner Joe Galbraith for tolerating all the highs and lows during this process, for enduring the long distance while I was studying and accompanying me while following my heart. The love I feel for all of you is intangible and deep, and I would not survive without it. Thank you.

And most importantly I would like to thank the participating family for opening their hearts and lives to me; you have been my greatest teachers. It was an honour I will never forget. Thank you.

CONTENTS

APPROVAL	2
ABSTRACT.....	3
ACKNOWLEDGEMENTS	4
IMAGE INDEX	8
THAT WHICH HAS CLAIMED ME	9
CHAPTER ONE: Navigating by the Literature Lodestar.....	13
Terminal Illness and the Individual.....	13
Terminal Illness and the Family.....	14
Terminal Illness and the Support Person.....	14
Parental Terminal Illness and the Child	15
Grief in Middle Childhood.....	17
Grief in Late Childhood	18
Shock-aftershock Model	19
Cascade of Events Model.....	19
Bereavement: Grief and Mourning	19
Bereavement: Anticipatory Grief	20
Companioning: Accompany, Comfort and to be Familiar	21
Art Therapy as Companioning	23
Art Therapy Approach: Person-centred	23
Art Therapy Approach; Existential	24
Doing With	26
Being Open	26
Honouring Pain.....	27
Art Therapy Approach: Family Systems and Crisis.....	27
The Art Process as Crisis Intervention	29
The Role of Art	30
Chapter Summary.....	31
CHAPTER TWO: In-between the Seeds and Seas.....	32
Researching the Lived Experience	33
Phenomenology.....	33
Getting to the Underbelly: Reflective Phenomenological Writing	34
Wholistic Approach to Thematic Analysis	35
Interpretation of the Lived Experience.....	36

Poetic Inquiry	37
Vox Theoria.....	37
Vox Autobiographia/autoethnographia	38
Vox Participare	38
A/r/tography	38
Artist/Researcher/Therapist.....	40
Response Art, Art Therapy and A/r/tography	40
Site Specific Installation.....	40
In-Between Methodologies through Arts-based Research.....	41
Canonical Generalizations.....	42
Chapter Summary.....	42
CHAPTER THREE: Topography of the Intuitive Process.....	43
Data Collection.....	43
The Process of A/r/tography	44
Art Installation and Exhibition: A Case Study Presentation	45
Finding and Losing the Research Through A/r/tography.....	46
Limitations	47
How It Came To Be	48
The Setting	49
Therapeutic Approach.....	49
The Family's Art Work	50
Chapter Summary.....	50
CHAPTER FOUR: The Lived Experience of Art Therapy with the Family.....	52
The Family	52
Treatment Goals	54
Session #1.....	55
Session #2.....	58
Adapting to the Family's Need for Safety.	61
Reality Sets In	62
Phone Intake with Paul.....	62
Session #3.....	64
Session #4.....	67
Session #5.....	69
Visiting the Hospital.....	71

CHAPTER FIVE: Distillations from the A/r/tography Case Study Exhibition	73
Artist Statement.....	73
Ethan’s Plane (Figure 14).....	74
A Journal for Simone (Figure 12)	75
Paul’s Clothes (Figure 13).....	77
The Installation as a Whole.....	80
The Exhibition.....	82
Validation	83
Response Art of Colleagues	84
Colleague response #1	84
Colleague response #2	85
Colleague response #3	86
Colleague response #4	87
Colleague response #5	88
Supervisor response	89
Chapter Summary.....	92
CHAPTER SIX: The View from a Hot Air Balloon	93
Relating Through Art Therapy; Within the Family	93
Relating Through Art Therapy; With the Art Therapist	95
Doing With.....	97
Countertransference	97
In-between Companionship and A/r/tography.....	99
Ripples of Relationship- Arts-based Research Value	99
Art as Indestructible Container	100
Universal Experience of Death	102
Chapter Summary.....	103
CONCLUSION.....	104
EPILOGUE.....	106
REFERENCES	108
BIBLIOGRAPHY.....	112
APPENDIX ONE.....	115
LJ’s HOTEL by Monica Carpendale	115

IMAGE INDEX

1. Figure 1 Art Process with Families in Crisis (Linesch, 1993).....	29
2. Figure 2 Paul’s plasticine impressions.....	56
3. Figure 3 Ethan’s “Hot air balloon”.....	56
4. Figure 4 Simone’s “Storm”.....	58
5. Figure 5 Ethan and Paul’s “Hearth”.....	59
6. Figure 6 Simone’s “Flower”.....	60
7. Figure 7 Paul’s pastel drawing.....	61
8. Figure 8 Ethan’s charcoal drawing.....	65
9. Figure 9 Paul’s wreath.....	68
10. Figure 10 Ethan’s “Diamond back cobra”.....	68
11. Figure 11 Ethan’s “Boat passing an island”.....	70
12. Figure 12 Simone’s Journal.....	81
13. Figure 13 Paul’s T-shirt with Ethan’s Plane shadow.....	81
14. Figure 14 Ethan’s Plane.....	81
15. Figure 15 Rear side of the installation.....	81
16. Figure 16 Front side of installation.....	81
17. Figure 17 Colleague Response #4.....	87
18. Figure 18 Colleague Response #5.....	88
19. Figure 19 Reconstructed “Hearth”.....	107

THAT WHICH HAS CLAIMED ME

My present work has been a sense of emotional responses to past experiences, especially childhood trauma of sickness and near death experiences.

Due to my early exposure to death, it informs my work like no other trope. My artistic actions are all emotional responses to the fear, anxiety, comforts and pleasures that death holds in my life (Hamilton 2008).

This quote is taken from my undergraduate praxis paper written in 2008. It became the essence of my artist statement as a professional artist in the following years. During my time as professional artist, I taught art workshops and frequently produced commissioned works of art. Despite having the skill and knowledge to produce art in order to make a living, something was elementally inapt with my drive to do so. I felt emotionally distraught when producing “art for sale”. I felt inauthentic and did not want my artistic process to be influenced by the intention of making money. I innately felt art has an important role to play in my life, beyond a means to create income. I was trained as a conceptual artist and I believe my training in the field of contemporary conceptual art added to my confusion after graduating from art school. Conceptual art (aka idea art, or post-object art) is characterized by the essence of art as an idea or concept that may exist distinctly or in absence of an object as representation. Conceptual artists work within and interrogate the potential of art-as-idea or art-as-knowledge and are often process oriented, revealing the dimensions of thought and aesthetics, and the unseen aspects of the institution and systemic structures of art making and displaying (Guggenheim Foundation 2014). Conceptual art is rarely object based therefore little to no object is available for commercial consumption by an audience. The means of generating an income from conceptual art is based on grant writing and funding and rarely commercially viable. These opportunities to create conceptually based art as a means of making a living at this time of my career proved challenging. Yet, conceptually based

processes are how I feel I most authentically express myself. I was frustrated and confused as to how to be a professional artist outside of academia.

What was this emotional reaction to creating conceptual art and selling commercial art? What other options did I have? I turn to depth psychologist and researcher Robert Romanyshyn's (2013) description of re-search as a vocation to explore these questions. Romanyshyn (2013) places the researcher in the context of the complex greater world; the researcher is born into the world of prior theory, history, cultures and ancestors. It is the "unfinished business of the ancestors" (p.62) that calls an individual to the work. He states in the "Orphic moments of re-search with soul in mind" (2013, p. 62) the calling is a "claim" being made by the research. One is called into the research by something other than one's intentions as unfinished business of the soul of the work. Further in my research journey I found the method of inquiry that is known as a/r/tography had also laid claim to me. With Romanyshyn's idea of "claiming" in mind, I can see that conceptual art, art therapy, a/r/tography, death, grief and loss have called me to research. Reflecting upon my professional life as an artist, I understand I may have been guided or claimed (Romanyshyn, 2013) by something beyond a commercial artist's career.

I followed my emotional intelligence into the discipline of art therapy and in art therapy I found that art is being harnessed for its capacity as a tool as well as an effective entity for healing and transformation. Upon reflecting on what claims me as a researcher is an interest in death and art. In my praxis paper from art school, I reflected upon death being an unconscious companion of mine, and a common theme throughout all my artwork before entering art therapy research. In my own personal art process, I have been exploring my grief, memories and thoughts around death and dying. To me, it seems a natural progression towards working with those living in the face of death and supporting their creative expression through the challenging and inevitable experience of death. It is now my focus to explore the relationship in-between art, death and therapy.

As I draw closer to graduating from the Kutenai Art Therapy Institute and entering the world as a fledgling art therapist, I feel a sense of reassuring stability and support that I followed what claimed me. I was searching for my purpose and I believe I have found it. Through engaging in art therapy with a family living with terminal illness, I am instilled with a deeper sense of purpose and meaning. The research presented is an exploration of vocation; where career meets life and how it can impact the people and families for whom I serve. This thesis expands upon the nature of practicing art therapy with a family facing the terminal illness of one of its members and seeks to discover where in lies the meaning and value to making and sharing art during intense moments of grief and loss. The participants of the research consist of a family; a mother, a son and a father who was living with brain cancer and subsequently died after the collection of the data for the thesis.

The first chapter of the thesis is an overview of literature regarding the impacts of terminal illness on family development, grief and anticipatory grief, as well as describing the theoretical approaches of person-centred and existential art therapy. ‘Companioning’ (Wolfelt, 2006), family crisis in art therapy and the role of art will also be discussed. This chapter acts as a guiding star which shines throughout the other chapters. The second chapter will discuss the particular qualitative research methodologies of the thesis focusing on the arts-based research practice of a/r/tography, poetic inquiry, and various phenomenological methods which enhance and interpret meaning. The third chapter will cover the research protocol of the thesis. We will meet the family and will be given the opportunity to contextualize that which brings them into art therapy. The fourth chapter presents phenomenological descriptions of the five sessions with the family with images of their artwork. The fifth chapter is the presentation and analysis of the a/r/tography case study exhibition which is based on the art therapy with the family. Poems and images from the exhibition as well as the artwork of my colleagues are part of this chapter. The sixth chapter will endeavour to synthesize through a wholistic approach (van Manen, 1990) to analyze the lived experience of the art therapy, the family’s artwork, the a/r/tography and my colleague’s response art in three essential themes that were revealed through the research. Through the

thematic analysis I will explore the value and meaning of making art as a family during a time of living with terminal illness. Art work, poetry and prose are peppered throughout the thesis as a way to enhance the meaning of each chapter. I have included an epilogue which briefly shares what occurred during the art therapy which continued with the mother and son of the family after the father's death.

CHAPTER ONE: Navigating by the Literature Lodestar

Those who are in love with practice without knowledge are like the sailor who gets into a ship without rudder and compass and who never can be certain whether he is going. Practice must always be founded on sound theory, and to this perspective is the guide and the gateway.

Leonardo Da Vinci

The theoretical frameworks discussed in this chapter provide grounding and guidance in order to navigate and understand the experience of art therapy with a family living with terminal illness.

Utilizing contemporary theories generated by the many academics, therapists and theorists cited in this chapter has been like looking to the North Star when traveling at night; many other things swirled around, disappeared into the darkness, or changed position, but the pole star of these particular theories stayed a fixed point for the direction and understanding of my clinical practice and research. When I strayed or was lost, researching relevant theory helped me find my course off a wayward path.

Terminal Illness and the Individual

Adjustment to the loss of a family member involves inter and intrapersonal processing within an individual and family. Cognitive reappraisals of the relationships within the family system is important in order to create new meaning and enduring memories (Worden, 1991; Stroebe & Schut, 1995; as cited in Kissane & Bloch, 2002). The interpersonal sharing of feelings, memories and inner experiences contribute to the adjustment process of the individual and family (Walter, 1996; as cited in Kissane & Bloch, 2002). Terminal illness is a diagnosis given to an individual who has an incurable condition caused by an injury or illness. According to the Canadian Hospice Palliative Care Association (2015) even with life support, the conditions of terminal illness will lead to death in a certain amount of time. Along with the diagnosis dramatic unwanted changes for the individual and the family may occur; physical manifestations of the disease, changes in roles and relationships, and loss of opportunity and income. The changes may threaten the individual and family's capacity for meaningful experience and

to future quality of life. Furthermore, it may be the first time the individual and family have acknowledge mortality (CHPCA, 2013).

Terminal Illness and the Family

With medical advances the human lifespan has been extended often creating prolonged experiences of living with chronic or terminal illnesses. Many families and individuals will turn to hospice and palliative care in order to address and cope with these issues. There are specific issues for those living in the face of terminal illness; to adapt to life with the illness, to find opportunities for growth, and to find meaning in living and dying (CHPCA, 2013). The approach of hospice and palliative care can apply throughout the course of an illness to aid in relief of suffering, improve quality of life, engage with families and individuals in care, potentially prolong life and strive for a comfortable death (CHPCA, 2013). Hospice arts practitioners Filipa Pereira-Stubbs and Chris Rawlance (2008) say that a terminal diagnosis dramatically disrupts the familiar order of life and impacts the identity and roles within the family; the relationship dynamic shifts as spouses or children become caregivers and the individual loses independence.

Where there was once a semblance of order there is now disorder, fragmentation, a lack of sense and meaning...there is a deepening loss of control, a progressive-and depressive-isolation from the network of relationships that once defined you (Pereira-Stubbs and Rawlance, 2008, p. 34).

A terminal illness can threaten an individual and family's sense of security and may undo years spent creating that stability.

Terminal Illness and the Support Person

As the family shifts their respective roles into that of caregiver's they may experience high levels of stress resulting in poor physical and emotional health. As the demand of care accelerates, career sacrifices, monetary losses, and workplace discrimination may occur. Particularly with brain tumor

patients, caregivers face special challenges posed by the neurocognitive and neurobehavioral effects of the illness. The diagnosis of terminal brain cancer is often accompanied by the presence of sudden symptom onset such as seizures, significant change in cognition, progressive limitations in physical functioning and a decline in the quality of life which pose specific coping skills of the caregiver (Schubart, Kinzie and Farace 2007). Transpersonal psychologist and author of *Grace and Grit*, Ken Wilber (1991) describes the most challenging aspect of being a support person is the “inner turmoil that starts to build on emotional and psychological levels...no matter how many problems you personally have, they all pale in comparison to the loved one who has cancer” (p. 357). Wilber recalls not expressing his emotional responses to his wife’s terminal breast cancer which resulted in his emotions intensifying. Attempting to repress his emotional state did not make his psychological turmoil disappear. Experiencing inner turmoil in such a way is normal and natural given the circumstances and the best way to cope with the emotional upheaval is to communicate with a trusted someone. Wilber (1988, 1991) then poses the question of ‘to whom is it safe to express these feelings?’ He advises that it is not the person with cancer but trusted friends, family, and professional supports that are capable of holding the diverse spectrum of emotions that may be experienced by a support person. The care-giver requires non-judgemental support and should be able to express their feelings without someone else’s personal perspectives or discomfort with the possibility of witnessing intense emotions. A caregiver requires ongoing compassionate support without any expectations of “fixing” the “problem” as the loved one and the caregiver will still be living with the terminal illness. Providing an emotional support for a caregiver to express resentment, guilt, and other painfully dark feelings may allow for the caregiver to provide the steady support needed by his or her loved one.

Parental Terminal Illness and the Child

The psychological effects of parental cancer in childhood rarely have been analyzed and many of the studies display conflicting results (Kornreich, Mannhiem & Axelrod, 2008). The effects on children

vary depending on age, sex of the child, sex of the ill parent, the family setting and any other complications related to the illness. Pre-existing developmental issues and other personality variables will also impact how a child copes with a parent's illness (Kornreich, Mannhiem & Axelrod, 2008). Witnessing the declining health of a parent may be difficult, drawn out and emotionally painful. A terminally ill parent impacts a child's life by altering a family's routine and parent-child interactions with additional responsibilities may be expected of the child.

Social worker Davida Kornreich, social service manager Harriet Mannhiem and psychiatrist Deborah Axelrod (2008) collaborated on a study on how children live with parental Cancer. They refer to Freud's (1962) latency period as the time between five years and puberty when infantile sexuality is repressed. Libidinal urges are sublimated in rapid formal learning through the process of education. Children in latency period think in terms which express an ability to concretely verbalize feelings, thoughts, and experiences with partial understanding of symbolic and abstract concepts. At this age they may or may not be able to grasp concepts about cancer, dying, and death and may have irrational feelings of responsibility for the disease or fear that it may be contagious (Kornreich, Mannhiem & Axelrod, 2008).

Another aspect of a child's development to consider is that a child's ability to verbally express emotional language and understanding is through physical play and unconscious behaviours. It is important to keep the child's cognitive abilities in mind when communicating about illness with them; irrational fears can lead to anxiety that can impact a child's emotions and behaviours (Kornreich, Mannhiem & Axelrod, 2008). Speaking concretely about the illness and death without the use of metaphor will be the most relatable for the child.

Often latency age children will cope with a parent's illness by oscillating emotionally and physically "in and out" (Kornreich, Mannhiem & Axelrod, 2008) of the stress. Children will intuitively divide his or her life into zones; illness zone and illness free zone. This approach provides refuge from the disease in order to create equilibrium in the child's life. It will be important to provide "free zones"

and attend to routine as much as possible for the child which will only be disrupted by dramatic changes in the health of the parent (Kornreich, Mannhiem & Axelrod, 2008).

According to pioneer child developmental psychologist and psychiatrist John Bowlby (as cited in Hooyman & Kramer, 2006) attachment is the protective biological mechanism which ensures survival through an individual species' need for safety and security. Attachment to a primary caregiver is an essential part of the child's individual and personal capacity and a loss of that attachment may impact the child's well-being (Hooyman & Kramer, 2006). A child invests almost all of his or her feelings into the caregivers and in childhood death limits the opportunity to experience love and to be loved by a primary care giver (Pratt, 1998). The child experiences loss as a form of separation anxiety and the intensity of the grief response appears to parallel with the strength of the attachment bond. Generally, a child has less supportive relationships to draw from compared to an adult (Pratt, 1998). The surviving caregiver to whom the child would naturally seek consolation may be immersed into his or her own grief. This may leave the child isolated from the surviving caregiver which may further damage the attachment to and hinder the child's development (Pratt, 1998).

Grief in Middle Childhood

Sociologists Nancy R. Hooyman and Betty J. Kramer (2006) describe, in their book *Living Through Loss: Interventions Across the Lifespan*, grief in middle childhood (ages six to nine) as a difficult time; the child may hold "magical thinking, irrational and non-reversible thought processes" (p.96) and be aware of irreversibility, non-functionality and universality (Backer, Hannon & Russel, 1994; as cited in Hooyman and Kramer, 2006). If the child witnessed the prolonged illness of a parent the presence of anger, sadness and rejection may be experienced. Death is often seen as something tangible or physical such as a spirit or ghost. This personalization and emotionality of external events may result in aggression towards God or the surviving parent and behavioural issues may be present due to an inability to manage sadness and fear appropriately (Hooyman and Kramer, 2006).

Grief in Late Childhood

Children in late childhood (age nine to eleven) often develop a better ability to describe feelings and verbalize needs. They tend to draw upon social supports and are likely to initiate meaning making of the loss (Aldwin, 1994; as cited in Hooyman and Kramer, 2006). In late childhood, a child better understands and integrates information without feeling overwhelmed and confused. They may openly communicate with others about the illness and death of their parent. Academic problems, hypochondria, identifying with the deceased, and extreme fear of the death of the surviving parent may occur. Grief may manifest in physical behaviours such as anger, disorganization, and boundary testing. Being overly critical and demanding may lead to a rise in conflicts with others (Hooyman & Kramer, 2006). The grieving process in late childhood leans toward balancing the control over emotions and reminiscing. Older children may be overwhelmed by their grief which makes for a low tolerance for the intensity of the emotions (Christ, 2000). They may not want to talk about the illness or the death of a parent and as a result they compartmentalized feelings or refuse to express or experience their sadness through intellectualization (Christ, 2000). They may escape into after school activities and other resources outside of the illness (Christ, 2000). Children in late childhood have advanced cognitive abilities and are capable of experiencing anticipatory mourning during the parent's terminal illness and may experience concerns about the surviving parent's health (Christ, 2000). Access to a continuous flow of detailed information can provide the older child with a sense of mastery and can also contribute to the avoidance of emotional expression except on infrequent occasions (Christ, 2000). It is important to honour the intellectual, non-emotional grieving of a child this age. These children can productively use opportunities to assist the ill parent and the family as long as the tasks are conducive to the child's development (Christ, 2000). Creating opportunities for remembering the parent who died helped give expression to feelings an older child often found too frightening to discuss (Christ, 2000). Rituals, traditions, observing anniversaries, and staying connected through special items such as photographs,

clothing, and art can enable a child to reframe and revise their experience and stay connect with the deceased throughout their lifespan (Hooyman & Kramer, 2006).

Shock-aftershock Model

The *shock-aftershock wave model* (Bifulco, et al., 1987; Brown et al., 1986; Harris, et al., 1986; Harris, et al., 1987 as cited in Christ, 2000) is based on a study linking the loss of a primary caregiver in childhood to depression in adulthood. Communicating openly about death, and having the opportunity to experience compassionate, empathetic responses from the surviving caregiver are shown to be preventative measures regarding the vulnerability to depression later in a child's development. Continued bereavement care for the developing child may be necessary as he or she may re-experience grief related to the loss throughout the successive developmental stages (Saler and Skolnick 1992 as cited in Christ, 2000).

Cascade of Events Model

The *cascade of events model* (Clark et al., 1994; Garmezy, 1983; Krupnick, 1984 as cited in Christ, 2000) focuses on the long term developmental effects of the death of a primary caregiver and how they carry forward (Rutter, 1994; as cited in Christ. 2000) when the child experiences stress and adversity later in life. The experience of the death of a parent is internalized by the child and "cascades" (Clark et al., 1994; Garmezy, 1983; Krupnick, 1984 as cited in Christ 2000) into the later stages of development. The experience may provoke the specific meaning of the parent's death, a variety of life stressors, and the possible vulnerability/ resilience of the individual throughout lifespan. In other words the loss of the parent changes the course of the child's life not only immediately but through his or her lifetime.

Bereavement: Grief and Mourning

Grief is described by the physical, psychological and social reactions to a loss of something or someone important. Physiological changes may manifest as a loss of appetite, mental confusion, and

sleep disturbances. Emotional responses of sorrow, distress, and guilt are likely to be experienced. Social and interpersonal relationships may also be disrupted. We all will experience grief at some point in our lives and the grief is as unique as each individual on this planet (Hooyman & Kramer, 2006). According to internationally acclaimed grief Counsellor Dr. Alan Wolfelt (2003) grief is the internal thoughts and feeling experienced during a loss. There are noted constellations of feelings associated with grief such as fear, numbness, shock, dread, anxiety, guilt, anger, rage and intense sadness (Hooyman & Kramer, 2006). The experience of grief in the face of loss is a normal reaction and is not pathological nor maladaptive. Grief is a part of loving and relates to surviving a loss. It can reveal various ways of living more fully and creatively (Hooyman & Kramer, 2006) and may be an opportunity to enter into the deepest part of the self in order to redefine what the loss means.

Wolfelt (2006) describes mourning as grief externalized or “grief gone public” (p. 22). Talking about the loss, crying, expressing thoughts and feelings through art, music or poetry, as well as observing anniversaries and cultural practices are a few ways of mourning. Through expressing grief openly and honestly, overtime and with support, one may use mourning as a way to heal and create new meaning after a loss (Wolfelt, 2006).

Bereavement: Anticipatory Grief

Having feelings of fear towards facing death and dying is a common part of the human experience. Denial of death may be attributed to cultural practices, worldviews and beliefs, and the painful suffering that coincides with death anxiety. One significant factor in facing terminal illness is the experience of anticipatory grief (MacIntyre & Raymer, 1989) either by those who find themselves with terminal illness or those who are caring for a loved one with terminal illness. Both are confronted by death and the process of dying. The emotional and spiritual distress experienced in the face of a loved one dying is not pathological nor is it maladaptive (Yoder, 2005); it is a natural reaction to the experience each individual family member is enduring and is as unique as each individual. Coming to

terms with an eminent loss of a loved one is a personal matter in which the bereaved endures an extremely individualized experience (Raphael, 1984; as cited in Kissane & Bloch, 2002). Some family members may voice concerns regarding the eminent death, others may avoid discussing the death in order to focus on living (Kissane & Bloch, 2002). Grief is often thought of as being experienced after the death of a loved one and in the case of anticipatory grief (Lindemann, 1944), the death has not occurred, but similar grief responses may be experienced. These may take form in anxiety, sadness, anger, social isolation, forgetfulness, depression, physical exhaustion, depletion of financial resources and many other grief-like symptoms (William, 2013). Experiencing anticipatory grief can take its emotional and physical toll on support givers and a wish for a release may exist. Of course, the only way to be released from the distress would be if the loved one dies. This may result in feelings of guilt and a sense of selfishness from the want to be relieved of the distress but not wishing for the death of the loved one (Williams, 2013). Excessive anticipatory grief may unsettle end of life satisfaction and decrease acceptance of a pending loss (Yalom, 1980; as cited in Kissan and Bloch, 2002).

There are many contradictory studies on anticipatory grief and the impact it may incur on negative post-death bereavement and adaptation (Reynolds & Botha, 2006). There is not a concrete definition or measurement of anticipatory grief. It may be defined by the length of the terminally ill condition; a sudden unexpected death; a short term chronic illness death (less than 6 months); or long term chronic illness death (more than 6 months) (Reynolds & Botha, 2006). A medical diagnosis of “terminal” is no indication that the individual or the survivors will accept or anticipate the death, or if grieving is experienced prior to the death.

Companioning: Accompany, Comfort and to be Familiar

Wolfelt (2006) created the “companioning” approach to grief therapy. He realized that grief is an aspect of life that cannot be handled with rational thought and that it responds best with “humbled souls” (Wolfelt, 2006). Companioning does away with the idea of “treating” grief, as it is a fact of life and not

a pathological illness from which one can “recover”. He acknowledges that a person’s life is forever changed through significant loss and the expectation for someone to return to “normal” after a loss is inappropriate and impossible. Wolfelt (2006) advocates for compassionate, mourner-led bereavement care with the soul and spirit of the individual in mind. Companioning is not about analyzing, fixing or resolving another’s grief but more so about being totally present to another and inviting the mourner to “teach” the companion about his or her individual grief experience. Wolfelt (2006) draws upon Henri Nouwen’s (1986) idea of providing hospitality to the bereaved; “hospitality is not about trying to change people, but offering them a space where change can take place” (Nouwen, 1986; as cited in Wolfelt, 2006, p. 18). At the centre of Wolfelt’s companioning (2006) is the desire to acknowledge each other, “therapist” and “client”, as equals in knowing the pain and suffering of loss of a loved one. No one has claim to understand another’s grief better than the grieving individual and acknowledging each other as equals is a reflection of love (Wolfelt, 2006) Compassionate curiosity, humility, an open heart and a willingness to “wander the wilderness into mystery” (Wolfelt, 2006) are important aspects of companioning the bereaved and often integration of the loss happens in an unknown space. Companioning is not a theory or a technique, but a philosophy of being with another with a heart open (Wolfelt, 2006). Below are the tenets in which a companion follows:

Wolfelt’s Tenets of Companioning the Bereaved (2006)

1. To be present to another’s pain.
2. To go into the wilderness of the soul with another and not be responsible for finding the way out.
3. To honour the spirit and not intellectualize the grief.
4. To listen with the heart and not analyze with the head.
5. To bear witness to the struggle and not direct or judge.
6. To walk along side and not to lead or to be led.
7. To hold sacred silence and not fill the space with talk.

8. To be still; it is not about moving forward.
9. To respect disorder and confusion.
10. To learn from others; it is not about teaching. They are the experts of their own grief.
11. To be curious; it is not about being an expert.

Art Therapy as Companionship

Wolfelt (2006) describes that in order to care for people in grief a safe and sacred space must be provided in order for those to gently turn into their feelings of loss. It is the responsibility of the companion to prepare and hold a physical and symbolic safe and sacred space. The art therapist as companion has the safety and sanctity of the studio to consider as well as the safety and sacred aspects of the client's creative journey.

An art therapist as companion adds another layer to honouring and bearing witness to the client's suffering through tending to the artwork and creative process. If grief is not something one can approach with rational thought (Wolfelt, 2006) than the intuitive and evocative nature of art making must lend itself as an alternative. Taking all of Wolfelt's (2006) tenets and extending them to how an art therapist conducts his or herself with the client and artwork seems like an appropriate fit.

Art Therapy Approach: Person-centred

One of the founding fathers of the humanistic approach in psychology is Carl Rogers. His work forms the basic conditions at the core of person-centred therapy which are empathetic listening, acceptance, openness, honesty and being congruent (Rogers; as cited in Silverstone, 1997). Rogers' theories have been further developed by his daughter and art therapist Natalie Rogers (2001) into person-centred art therapy. This kind of art therapy is based on the notion that every person has worth, dignity, the capacity to self-direct and an inherent impulse towards growth. A person-centred art therapist believes in an individual's creative capacity despite the individual's artistic training and skill level. They hold a deep faith in the individual's innate ability to reach his or her full potential by

following the client's lead. Person-centred art therapy draws from the idea that an art therapist is a companion on the path of self-exploration and not an authority. The person-centred approach is reflected in the therapist's choice to use directive or non-directive approaches to facilitating sessions. In addition, the types of art materials offered and how the space is maintained are shaped by the person-centred approach. It is a collaboration between the client and the art therapist to create a therapeutic relationship that is uniquely suited to the needs and goals of the individual or family. Person-centred art therapist Liesl Silverstone (1997) states when an individual feels authentically heard and understood, he or she may hear herself truly and trust enough to explore further. She also states "when a client knows all of herself is accepted unconditionally [by another], she may in turn accept all of herself and move on to discover what she may become" (Silverstone, 1997, p. 3). Furthermore Silverstone says if the client experiences the therapist as genuine, the client is more inclined to trust herself to be genuine and will potentially foster growth.

A person-centred approach to art therapy requires the art therapist to be empathic accepting, open, and congruent not only with the individual but with the creative process and artwork as well. A person-centred art therapist refrains from interpretation of the art and facilitates the individual to seek his or her own meaning.

Art Therapy Approach; Existential

Existential art therapy can be defined as a dynamic therapeutic approach which uses artistic processes and imagery to highlight or reveal the ultimate concerns of human existence (Moon, 1990; 1995; 2009). There are four universal concerns of existence which are death, freedom, isolation and meaninglessness. Existential art therapist Bruce Moon (1990; 1995; 2009) argues that all art is existential and the art process coalesces with the essence of human experience. When confronted by emotional distress, traumatic physical injury or illness one is often propelled into a sense of meaning loss and existential emptiness. The arts and the use of imagery can aid an individual in restoring a sense

of purpose and connection to the outside world (Moon, 1990; 1995; 2009). Existential art therapy is a model for understanding the healing role of art attuned to the basic human need for self-expression (Moon, 1990; 1995; 2009).

The art process in existential art therapy is believed to be “powerful medicine that evolves through stages of creation and contemplation” (Moon, 2009; p. xix). The central therapeutic instruments are the art materials, processes and end product. Existential art therapy does not focus on the importance of resolving conflicts or alleviating stress, which may occur. More importantly, existential art therapy offers an opportunity to regard the artwork and process with wonder, and to engage in creative dialogue and narrative and to “figuratively invite artworks to teach what they know” (Moon, 2009, p. xx). Existential art therapy emphasizes a “willingness to embrace multiple possibilities and meanings in life which can be discovered through art making even when meanings are unclear or perplexing” (Moon, 2009, p.xix). The existential art therapist holds an unwavering faith in the client and artwork in regards to what is needed to be expressed will be expressed.

An existential art therapist keeps three propositions in mind when working with clients; individuals long for and require meaning and purpose in his or her life; nothing is absolute; and an individual can only create meaning in the context of his or her relationships with others and the world (Moon, 1990; 1995; 2009). Meaning making is a complex process as it must come from the individual and cannot be imposed by others (ie. The art therapist). It is a self-transcendental phenomenon which upholds being in relationship, to others, to artwork, to the world, and is the manner in which purpose and meaning is realized (Moon 1990; 1995; 2009). An art therapist can facilitate an individual’s exploration through the three propositions; *doing with* (art making, role modeling etc); *being open* (to the artwork and client) and *honoring pain*.

Doing With

Moon (2009) describes an art therapist as “doing with” (p.87) by modeling authentic and focused engagement with art. The art therapist who makes art with and or alongside the client non-verbally communicates a shared artistic journey of self-exploration. Through material struggles and encounters, the art acts as a chart of the therapeutic collaboration. Moon elaborates by saying that engaging in art making as a therapist is a way of engaging a “ritual re-enactment” (p.88) of a personal journey. An art therapist’s willingness and enthusiasm towards the art influences the client which may afflict, affirm, challenge and assure the client that artistic self-exploration is a worthwhile endeavor (Moon, 1990; 1995; 2009).

Being Open

To be open as an existential art therapist requires the ability to work with and accept whatever it is a client expresses. A client’s artwork will often be painful, embarrassing or disturbing. They may share stories that are not easy to tell, nor are they easy to witness. An existential art therapist is open to all the hurt and pain a client shares for if the client is to heal they must be seen, felt, witnessed and heard. The capacity of the art therapist’s ability to be open and hold the expressions of their clients is directly related to the client’s capacity to creatively share their story (Moon, 1990; 1995; 2009).

Art therapist Catherine Hyland Moon (2002) describes that in order to develop an artistic perspective in art therapy, an art therapist must come to know the ordinary stories so that we may make meaning. She states that;

We often think it is only in the dramatic moment or the monumental event that is worthy of being told as a story. But really, it is the small and seemingly insignificant occurrences that build one upon the other to create life...to give honour to the ordinary, to see significance in the mundane (2002 p. 34).

An existential art therapist is open to the idea that everything potentially has meaning, even if at first it appears banal.

Moon (2009) correlates the phenomenon of openness with opaque, translucent and transparent relations with clients. An opaque therapeutic relationship is one where the therapist will withhold all aspects of his or her personal life from the client. Translucent therapeutic relationship is one where the art therapist is cautious about sharing personal information and is critical to ask him or herself if the disclosure will be helpful to the client. A transparent therapeutic relationship is viewed as a mutual exchange of self-discovery and occurs for both therapist and client. Each therapist will have his or her own boundary limitations and reasons for self-disclosure and may fall anywhere in-between the spectrum of opaque to transparent. Moon's (2009) personal approach is more on the side of transparency. He says "I believe that people discover meaning in their lives by being open to another. Meaning is not an exclusive process" (p.98). If the client does not feel valued or connected to the art therapist, they will not invest in the relationship and the opportunity for change or growth will not be made possible.

Honouring Pain

Moon (2009) states that it is important to bring a sense of honour to the pain of the client. In order to do so the therapist must honour his or her own pain. It is not about alleviating the pain, or making the client feel better. Its focus is on understanding and discovering the meaning of suffering. This gives the client the freedom to feel exactly as they do, without riding or hiding the intensity of the emotions. To honour another's pain is empowering as it shifts the role of victim to one who "embraces life as it is" (Moon, 2009; p.106).

Art Therapy Approach: Family Systems and Crisis

A family systems approach (Bowen, 1978; as cited in Kerr, 1988, 2000) visualizes the family as a homeostatic system; change in one family member in turn affects change in all the other members

(Wadeson, 2010). The threat of losing a family member can have immense impact on the family's system and structure. It may expose the flexibility and rigidity of the roles within the family system and will require reorganization to adapt to the changes in the family (Hoshino, 2008). Every family has their own unique implicit family structure that governs the emotional and physical ways of relating to one another. All behaviour, verbal and non-verbal, active and passive, is a form of communication. A family's communication functions in a recursive and circular manner and tends to respond to uncomfortable and unacceptable situations or behaviour by initiating interactions which re-establish the familiar ways of relating (dysfunctional or adaptive; Sobol & Williams, 2001). A crisis occurs when the habitual automatic responses fail to correct the uncomfortable situation or unacceptable behaviour (Sobol & Williams, 2001). An illness can threaten a family with separation and loss and directly impacts attachment and caregiving behaviours (Kissane & Bloch, 2002). Habitual ways of relating within the family system structure may be adaptive (secure), or dysfunctional (insecure) and different styles may appear during a threat of loss; detached (avoidant), clingy and anxiously overinvolved (distorted), or hostile and critical in nature (Kissane & Bloch, 2002). Insecure attachment styles are often unable to offer the individual and family a 'holding environment' (Kissane & Bloch, 2002) for the stress caused by the terminal illness. In therapy the patterns of attachment can be reinforced or revised in the course of working with a family facing terminal illness and can provide the family with a supportive environment to persevere through the challenge of terminal illness (Kissane & Bloch 2002). A therapist can draw awareness to ways the family may balance anticipating the death and the feelings of grief that may accompany living out the remaining life which may give the family a sense of empowerment through the experience. It will be important for a therapist to obtain the family's permission to talk about death and dying and to respect the cultural, spiritual and personal realms the family holds (Kissane & Block, 2002).

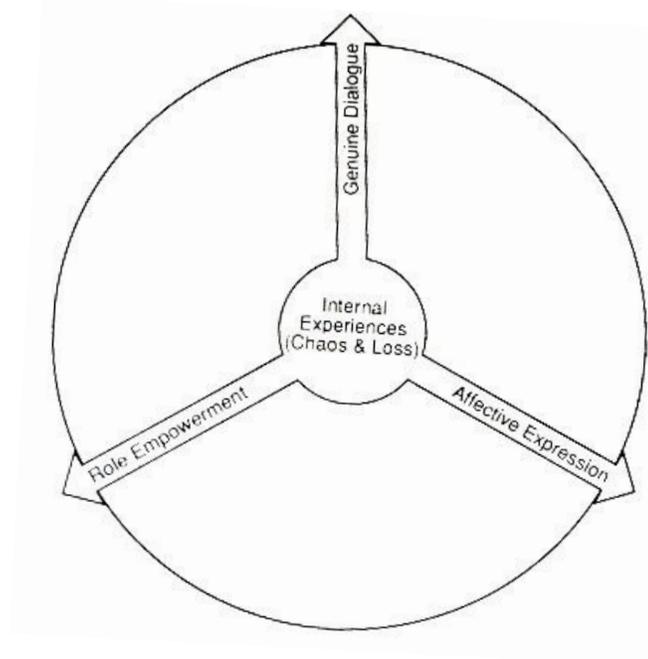


Figure 1 Art Process with Families in Crisis (Linesch 1993)

The Art Process as Crisis Intervention

This diagram, borrowed from art therapist Debra Linesch's book *Art Therapy with Families in Crisis: Overcoming Resistance Through Nonverbal Expression*, illustrates how the art process fundamentally assists the surfacing of internal experiences of chaos and loss that may be meaningful to the family in crisis. Affective expression regarding the crisis can be supported and released, genuine dialogue and communication can be strengthened and role empowerment can be achieved through art expression. Linesch (1993) offers insight into the art process with families in crisis and its role in intervention; as a cognitive procedure and an opportunity for problem solving; as ventilation of affect; and as a way of working within the family system. Attaining cognitive understanding of crisis dynamics is vital towards regaining psychic equilibrium. It may offer an opportunity for a family to objectively evaluate the meaning of the crisis through a subjective art experience and art making offers a forum to express multiple layers of meaning. Another aspect that is beneficial of art making for crisis intervention is that the art activity demands problem solving choices asking an individual to weigh alternatives, to

critique and assess and follow through with decisions. The end art product is durable and allows for an individual and family to review, respond and share what is being expressed.

The Role of Art

Art making has a powerful ability to heighten the individual's emotional experience and provides a space for the ventilation of affect. The art helps by-pass the defense mechanisms (Horowitz 1971 as cited in Linesch 1993) and can allow for safe psychic distance necessary to recognize the existence of particular feelings (Wadson 1980 as cited in Linesch 1993). With the safe distance and tangible display of affect through the art an individual can integrate the affect as part of themselves. Lastly, engagement with art material provides an opportunity for cathartic release, self-soothing, relaxation and enjoyment in times of stress.

Art therapy can be used to illuminate the family system structure and dynamics by observing the family collaborating or creating art either with or beside each other. The art making process can be used as a diagnostic, interactional, and rehearsal tool and the content of the art can portray unconscious and conscious communication. In the end the art product is lasting evidence of the family's experience (Landgarten, 1987; as cited in Linesch, 1993) which can be kept, or disposed of as the family deems appropriate. Most importantly art therapy provides a family with a unique safe space to be with each other, to be seen and supported through life's struggles together in order to strengthen the attachments and bonds and to create a meaningful experience out of the struggle.

In times of distress and survival art making may appear as a superfluous activity. After all painting a pretty picture does not cure nor remove the reality of dying. It is not a defense against suffering (Levine, 1992) nor a veil to cover up the horror. American poet, author and teacher Stephan Levine (1992) speaks to what the sufferer must do when facing great pain; find a way to contain the pain truthfully "just as it is" (p. 120). Therapeutic art has the important role of providing the opportunity to

display that truth as far as possible for the sufferer. Levine (1992) explains why art is a valuable form to support truth when expressing suffering and pain;

Nothing else is strong enough to contain the destruction of the self. Not art as entertainment, or art as high culture, or art as kitsch, but art as the form of infinite suffering.

The therapeutic value of art is inherent in its capacity to represent life as valuable by authentically

showing pain, suffering and the shadow side of the human existence ‘just as it is’ (1992, p. 120).

Art in times of suffering is an opportunity to be with another’s suffering without illusion, or desire to give hope. It is about asking another “what is there to live for?” and to witness and receive the images and words that come from this kind of questioning (Levine, 1992). Underneath the pain, suffering, confusion and distress is a will to live and a will to be with others (Levine 1992). It is this will that creates meaning and the meaning re-affirms life in the present. Art functions as a mirror and indestructible container for our suffering, like no other tool known to man.

Chapter Summary

This chapter expands upon an individual in a family participating in art therapy and the possible experiences and issues one may encounter through a variety of therapeutic theoretical frameworks regarding terminal illness, caregiving, developmental impact, existential crises, bereavement and relevant art therapy approaches. I wish for the contents of this chapter to shine as a theoretical guiding star for the following chapters to come. The next chapter will address the methods of inquiry utilized for the research of the thesis.

CHAPTER TWO: In-between the Seeds and Seas

In-between the Seeds and Seas

*A gardener's intentional space is in-between the seeds
It is unknown the exact manner in which the roots will venture or
if the plant will grow.*

*A gardener can hope through giving space, nurturing
observing and waiting for the fruit to ripen.*

*Like a gardener follows an almanac
the sailor seeks the direction of the wind
To plan the course of the roaming mind
stretch and focus the telescope
To find the horizon where the light breaks through.*

*In order for a sailor to secure the craft one must learn to tie knots
before unraveling them.*

*A sailor who creates poetry may use a taut line hitch
to tighten and expand a knot around meaning.
The knot slides and loosens with ease to accommodate shifts in understanding.*

*A double fisherman's knot attaches two ropes together;
A sailor ties an arts rope to a literary rope.
Poetry is a bind in-between disciplines.*

*The art process is much like sowing earth and hoisting sails.
It is not separate and somewhere in-between the seeds and seas.
Both a life cycle and a long journey.*

*In the borderlands critical and aesthetic currency is exchanged.
An economy of continuously becoming.
No moment at the market is the same.
The harbour's berth changes despite assigned moorage.
All relations to soil, sea and sky.*

*In-between birth and death is life.
Life is encounters, moments, exchanges, shifts and transitions.
Especially in ways of knowing.
To perceive differently is a living practice.
Every morning I tend a different garden plot found in the same spot.
Every time I board my boat, I find new ways to stay a-float.
It is an art and art is environment, experience, and relationship.
Art is becoming.*

This chapter discusses the research methods utilized in my inquiry into the value and meaning of art-making in the face of terminal illness in a family. The chapter will include aspects of qualitative research methods including phenomenological writing, hermeneutics and interpretation, and the wholistic approach (van Manen, 1990) to thematic analysis. As a way of generating and enhancing the data of the thesis, arts-based research practices such as poetic inquiry and a/r/tography are explored to reveal meaning. Somewhere in-between the inquiries the meaning and value of art making while living with terminal illness lies to be discovered.

Researching the Lived Experience

Qualitative research has a variety of definitions and approaches; it is research into understanding constructed meaning and how people make sense of their experiences of the world. It can be narrative and a descriptive account which includes the researcher-in-the-world as part of the data. Qualitative research embraces dynamic kinds of data collection, analysis techniques and offers a format that allows for diverse and eclectic theoretical frameworks for interpretation (Guest, Namey & Mitchell, 2013). While quantitative research focuses on cause-and-effect relationships and testing the premise of the research, qualitative research focuses on discovery or understanding a phenomenon (Kapitan, 2010). Qualitative inquiry is meant to maximize the interactions with the data that emerge. The research is allowed to change in order to accommodate new understanding as the previously unknown variables of information emerge (Kapitan, 2010). Qualitative research is appropriate as an approach for this thesis as it provides flexibility and adaptability with incoming data and allows me to put the needs of the participants first without compromising the research.

Phenomenology

Phenomenology has grown from philosophical inquiry into a qualitative and scientific research method that studies the essence of a phenomenon as it appears (Higgins, 1996). The research is focused on *describing*, not explaining or analyzing, the essence of a subject or object as it appears in the present

moment (Merleau-Ponty, 1945). This methodology emphasizes the immediate encounter, utilizing all the senses without any particular analytical framework with a phenomenon (the clients and the art work) prior to theorizing. Phenomenology provides systematic analysis of the awareness of a phenomenon which may include material objects, immaterial objects (music, math etc.) and human experiences of thoughts, emotions and memories (Higgins, 1996). Phenomenological reduction (Husserl; as cited in Merleau-Ponty, 1945) provides an opportunity to bracket out assumptions, biases, and prejudices that may obstruct an objective observation of the phenomenon. According to art therapist and researcher Lynn Kapitan (2010) phenomenology is well suited to art therapy research as art therapists understand the essence of a person's experience when represented in aesthetic or visual art form. Art can display the quality and meaning of an experience more fully than otherwise possible; "Artists are involved in giving shape to their lived experience, the products of art are, in a sense, lived experiences transformed into transcended configurations" (van Manen, 1990 p. 74).

Getting to the Underbelly: Reflective Phenomenological Writing

Art therapist and executive director of the Kutenai Art Therapy Institute Monica Carpendale (2003; 2009; 2011) has developed a reflective phenomenological method of writing as a process of discovering meaning called "Getting to the Underbelly" (p.110). This method is not about pre-conceiving a specific idea and writing down the insight, but tracking the roaming mind in order to free associate through writing about a phenomenon (an artwork, a feeling, an object etc.) without editing. Once the writing has come to a completion, the writer reviews the script and underlines key phrases, insights and other valuable prose. This is an intuitive process in which Carpendale describes as "looking for the horizon or gap where the light can get through" (2009, p.215). The underlined script is the essence of the phenomenological writing which then can be distilled into prose or poetry for further interpretations. The final aspect of the process is for the writing to be witnessed; having another read the poem, or reciting the poem out loud for others can potentially deepen the understanding of the essence

of the writing. Carpendale's (2009) method focuses is on discovering "what is" and allows meaning to emerge through an interpretive practice such as hermeneutics and allows for the writer to "unravel the knots" (p.217) to find the meaning.

Wholistic Approach to Thematic Analysis

Phenomenology professor and author Max van Manen (1990) has develop three approaches to thematically analyze phenomenon; 1) wholistic approach; 2) selective or highlighting approach; and 3) the detailed or line by line approach. Wholistic approach will be the focused way of thematically analyzing the data of the thesis. The other approaches are very intriguing and although much data and understanding would present itself if I were to take these approaches in this research, it would be too much for this thesis at this time.

Carpendale's highlighted horizons in a phenomenological writing can be expanded into a form of thematic analysis in what van Manen (1990) calls the "wholistic approach" (p. 92). This is a way to study the lived-experience by discerning themes that emerge. Certain experiential themes occur in-between data and it is the task of the researcher to hold on to these themes by expanding and distilling the meaning (van Manen, 1990). In the wholistic approach the researcher attends to the text/phenomenon as a whole to find the fundamental meaning or main significance.

In order to find the structure of meaning in a phenomenon, van Manen (1990) finds that uncovering themes embodied in the phenomenon helps to ground the research. The themes act as 'structures of experience' and when a researcher analyzes a phenomenon, they are determining the themes that make up the phenomenon of the lived experience. van Manen (1990) has thoroughly broken down to what a theme may be into four notions;

- Theme is the experience of focus, of meaning and of a point.
- Theme formulation is at best simplification.
- Themes are not objects one encounters. A theme is not a thing but is intransitive.

- Theme is the form of capturing the phenomenon one tries to understand.

Van Manen (1990) continues to elaborate about how themes appear. The nature of a theme comes from a need or desire to understand or make sense. A theme is the sense we are able to make from a phenomenon and it is an openness to something. Finding theme is a process of insight, discovery, invention and disclosure.

For research sake, themes relate to the notion of being studied as they are means to get to a notion. They give shape to the shapeless and describe the content of the notion. Finally, theme is always a reduction of a notion. Theme can never unlock all the true deep meaning in a phenomenon which acknowledges the mystery behind every phenomenon (van Manen, 1990). Van Manen's (1990) phenomenological thematic analysis is a systematic method to develop a certain narrative that "explicates themes while remaining true to the universal quality or essence of a certain type of experience" (p. 97).

Interpretation of the Lived Experience

One way to distill meaning from a phenomenological approach is through hermeneutics which tease out possible interpretations and meaning from the phenomena. Taking the direct description of the lived experience from phenomenology and focusing on the structures of meaning contained in the experience is the essence of hermeneutics. Hermeneutics uphold that meaning is contextualized by the researcher's cultural, historical and academic background and in-between the researcher and phenomenon something of interest is being produced (Kapitan, 2010). The hermeneutic spiral or circle (Gadamer, 1976; as cited in Kapitan, 2010) is the process utilized to interpret the data and analyze the described phenomenon. The hermeneutic circle functions within the interrelationship between the therapist and client, artist and artwork, and/or researcher and subject. This interrelationship shapes an initial interpretation and simultaneously remains open to a revision and elaboration of that interpretation as the relationship deepens over time. The hermeneutic circle utilizes the impulse to comprehend with

the desire to connect and respond with others. When themes are extricated from phenomenological writing, the hermeneutic circle can be used to examine and interpret the themes in relation to all aspects of the research.

Poetic Inquiry

According to Monica Prendergast (2009), professor of interdisciplinary studies in theatre, philosophy & education, there are a plethora of terms which fall under the category of poetic inquiry and this is an expanding area of interest in arts-based qualitative research and throughout the social sciences. The ability to synthesize an experience while simultaneously leaving space for interpretations is the inherent power of poetic inquiry. Poetic inquiry is a form of qualitative research which incorporates components of poetry as a form of meaning making, displaying data and as a tool of investigation (Prendergast, 2009). It is like narrative inquiry in that it draws from the literary arts ability to present and explore human experiences and research in an authentic manner. Poetic inquiry is an interdisciplinary field merging literary arts and the fine arts. Furthermore, it allows for the voices of the participants to be represented ethically. Poetic inquiry can be many things and for the sake of the thesis, poetic inquiry is a way of knowing through the use of poetic devices such as metaphor, lyric, rhythm, imagery, emotion, awareness and self-revelation, as a way of meaning making and being-in-the-world (Prendergast, 2009).

Prendergast (2009) streamlines poetic inquiry functionality into three categories; (1) *Vox Theoria*; (2) *Vox Autobiographia/autoethnographia*; and (3) *Vox Participare*;

Vox Theoria

This occurs with poems written from or in response to literature or theory in any given field. It may also be self-referential; poems written about poetry or inquiry in and of itself. *Vox Theoria* may have a political or critical tone and is considered to be “literature-voiced” poetry.

Vox Autobiographia/autoethnographia

Poetry which falls under this category makes up the bulk of poetic inquiry. The poems are “researcher-voiced” and are based on field notes, journals entries, and writing that is reflective, creative, autobiographical or auto-ethnographical. This category essentially can encompass all poetry especially if data is taken from the researcher’s lived experience. In order to fall into the category of *vox autobiographia/autoethnographia* the poem must be in the context of research (re-searching experience, re-interpreting poems and writing, and sorting a variety of artistic expressions).

Vox Participare

Vox Participare accommodates an action based research method in that it draws directly from participants through interviews/participant created poetry and then becomes a poem based on the participants’ generated data. The voices in the poem may be individual or multiple.

A/r/tography

The practice of *a/r/tography* is a way to inquire about the human experience in the world through an on-going creative process by any art form and writing. The art process, product and writing is not separate or illustrative of the subject but interconnected in order to create relational and/or enhanced meaning (Irwin & Sinner, 2013). *A/r/tography* is metaphorical for the artist-researcher-teacher who integrates these roles and disciplines into his or her personal/professional lives. Knowing, doing, and making merge and disperse in the borderlands of *a/r/tography* (Pinar, 2004); it radically transforms theory as an abstract system separate from practice and replaces the idea that theory exists through critical and aesthetic exchange that is reflective, responsive and relational. In *a/r/tography* theory and data is in a continuous state of reconstruction, becoming, folding and unfolding (Irwin & Springgay, 2008). *A/r/tography* is an arts-based research method of inquiry, a creative practice and a performative pedagogy that exists in-between disciplines (Irwin, 2004; cited by Irwin, 2013). *A/r/tography*’s concept of the in-between is an important aspect to highlight as there are many in-betweens present in this

research; The in-between the art therapy intern and clients; the in-between of the sessions; the in-between the individual family members; the in-between the art and the text of the research; the in-between of student and teacher; the in-between of supervisor and art therapy intern; the in-between of myself and colleagues; the retrospective time in-between lived experience; and the in-between of life and death.

No role or discipline takes more importance than the other. Acknowledging the in-between spaces disrupts the potential of splitting into binaries, or being stuck in one identity and alleviates the “rush to certainty” (Irwin, 2013, p.2).

The Arts offer moments of encounters, shifts in consciousness, and opportunities for other ways of knowing (Irwin, 2013). Artwork created as a/r/tography attempts to integrate these aspects in order to question traditional methods of research, knowing and being and enhances meaning, stimulates creativity and represents the in-between of certainty and ambiguity (Irwin, 2004). A/r/tography is a living practice of research, art making, and holding space where thought and action are joined.

To live the life of an artist who is also a researcher and teacher is to live a life of awareness, a life that permits openness to the complexity around us, a life that intentionally sets out to perceive things differently (Irwin, 2008, p.33).

Through memory, identity, reflection, meditation, narrative, creativity, interpretation and representation the a/r/tographer searches for new ways of inquiry regarding his or her roles of artist, researcher and teacher [therapist]. A/r/tographer's have multiple identities in order to re-create, re-search, and re-learn ways of understanding, appreciating and representing the world (Finley & Knowles, 1995; as cited in Irwin, 2004). The work is science and art, but closer to art as a/r/tographer's strive to enhance meaning through aesthetic experience rather than reveal facts or certainty (Ellis & Bochner, 2000 as cited in Irwin, 2004). In the case of this thesis a/r/tography is a form of living inquiry which remains open to the ways of describing and interpreting complex experiences as the self as researcher, artist and art therapist in relationship to clients, colleagues and the world (Irwin & Springgay, 2008).

Artist/Researcher/Therapist

An a/r/tographer has historically been Artist/ Researchers/ Teachers and in the case of the thesis the “teacher” will be replaced with the “therapist”. There is limited theory written in regards to art therapists becoming a/r/tographers and this may be a new horizon for the field of art therapy research and practice (Irwin & Sinner, 2013). I believe the ability to be aware, open and to perceive differently the complexities of life are as an important to teaching as they are to art therapy. An art therapist can benefit from a/r/tography research in that we already work with interpreting and understanding aesthetic and symbolic information clinically and personally. I believe transferring these skills into research only deepens an art therapist’s appreciation for art as a way of knowing and understanding the world.

Response Art, Art Therapy and A/r/tography

A similar aspect of art therapy and a/r/tography occurs when an art therapist creates “response art” (McCune, 2013, p. 3) to issues pertaining to a client, the therapeutic relationship, artwork or goals. The intention of response art is to develop new understandings regarding the art therapy conducted with the client as well as it may reveal transference and counter-transference (Freud 1905, 1955; Heiman, 1950; Little 1951; as cited in McCune, 2013). The focus of response art in art therapy is the client and his or her therapeutic process through specific methods, techniques, interventions and on occasion assessment (McCune, 2013). A/r/tography differs from art therapy response art in that the exploration and meaning is what is intended to be explored. Its focus is on the practitioner’s lived experience through artistic means for insight into a phenomenon which then informs the practitioner’s professional practice (McCune, 2013).

Site Specific Installation

Installation art is a medium which is comprised of more than an assemblage of art objects and includes the architecture, the site and/or the environment (physical, social or political) in which the objects are placed or installed as an integral aspect of the art. This offers an environment of art

(Atkins, 1990: as cited in Moon, 2002) and provides the viewer with an opportunity to engage his or her senses, activates movement through the space, and offers multiple perspectives of the art in order to create not just a view, but an enriched overall interpretation (Moon, 2002). Often installation artists include traditional and non-traditional art materials such as found objects, and will draw attention to the overall environment through lighting, sensory elements and the trajectory of movement through space. Installation art harnesses time and chance as part of the artwork (Moon, 2002). Most importantly, installation art draws the viewer's awareness to his and her relationship to the specific environment and to others who may interact with it as well (Moon, 2002).

In-Between Methodologies through Arts-based Research

According to James Hayward Rolling Jr. (2013) arts-based research is a flexible form of inquiry; a process and or product driven method which aims to generate meaning making from rich observations and descriptions of human perceptions, social behaviour and common qualities of shared experience. There is an emphasis on aesthetic experiences and spontaneously improvised methods of meaning making and documenting understanding (Rolling Jr., 2013). Arts-based research engagement provides unique theoretical approaches based on the phenomena that is present and may fall into four categories;

- Analytical material explorations such as thinking in formed material, mediums, and curated artifacts;
- Synthetically thinking through language, shared symbols and problem solving systems;
- Critical-activism which requires thinking through context, circumstances, lifestyle, ideologies;
- Improvisatory thinking which harnesses reflexive, spontaneous and idiosyncratic approaches to the prior three categories (Rolling Jr., 2013).

In other words arts-based research takes many forms and may exist in-between many approaches. The nature of the blurred lines in arts-based inquiry creates an opportunity for openness, to

overcome the biases inherent in scientific research writing and to work flexibly with the emergent data as they reveal themselves in the present (Rolling Jr., 2013).

Canonical Generalizations

Arts-based inquiry has the ability to visually represent how and why a study of one person (or family) can resonate with the lives of many. Kapitan (2010) refers to the nature of “canonical generalizations” (p. 164) in arts-based inquiry as concerned with illuminating the unique in time and space and simultaneously conveying insight beyond the limitations of the situation. Through the use of heuristics, the researcher draws upon themselves to define a sensory distillation of experience that performs beyond the individual by vividly reminding the reader/viewer about what a particular experience is like (Eisner, 2003; as cited in Kapitan, 2010). Canonical generalizations are validated by arts capacity through imagery and material to convey a person’s reality.

Chapter Summary

If there is a collective essence of the methodologies explored in this chapter, it would distill into methods that focus on inquiry of a phenomenon, methods of maximizing the encounter with the phenomenon, the study of interpreting the meaning of a phenomenon and the thematic analysis of a phenomenon. The phenomenon under which these inquiries will be explored is the lived experience of art therapy with a family living with terminal illness. To illustrate “getting to the underbelly” I have included the poem at the beginning of this chapter. It is poetic inquiry in which I distilled from particular methods of inquiry covered in this chapter. By including this poem I hope to offer an example of how poetic in functions to the reader. It is also an example of *Vox Theoria*. The next chapter will discuss the research protocol and demonstrate how the thesis adopts the methodologies in order to observe, explore, enhance and thematically analyze the meaning of the lived experience and value of art therapy with a family facing terminal illness.

CHAPTER THREE: Topography of the Intuitive Process

This chapter has the role of articulating the lived experience and the research protocol of the art therapy with a family living with terminal illness. Due to the nature of a/r/topography and phenomenology, the research protocol unfolded as a fluid, intuitive process that included many steps. Writing has been an integral aspect of the research. The writing as research came in many forms; the clinical notes documented after sessions, the clinical case study written after the final session with the family, drafted outlines of the thesis, and various phenomenological writings in response to the lived experience of the art therapy. I cannot forget the importance of distilling the essence of significant phenomenological writings into poetry and the many forms of reflective writing that occurred over the course of the thesis.

Between the art therapy sessions with the family I personally engaged with art making which played an important part of the research protocol. This occurred simultaneously with the process of writing. I chose one aspect of the lived experience with each family member individually and created art as a form of inquiry around that aspect. I drew from something the mother said and found a material that related to make art with. I took a sentence the son said to me, and I created a sculpture and a poem from it. I took my awareness of the father's physical state and found a way to represent it through art. I could not say this was a disciplined academic practice per se. It was an intuitive creative process that stayed open and conscious to any insights the art making provided. Only poetry and art could capture the intangible nuances of this kind of research. The writing of the thesis alludes, or points to parts of the infinite meaning that exists in this kind of inquiry.

Data Collection

The data for the thesis was collected through lived experience and observations during art therapy sessions with the family, as well as intakes and phone meetings. Clinical session notes were recorded by phenomenological writing after every session, as well as photo documentation of the

family's art work. Further exploration was extracted through an a/r/tographical case study exhibition which allowed for a distillation of an essence of the therapeutic relationship with the family, as a whole and individually, as well as my own personal growth from the experience of working with this particular family. Data was also generated by my colleague's art and writing that was encouraged in the a/r/tographical case study exhibition.

By reflecting upon all the data collected I will attempt to use a wholistic approach (van Manen, 1990) to find the value and meaning of the lived experience of the research. Through retrospective analysis of the family's art, the lived experience in art therapy sessions, my art, writing and prose, and the art and writing of my colleagues, I will uncover the wholistic (van Manen, 1990) themes. I seek to apply the uncovered themes in order to reveal the value and the meaning behind art therapy with the family living with terminal illness. I will harness the hermeneutic spiral in order to fold and unfold the relevant theory so that it may enhance the meaning of the themes and reveal the inherent meaning of art therapy with the family.

The Process of A/r/tography

Early in my research I endeavoured to see how a/r/tography could be applied to a case study presentation through an exhibition. In order to prepare for a case study of the family I adopted an a/r/tographical form of inquiry and analysis in order to explore the potential ways of knowing and meaning making. Through engaging in various creative processes in response to the art therapy with this family I found various insight regarding my therapeutic approach. Certain dialogues and experiences with each family member would strike me intuitively in which I would explore further through a creative intervention with a particular material. Found objects that directly related to the art therapy experience with the family were gathered and then altered through art material encounters and following my intuitive artistic process. I worked sporadically with the materials after sessions until insight came to me. I intentionally paid attention to the thoughts and feelings that had arisen through the material

engagement in which I documented in phenomenological writing after the initial art material encounter occurred. Once the phenomenological writing concluded, I distilled an essence from the writing into poetry inquiry. I stayed attuned to the creative process throughout the course of creative engagement with a material, writing, and poetry and returned to the object to alter it as it seemed appropriate. This process was not disciplined or structured; it was fluid and intuitive. I was unsure of what was to come of the whole process. The result of the process was three art pieces that represented my relationship with each family member. In-between each step in the creative process data was documented and collected. Images, poems and artist statements related to the artistic process of creating the art were included as data. These pieces were then assembled into an art installation with the intention of being viewed as parts to a whole. The art installation was unified with digital slide presentation projecting upon the art pieces. The slide presentation consisted of photo documented images of the family's art work. The result was a site specific installation put on exhibit for my colleagues and supervisors as part of the a/r/tographical case study.

Art Installation and Exhibition: A Case Study Presentation

The large studio of the art therapy graduate institution was converted into a gallery space for the exhibition of the case study. The whole studio was used to display the family's art work, my installation and an interactive artwork. Surrounding the art installation were the original artworks of the family in chronological order and the interactive art piece which took the form of a suspended hula hoop from the ceiling. The exhibition activated a conversation and a relationship in-between all the artworks. The viewers of the exhibition were made up of the student body and faculty of the art therapy graduate institution. For the interactive artwork I asked the viewers to quietly view the exhibition and reflect upon his and her immediate responses. I offered the viewer lined duo-tang paper with a variety of drawing materials to document in drawing and/or writing their immediate responses to the exhibition. I gave an oral presentation of the case study which introduced the family, highlighting the presenting issues and

therapeutic goals and then phenomenologically described the five art therapy sessions. During the oral presentation I spoke to the intentions, creative process and insight gained from creating the installation as a way of touching upon the analysis aspect of the case study. Once the case study was complete, I invited the viewers to fold the duo-tang paper with their reflections into paper airplanes and throw them through the suspended hula hoop. This was a way of gathering anonymous data from the viewers and as a gesture to complete the exhibition and case study presentation. The exhibition was meant as a way of visually articulating the analysis and essence of the therapy up to that point. This created an environment in which myself, colleagues, and supervisors were to experience and be immersed in the art as a whole. Selected written feedback and creative responses from my colleagues and supervisors are a part of the data of the research.

Finding and Losing the Research Through A/r/tography

In researching what the value and meaning of art therapy with a family facing terminal illness, I have found that it is extremely challenging to pin point exact aspects. Much like what Romanyshyn (2013) describes as “the unfinished business of the soul of the work” (p. 4). I have consciously put aside overanalyzing the data to allow what needs to come forward and be revealed. Phenomenology, hermeneutics, poetic inquiry, a/r/tography and arts-based research provide an avenue for the data to emerge and to be retrospectively discovered. With these methodologies I am able to intuitively respond and reflect upon the experience of art therapy with this family. Again, the in-between is an important space for the meaning to be revealed. Romanyshyn (2013) states that when a researcher feels they have the work in his or her grasp, or sense of it, they may feel like they own the work and that it belongs to them. Yet, this sense or grasping of the work actually causes the researcher to lose sight and lose track of the research. Being “claimed by the work” puts the researchers in “service to the unfinished business in the soul of the work.” (Romanyshyn, 2013; p.4) and in service to those for whom the work is being done. Romanyshyn (2013) elaborated on “the struggle to recover that what is being lost and found again

is the struggle in the gap between what is said and what wants and needs to be spoken” (p.4). By tending to the in-between or the “gap” I feel I honour what wants and needs to be manifested as data pertaining to the art therapy with the family.

Limitations

The research will be limited by its subjective and personal tone. The thesis does not seek to generalize or objectify the experience of the participating family, nor to name cause-and-effect but to provide insight into the complexities of meaning and occurrences in art therapy with a particular family. This is not meant to be read as a universal example to all those experiencing terminal illness within a family but a canonical generalization (Kapitan, 2010). Wholistic approach by nature seeks an overall, or fundamental meaning of a phenomenon, therefore it is based on the judgement and attention of the specific researcher. Different readers and researchers may discern other fundamental meanings or values. This does not mean one interpretation has more authority than another but there is the possibility of idiosyncratic meaning (van Manen, 1990). I want to acknowledge the research may be limited by my subjective and interpretative influence as qualitative research is not concerned with documenting one “true” objective (Guest, Namey, & Mitchell, 2013). Phenomenology depends on the researcher’s ability to be mindful of personal subjectivity which may affect the data presentation.

My method of inquiry provided a plethora of data; phenomenological writing evolved into poetry and moved into art which was then exhibited for colleagues to create response art and it has become a thesis. I obtained so much data that it was difficult to edit and focus. Inevitably data has been omitted for the flow of the thesis. Another limitation is the various ways the data could be interpreted that are not used in this thesis and would alter the approach to researching the subject matter.

I also want to acknowledge the limitation of my research regarding a/r/tography in art therapy research for I could not find more than one publication regarding its use by art therapists (McCune, 2013). A/r/tography provided me with a framework in which I could harness my skills as a conceptual

artist in research. Through a/r/tography I have been able to utilize all of my prior education and experience in the Fine Arts for the purposes of study and understanding. It has allowed me to bring all of my roles as an artist, art therapist, poet and researcher into a tangible form to share with my colleagues and peers. Each role helped invigorate the study into what I believe is open to interpretation while still being grounded in theory. As a conceptual artist, I have always been interested in innovative thinking and the Avant-garde art movement (Scheunemann, 2005). I seek the edges and the cross overs of disciplines and I believe the in-between is the space of innovation.

How It Came To Be

I had voiced an interest in gaining practicum experience at the graduate institute by working with those living with grief and loss. When a referral from a local hospice was made to the graduate institute, I was offered an opportunity to work with a family facing the father's terminal brain cancer. The names of the family have been changed to ensure confidentiality.

After the initial intake with Simone (mother), four sessions were conducted with the family as a whole with the fifth session held as two simultaneous individual sessions; Simone with an art therapist and Ethan (son) with me, the art therapy intern. In-between the second and third session I conducted an intake over the phone with Paul (father). The fourth session was held in the family home for safety reasons. In-between the fourth and fifth session, Paul had been hospitalized with a brain hemorrhage which left him unable to attend the fifth session with the rest of his family. During Paul's hospitalization, I presented the a/r/tography case study exhibition for her colleagues. I visited him briefly in the hospital before the exhibition. He died shortly after the exhibition case study. Following a holiday break, the mother and son continued art therapy as a child-parent dyad for four months. The dyad sessions will not be used in response to the thesis, but an epilogue has been included highlighting the nature of the art therapy as it resumed.

In the early sessions, the family had consented to conducting research on our art therapy experience together. I thought the research would extend to a case study, and not much more than that in the beginning. It is unclear to me exactly when I decided to write a thesis about art therapy with this family. I had been researching arts-based methods of inquiry and found a/r/tography peaked my interest. In-between sessions I made art in response to the dialogue that occurred with the family and myself with the intention of presenting a case study presentation (a required assignment of the graduate institute) in the form of a/r/tography. This was a fluid intuitive process and difficult to confine into a specific framework. In hindsight, I believe it was when I found out Paul had died that I decided to write my thesis about his family. The enthusiastic and positive feedback I received from my colleagues and supervisors after presenting the a/r/tographic case study exhibition re-enforced that there was a profound phenomenon occurring with art therapy and this family that deserved attention and research. I decided retrospectively that this would be the subject of my thesis.

The Setting

The art therapy was conducted in an art studio at a graduate training institution for art therapists. Fluorescent ceiling lights lit the studio space and corkboard panels are on the walls for tacking up artwork. Shelves are found on the periphery of the room, containing a plethora of materials for art making. Drawers full of various paper sizes and weight greet those who enter through the studio door, and a table waits to be occupied in the middle of the room. The north facing window of the studio looks out upon the mountainous community. A short table supports a sand tray which sits quietly under the window.

Therapeutic Approach

Each session I offered a choice of several 3D and 2D materials, and the studio was set up prior to the family's arrival. The art therapy with the family took place in the studio once a week for an hour and a half over the course of three months. It was appropriate in this time for me to focus on establishing a

trusting relationship with the family first and foremost. I drew from Wolfelt's (2006) tenets as a guide to 'companion' the family through art therapy as a way to establish trust. Safety, comfort and support were what I wanted to attend to during the sessions. I did so by providing adequate lighting, healthy snacks that catered to the father's specific diet and holding the therapeutic space. I also provided technical advice on the use of certain materials and made sure to bring any other material requests within reason. I also felt it was important to provide consistency and predictability within the studio. I realized early in the first session that insight oriented art therapy would not be appropriate for this family and felt the freedom of spontaneous art making and art-as-therapy approach would better suit the needs of the family. Person-centred art therapy (Silverstone, 1997) seemed the most supportive in meeting the family's needs for adapting to the physical state the family arrive in. They were offered the opportunity to choose the art materials that best suited their needs and set the course of their own creative focus in the sessions. Doing with, remaining open and honouring the pain (Moon, 2009) were approaches that allowed me to hold an existential framework in sessions. Adopting Linesch's (1993) art therapy with families in crisis model I encouraged each individual to take their inner experience, put it into the art in order to have a sense of empowerment, to express affect and to engage in genuine dialogue.

The Family's Art Work

The family's artwork spans a variety of mediums; chalk pastels drawings, tempura paintings, clay and plasticine sculptures, found object assemblages, and material experimentations. Physical movement and narrative were also important aspect of the therapy. The art-making slowed down over the course of five sessions as the father's health declined. The son made art in every session. Each art work is documented in chronological order and are included as data.

Chapter Summary

My research protocol follows a fluid and intuitive structure allowing the data in-between inquiries to unfold. This was, I feel, a way for the protocol to align with the phenomenon instead of

directly analyzing it. It is a way of honouring all that comes out of interacting with the lived experience, the art, the family and the research. I am aware now that the thesis can be a time capsule for the work that occurred. It is a way I can honour the experience I had with this family and is in memory of the father.

The following chapter will present the lived experience of the art therapy with the family. Phenomenological descriptions of the sessions, the family's artwork and the events in-between will be included. Chapter five will present the data that was revealed by the *a/r/tography* case study exhibition; my artistic process will be described along with my artwork; a description of the exhibition with examples of my colleague's artwork and poetry which was created in response to the exhibition. Chapter six will provide a hermeneutic discussion and wholistic analysis of the themes that emerged in order to find the value and meaning of creating art in the face of terminal illness.

CHAPTER FOUR: The Lived Experience of Art Therapy with the Family

A family, terminal illness, and art therapy; what is the value and meaning when the three intersect? In this chapter I will provide a pre-reflective description of the lived experience of the art therapy with the family using phenomenological writing in the present tense. Five session descriptions, events that occurred in-between sessions and images of the family's artwork will be presented.

The Family

The family consists of Paul (father, age 44), Simone (mother, age 50) and Ethan (son, age 9). These names have been changed to ensure confidentiality. Paul is at least six feet tall and heavy set. He is dark in complexion and often layers a plaid button up shirt over t-shirt, jeans and work boots. Simone is Caucasian with light brown wavy long hair, often worn up with a clip. She is average height and has voluptuous build. She often wears yoga pants, a tank top and a hoodie when attending art therapy. Ethan is tall for his age. He has light brown straight hair which frames his bright brown eyes. He wears t-shirts and jeans with boots.

Simone attends the intake appointment individually and shares her family was experiencing many issues related to Paul's recent diagnosis of terminal brain cancer; anger and intense emotions, traumatic experiences related numerous medical emergencies, financial stress and conflicted relationships within the family system. In the phone intake, Paul described concerns for his family during his illness; he feels that he must "put on a brave face" for Ethan and wonders about Simone's emotional well-being. Paul utilized the phone intake to inform me about his family of origin, his experience of terminal illness with his father and as a time for reflection.

Simone and Paul have been together for 10 years. They live in a home currently under construction of a new addition in rural community. Ethan was born a year into Simone and Paul's relationship.

Paul was diagnosed with terminal brain cancer eight months prior to entering art therapy. Multiple near death experiences and stays in the hospital occurred since his diagnosis. Re-occurring brain hemorrhaging had brought Paul to near death. Radiation was used to shrink the tumor and extend Paul's life, but it did not cure the disease. He speaks of "just getting my mind back" after his first brain hemorrhage. He is on anti-seizure medication, as he has recently been experiencing frequent seizures despite the medication. The family reported Paul's physical health was noticeably be affected by the brain tumor. The tumor and swelling of the brain affects Paul's general functioning. As his cancer progresses it will likely produce symptoms of increased sleepiness, decreased ability to move around, trouble speaking or understanding conversation, loss of memory (especially the ability to form new memories), impaired judgment (especially the ability to judge how much help one needs), weakness, seizures, headaches and extreme mood changes (Canadian Virtual Hospice 2003, 2014). The possibility of falling is an increasing concern. With brain cancer there are issues of balance, coordination and judgment, which may prevent Paul from asking for help or understanding he requires help. It is challenging to prevent falling when both mobility and judgment are affected (Canadian Virtual Hospice 2003, 2014). Throughout the sessions I witnessed Paul progressively exhibiting most of these symptoms.

In the intake and early sessions Simone contextualized Ethan's behavioural issues and prior experience with therapy; in kindergarten there were concerns about Ethan's behaviour as he was observed by his teacher to not participate, often walking out of the class and was unable to focus. These behaviours were present a few years before Paul's diagnosis. At the request of the school it was suggested that Ethan be assessed by a psychologist but this assessment proved problematic and was incomplete. Simone had mentioned that Ethan was misdiagnosed as "autistic" by a therapist and which has left a negative impression of therapy on Ethan. Since the situation with the school, Simone has been responsible for home-schooling Ethan through alternative online education. Simone voiced concern that Ethan would resist coming to session if he knew what occurred was indeed "therapy". She worries he

would reject the art therapy, and worried about the impact of not having an opportunity for Ethan to express his feelings in regards to experiencing his father's illness.

Simone and Paul were separated before his diagnosis; she had left him and returned to her country of origin. Simone said she had a conflict with her father and came back to her family in Canada. Shortly after her return, Paul had his first medical emergency which lead him to the hospital and to his diagnosis. Simone said that she had met someone else but in her words "called it off" in order to support Paul through his illness. A few months after Paul's diagnosis, Simone described that she "shut down" from exhaustion that resulted in a stay at the hospital. Simone has taken on the role of primary caregiver for Ethan and Paul.

Simone, and Paul have no extended family in which they would consider supportive in the area; both Grandparents live outside of the country and Paul feels they have no reliable siblings to call upon. Ethan's home-schooling limits his peer interaction although the family often draws upon their community for support. With the potential loss of his father, Ethan has only his mother to draw upon for support. It is within reason that Simone claimed that "this is our last chance" at providing Ethan with support through this challenging time.

In a phone intake with Paul, he states his concern for Simone presenting as "unemotional". He also acknowledges "putting on a good face" for Ethan in regards to his illness. Simone has said many times that "Ethan likes to know what is happening with Paul, but doesn't want to hear anything bad".

Treatment Goals

Simone cites her treatment goals are to have an opportunity for fun, to strengthen the bonds between Paul, Ethan and herself and share stories with each other. She emphasizes her intention is to "keep my family together". I would like to establish my therapeutic intentions are not to "treat" this family. The emotional and spiritual distress experienced in the face of a loved one dying is not pathological nor is it maladaptive (Yoder, 2005). I wish to "companion" (Wolfelt, 2005) this family

through art therapy and in the case of Paul's death, I believe it is Simone's intentions to continue with art therapy in order to provide Ethan with a creative support through the transition.

Session #1

I greet the family in the lobby of the institution and invite them into the studio space. As each member finds a comfortable spot around the table, Simone and Paul account for their moments prior at the doctor's office. Simone excuses herself from the session for a coffee. Ethan explores the space, and remarks on the variety of materials available to him. He grabs a ball of brown plasticine and powerfully throws it at the wall. His eyes dart around to Paul and then to me. He retrieves the ball from the ground and says "I want to throw this at the window" to which I reply "You want to throw that at the window. What would happen if you threw it at the window?" a grin spreads across Ethan's face. "It would break." I assure Ethan that "it is okay to throw it but let's make it safe. How can we make it safe?" Ethan decides he needs a target. A piece of large brown paper is tacked to the wall. Ethan paints a red oval outlined in white paint and continues to move around the room throwing the brown ball of plasticine in the direction of the target occasionally tearing and leaving a dint in the paper. Missing the target he exclaims "ah, bugger". Ethan sits beside me and says "If my dad acts weird it's because he has a brain tumor. Did you know that?" I confirm my awareness of Paul's illness. Ethan picks up the ball of plasticine and throws it at his target.

Paul kneads small pieces of plasticine and asks about where I am from. He slowly presses the plasticine into a few objects found on the table; a mold of teeth, a thrust ball bearing, and a square cookie cutter (Figure 2). He piles his shapes on top of each other. I notice Paul's difficulties pressing hard enough to make an impression with the objects and offer him a hammer which he taps the objects into the plasticine.



Figure 2- Paul's plasticine impressions

Ethan finds a balloon which he blows up and ties off. He uses the hot glue gun and glues a cork to the balloon tie. Ethan calls his art a "hot air balloon without hot air" (Figure 3).



Figure 3 - Ethan's "hot air balloon"

Ethan discovers a straw and fills the end with brown plasticine and blows in the direction of the target. The plasticine sticks inside the straw making him have to blow with force. Nothing comes out and he exclaims "ah, bugger." Paul retorts "Why do you say that? Do you know what it means? I don't like it when you say that." Ethan shrugs and digs into a basket of art materials.

Simone returns to the studio and I assist her to set up a large black paper to the wall. She asks Paul why he isn't making art and he replies "I am. I'm doing tactile stuff". Simone and Paul discuss the

meaning of their names and how they decided to name Ethan. Simone pauses from her painting as she talks. She hums to herself while she focuses on her painting. Ethan assembles a “paint brush” from wood cylinders and string and shows his creation to Simone. He dips it into the paint and applies a small amount onto her painting without asking. Ethan remarks how he thought the studio was going to be a “stuffy old studio” but in fact it was fun and that the studio space is “great”. He says we should call the space “L.J.’s Hotel” in honour of my nickname.

Ethan finds a nut amongst the art supply and he gestures behind his father as if to crack it upon his head. He refrains before hitting Paul. He grabs the hammer and is about to smash the nut when I offer to take him to another room so he may smash it without disturbing the others. Ethan chases the nut around the room until he decides it is not going to break. We return to Paul and Simone in the studio. Ethan collects two conical wooden bits with swirls on the bottom. He puts them to his eyes and looks at his father to say “Poppa, I am hypnotized” as he sways back and forth. They laugh and Paul takes the pieces and mimics the gesture. Ethan excuses himself to the bathroom. At this time Paul says he is uncomfortable with not telling Ethan that he is engaging in art therapy. Simone elaborates that Ethan’s prior experience of “therapy” was not positive, as he was improperly labelled as autistic. She informs me that an assessment was never completed. Simone expresses concern about using the term “art therapy” with Ethan as he may resist it if referred to as such. The conversation ends upon Ethan returning to the room. The family moves into closing the session; Paul shares his plasticine pieces by reflecting upon how relaxed he feels. Ethan shares his “hot air balloon without hot air” and requests a helium tank for the next session. Simone shares her painting (Figure 4); an image of clouds and a moon reflecting off the “waves”. She says “it’s a storm” and is “proud of how it turned out.” Ethan and Paul both compliment her on her artistic ability.



Figure 4- Simone's "Storm"

The family shares that they like the studio and Paul voices an interest in splatter painting. The session closes fifteen minutes late. I escort the family to the lobby when Simone turns to say she felt "limited" in the session. I mention that individual time could be arranged for her or any member of the family if they request it, but because the family was exiting the building no conclusion was made.

Session #2

Two weeks pass between the first and second sessions as Paul was out of town visiting his family. Simone and Ethan arrive ten minutes late for the session. Simone informs me she needs to pick Paul up from the doctor's office and will return shortly. Ethan enters the studio with his jacket and bike helmet on. I offer him a place to put his things. He takes off his jacket, and leaves his helmet on (for the remaining of the session). Ethan rummages through a box full of various metal pieces, tools and construction bits. He picks up a metal piece attached to a chain and says "Is this a hypnotizer?" as he swings it back and forth.

Fifteen minutes pass and Simone and Paul arrive in the studio to settle into drawing with coloured chalk pastels on large white paper across from each other. Ethan shows his parents the "hypnotizer". I ask Ethan what he knew of being hypnotized and he explains that he would hypnotize a

person “to do the things you want like clean my room and buy me a car that I want [and the hypnosis stops when]the guy finishes doing all the jobs.” Paul says “that’s not a very good way to live your life”. Paul finishes his drawing and sits looking upon Simone and Ethan. He occasionally shuts one eye and mentions that the fluorescent lights bother him and he feels tired.

Simone playfully wipes green chalk pastel on to Ethan’s nose. He moves to the other side of the studio and to wipe the chalk off with a tissue. This proves difficult to wipe; he leaves for the bathroom to better clean himself. While Ethan was out Paul says to Simone “You are in trouble now.” Ethan re-enters the studio, grabs a piece of chalk and attacks Simone with it, getting her arms and chest. Simone laughs “Are you done?” Ethan stops but does not seem satisfied with his retaliation. He moves around the studio looking for another way to “have revenge”. Simone returns to her drawing. Ethan pinches sand from the sand tray and throws it down the back of Simone’s shirt. Simone gasps, laughs and then firmly says “You got me back and see, I am not doing anything. It stops here.” She returns to her drawing. Every few minutes Simone would look from her drawing at Paul “Are you alright?” he replies “yeah, I’m fine, why?”

Ethan discovers marble tiles and suggests “Hey Poppa, let’s make a family hearth” (Figure 4). Ethan arranges the tiles while Paul struggles with attaching the tiles before the hot glue cooled.



Figure 5- Ethan and Paul’s “Hearth”

Simone and Paul discuss the construction happening in their home and to the amount of responsibility Simone has taken on since Paul's diagnosis. Paul states he needs to go to the bathroom and moves to the studio door, bracing himself with the table and surrounding furniture. Ethan assists Paul to the bathroom and returns back to the studio. Moments later Paul enters through the studio door, and almost collapses. Simone rushes to his side to catch his fall, and sets him in the closest chair. She stays with him, wrapping her arms around his neck quietly speaking to him. Paul explains that he is feeling dizzy and has been experiencing dizziness like this since his trip. Simone and Paul share their disappointment with the neurologist and explain the anti-seizure medication Paul takes may be the cause of the dizziness. Paul informs me that he had a seizure in front of the doctor earlier that day.

Ethan requests plaster. I offer him plaster bandages and water. Ethan asks to what is the purpose of the plaster bandage? I explain that it is often used for mask making. Simone recalls Paul had a mask made during his radiation treatment in which they intended on keeping, but they left it at the hospital. During the conversation Ethan scrapes the plaster off the bandages into a tiny cup and mixes water to make a paste. With ten minutes left in the session I tack Simone and Paul's pastel drawings to the corkboard. Simone shares her artwork first (Figure 6); a pastel drawing of a "flower" central to the page. Blues and purples surround the teal and green petals. In the top right hand corner there is a "moon reflecting off the water". Simone says "I don't know if this is significant but it reminds me of a poem...the poet's wife was dying of cancer and he saw the cancer in her growing like a flower."



Figure 6- Simone's "Flower"

Ethan takes his turn to share the hearth; he states his disappointment with the materials and asks if I could bring plaster, wood paneling and "more marble" to make a "cabin" for the next session. Paul shares his artwork (Figure 7); he remembers using pastels in early childhood and his drawing reminds him of something he created when he was six.



Figure 7 – Paul's pastel drawing

He sighs and states that he needs to go the bathroom again. Simone helps him and on their way out the studio door she says "You really are getting the whole show tonight". Ethan states to me that "This must be weird for you" outside of the bathroom. The family sits in the student lounge while Paul gathers up the strength to head home. An intake with Paul is arranged for the following Monday. Before the family leaves Paul says to me "We very much look forward to hearing from you."

Adapting to the Family's Need for Safety.

At this point I have growing concerns for Paul's physical safety. His symptoms have made it difficult for him to leave home to attend sessions. The staircase at the entrance of the institution, the concrete floors, and the small bathroom prove challenging and potentially dangerous in Paul's weakening physical health. The scheduled time of the art therapy may have been unfitting as well; late in the afternoon is a time Paul has observed to be the most fatigued. I bring my concerns to supervision and arrangements are made to continue art therapy at the family's residence. Simone expresses relief and

Paul is touched that the institute would offer this form of support. I would be accompanied by the executive director of the art therapy institute to the home sessions. In the following, the executive director will be referred to as the Art Therapist (AT). The AT has extensive experience with grief and loss art therapy as well as personal experience with terminal illness which lends further support for the whole group. The family decides to return to the institute for one more art therapy session in the studio and then be adapted to art therapy in the home.

Reality Sets In

After this session I notice within myself a deep insecurity in regards to working with the family. I feel as if I am in over my head, and that I am providing inadequate service. I doubt that art could be of any help to the family, and I am not “good enough” to be working with them. I resonate with what art therapist Joy Schaverien says in *The Dying Patient in Psychotherapy*; the experience of working with the dying “takes the analyst to the limits of their experience” and “may justifiably complain that this was not addressed in their training” (2002). I feel unsupported and victimized by my graduate institution. I am sure to bring my low self-esteem, pity and insecurities to supervision.

Phone Intake with Paul

An intake with Paul occurs over the phone the following week after the last session. “It was a rough weekend...he hasn’t got up in a couple of days.” Simone informs me before passing the phone to Paul. I ask Paul about his family of origin; Paul remembers his mother as “a saint” and he was a “rug rat terrorizing her until she flipped out”. He describes “flipped out” as being angry and he often experiences this with Ethan. He speaks to “putting on a good face for my son.” He describes his father as a “war resistor”; someone who is politically engaged against the War in Vietnam, more so than a “draft dodger”. Paul’s father was active in the politics of the 1960’s. I notice and reflect a sense of pride in Paul when he speaks of his father. He especially admires his father’s “willingness to do the right thing.” He admits to feeling emotional at this point of the conversation. Paul shares that he has no siblings (later

I am told he does have a brother). He describes his parent's relationship and reminisces about a dear friend he has had since childhood. He elaborates his friend is a "strange guy, doesn't age." He says he spoke to this friend a few weeks prior and thought "he must know by now [about Paul's brain cancer]."

Paul shares that his father died fourteen years ago, at age 53, of esophageal cancer. His father refused the treatment for his cancer because it would have "took too much away." Paul was responsible for his care and remembers witnessing his declining health. "He never knew how to take care of himself" and his father was a "bright light burned out quick." His parents moved to the area in which he now lives and became involved with the Quakers. Paul elaborates on his parent's lifestyle; they were high profile figures in a "back-to-lander" movement in their area. He reflects that his father "stayed the same" throughout his life. Paul went on to explain his father's employment which kept him away from home often. He recalls various accidents his father had experienced while away and expresses that his father did not have "anyone there to help him." He reflects that at that time "men did not complain about this". I sense that Paul is experiencing strong emotions about this topic. He agrees. Simone calls to Paul for breakfast. "Is this a good place to leave it for now?" He asks. Before we can conclude the conversation Paul has a seizure and the call disconnects. After several attempts at redialing Ethan picks up the phone "Something happened with my Dad, hold on." Simone is now on the phone "Yeah, he had a seizure". I took this as a conclusion to the intake and re-scheduled to continue the intake for the next day if Paul is feeling well enough. "Emotions may trigger seizures but we are not sure at this point." She sighs. "[Paul] said that you had a good talk" She mentions before hanging up.

The next morning I call Paul to continue the intake. He discusses his family ties to Cherokee culture and says his grandfather (on mother's side) identified as Cherokee and that his grandmother was Ukrainian. Paul does not identify as "Cherokee". He speaks about a time when he was three; his father suffered a "nervous breakdown" but did not spend time in the hospital. To Paul the "nervous breakdown" appears to be connected to his mother leaving his father; he retreated to a cabin in the woods and gained a great amount of weight. Paul remembers this had upset him. "Why did they have to

go through that in the first place?” His parents eventually reconciled. Paul discusses his grandmother on his father’s side; she “insisted” they were Penobscot, an eastern maritime indigenous nation. Paul shares his spiritual beliefs; he feels connected to the “lost tribe but not on an individual level, [but] more based on land ethics.” Paul discusses learning French from Simone and Ethan’s communication and that he considers himself bilingual.

I ask if there was anything else he would like to discuss and he mentions that “[Simone] is amazing in regards to work and getting things done but she is unemotional.” He explains the pair “know each other pretty good.” He describes his frustration with “being told what to do” and elaborates on his feelings of his freedom being restricted; “we choose what we want to drink in the morning, but I don’t” in regards to his restricted diet. He describes falling asleep and feels like it is morning when it is night and it confuses him. “I don’t like not knowing what’s going on.” He expresses he would like to know more about mindfulness techniques. Paul says he would like to create wreaths in the art therapy session possibly to sell, donate or give away.

When asked about the family’s personal strengths, he mentions his father “not being strong forever”. He acknowledges “I have a lot of strength but I don’t know how it transforms”. He mentions “It’s great to have a good Dad...I got strengths from my mom too, I just can’t name them right now.” I sense Paul growing weary. Before the conversation ends I ask Paul to recall what it felt like before he has a seizure. “Well, my hands are shaky right now.” I felt growing concern that Paul is experiencing an onset of a seizure and end the conversation by inviting him to focus on his breath. We engage in a breath work exercise for a few moments following a short quiet moment over the phone. “I think I am gonna go and lie down now.” He says quietly.

Session #3

I bring three lamps in the studio to minimize the effects the fluorescent lights. The family arrives thirty minutes late to the art therapy session. Simone opts to run errands while Paul and Ethan participate

in art therapy. Ethan sits at the far end of the table and quietly draws with charcoal on a white paper a mountainous landscape (Figure 8).



Figure 8 – Ethan’s charcoal drawing

Paul lets out a sigh and says “I am tired.” He finds a branch from the art materials and breaks off the stubs with the side of the table. With a screwdriver he attempts to attach a screw to the branch. Paul fumbles to get the screwdriver into the branch. He stops to watch Ethan. The Art Therapist (AT) joins the session to introduce herself to Paul and Ethan. Paul voices an interest in making wreaths in the next session.

The AT leaves before Simone returns. Ethan shares his drawing with Simone, but is interrupted when she notices Paul growing weary. “Are you feeling okay? Should we go home?” Paul says he is tired and needs to go to the bathroom. Simone helps him; he was noticeably uneasy on his feet. He braces whatever is around as support. When they get to the bathroom door, Paul collapses. Simone puts herself under his head before he hit the ground. “You stayed awake for that seizure, Poppa.” Ethan exclaims. Simone stays with Paul until he musters his strength to get back up. Ethan and I look at his drawing; He describes the drawing to be like “friend’s drawing” with “trees disappearing up the mountain.” Ethan quickly loses interest in his drawing and leaves the studio to check on his parents. I

follow Ethan with a box of metal bits he often likes to rummage through. We sit outside the bathroom and dig around in the box. This permitted Ethan to keep an eye on his parents as they recuperate.

Ethan asks me “Is this art class, or is this art therapy” with an emphasis on the “th”. We discuss the similarities and differences of art class and art therapy. Ethan observes “this one time my mom accidentally slammed my fingers in a door but I forgot about it because I went to a friend’s house and was having too much fun. Art therapy can be like that?” I agree to his description. Ethan then speaks about liking to make “realistic art” and that “if I make a model plane, I don’t make it to sit on the mantel, I want to make a model plane so I can fly”.

At this point I have a growing concern for the privacy of the family. The bathroom in which Paul and Simone are in is accessible from other parts of the school, which meant the situation in the bathroom could be seen by other clients, faculty and students. I felt the need to protect the family in this vulnerable state and I did my best to close doors and provide as much privacy as possible while honouring Ethan’s desire to be near his parents.

Simone and Paul manage to get off the bathroom floor and move into the lounge area of the institution. I voice my concerns about how the situation in the bathroom may have threatened the family sense of safety and privacy. Simone replied that “nothing is private anymore”. Paul rests on the couch. Ethan finds a heavy metal cylinder in the box and rolls it around the floor, making lots of noise. The AT joins the group to introduce herself to Simone and address logistical information about art therapy in the home. Simone leaves to move the family vehicle closer to the institution. Ethan jumps back and forth across the coffee table multiple times and then throws the heavy metal cylinder at the couch where Paul sits slumped over. The cylinder falls between the cushions, out of sight. He delights in this action. He retrieves the metal piece and throws it repeatedly “Want to see a magic trick, Poppa?” he asks. “No” Paul says quietly. Ethan throws the metal cylinder close to his father’s head. Concerned that Paul may be struck by the object I encourage Ethan to try his magic trick on the vacant couch. Simone returns “Look, I can make this disappear” he says to his mother and throws the metal chunk at the couch.

Simone collects her family and they slowly move to the stairs; Paul is very weak and unsteady on his feet, Simone is under his arm supporting him with Ethan towing behind.

Session #4

The AT and I are welcomed by Simone into her home. She mentions the kitchen table had not been cleaned off yet. We offer to help put things away in order to have space for art making. Simone informs us that she had a “rough morning” and has not slept enough due to having to deal with frozen pipes. Once the table is clear and set up with art materials, Paul and Ethan join. Simone and Paul discuss with the AT’s experience with terminal illness. A pot of milk is on the stove in which Ethan puts a straw and blows bubbles until the milk is frothy. I rhetorically ask him if that is how they make milk for lattes. He says no, in fact “they have a spout which blows out steam.” He sits beside the AT and draws a rectangular shape with pencil in the middle of the paper, and then scribbles it out. He moves to the right of the scribble to draw the profile of an animal. He colours the eye of the head in with green pastel. The AT and Paul discuss social connections and the AT discloses having known Paul’s late father. Paul speaks about his brother to whom he is distant due to substance use issues and troubles with the law. The AT spreads green plasticine onto a piece of white paper and offers it to Paul; he could make a “wreath” with this technique (Figure 9). Paul continues spreading the plasticine into the paper and recalls the smell of the cedar boughs on wreaths. We collaborate to decorate the wreath; red and yellow balls; points with yellow stars; blue, red and white coils form candy canes; a white bird; and a small ball of white and red added to the bottom of the wreath. Two small snowflakes are created from paper for the final touches on the wreath. He places a snowflake to the top and the other to cover the red and white candy canes.



Figure 9 - Paul's wreath



Figure 10 – Ethan's "Diamond back cobra"

Ethan starts rolling green and orange plasticine into a coil. He forms diamond shapes from brown plasticine. He adds black circles to create the eyes and states he was making a "diamond back cobra" (Figure 10) and the brown is not the "right colour". I inquire about the kind of habitat the snake lives in and he replies "a tropical swamp." I ask if I can help make a habitat for his snake; he instructs me to make rocks which I form from grey and black plasticine. I add a few strands of green plasticine as foliage. He adds a white tip to the snake as the rattle. He coils the snake around the rocks and adds the foliage.

While Paul and Ethan are creating art, Simone makes omelets and offers tea and coffee to the group. She speaks of enjoying creative writing but does not have the time. She has "books written in her head" and shares a narrative she wrote about her first memory as a child of four; she is at her great grandmother's funeral. She remembers being little, looking up from around her mother's legs, at her mother and grandmother discussing Simone being exposed to the body of her great grandmother. She recalls her mother advocating for her to see her great grandmother's body. She plates the omelets and hands the bowls to Paul and Ethan.

Simone asks Ethan to get ready as they have a meeting with the coordinator of home-schooling program. A friend of the family enters the home to stay with Paul while Ethan and Simone are away.

The AT asks how everyone felt about the art therapy arrangement in their home and everyone agrees they feel more comfortable. Ethan says that even though he would miss the studio, he felt that this was better. The AT offers to Ethan that he may have the opportunity to come to the studio while Paul and Simone attend to errands and appointments in the future.

Session #5

The weekend before the next session, Simone calls and informs me that Paul's brain is hemorrhaging again, and he is in the hospital. The following session is arranged to be at the institution, and that Ethan and Simone will be attending. They arrive twenty-five minutes late to the session, and Simone indicates her wish to have individual support from the AT. Ethan and I have an individual session together while Simone spends the session with the AT in another space. Ethan draws with coloured pastels on a large piece of white paper tacked to the corkboard in the studio (Figure 11). He draws four wave-like shapes at the bottom of the page, and then scribbles over the lines. He spreads the pastel pigment over the scribbles. With the excess pastel on his hands, he smudges blue pigment to the top of the paper. He makes an island with brown pastel, and atop he draws a coconut tree with many coconuts. He dips a black chalk pastel stick into black paint. He draws a boat with three black stacks protruding with black pastel smeared as "smoke".



Figure 11 – Ethan’s “Boat passing an island”

While waiting for the paint to dry, Ethan finds a wooden ball and throws it at the door. He proceeds to walk counter clockwise around the studio table throughout the rest of the session. I acknowledge to Ethan that his father was in the hospital to which he replies “He’s not in the hospital for the reason you think he is in the hospital. He is in the hospital so that my mom can recuperate.” I ask how he is feeling; “Its outta this world” He says. I invite Ethan to elaborate; he says “It’s like a house that turns into a boat that turns into a rocket ship that flies to the moon.” I ask him what things he would need to live in that house. He says he would need a “safety buoy, a lawn chair, a row boat, and some lemonade”.

Ethan paces around the table as he talks about Aikido, a type of martial art he is learning. He tells a story he learned from his Sensei. Below is the paraphrased story;

A group of villagers were going on a voyage, and an Old Samurai volunteers to join the trip as protection. A Young Samurai also joins the crew for the journey, but he makes the villagers bow to him.

The Old Samurai takes offence to the Young Samurai's behaviour and he challenges him to a fight. The Young Samurai has two big samurai swords, whereas the Old Samurai has only a small knife to fight with. The two samurais take a row boat to an island. The Old Samurai asks the Young Samurai to tie up the row boat. When the Young Samurai ties the boat the Old Samurai cuts the rope and leaves the Young Samurai stranded on the island. The Old Samurai rows back to the ship with the villagers. A few weeks later the Young Samurai is rescued by a fisherman. The Young Samurai seeks out the Old Samurai upon his return to land. He knocks on the Old Samurai's door. "Have you come to fight me again?" asks the Old Samurai to which the Young Samurai replies "No, Sensei, I have come to learn from you."

Ethan thinks he has more "brains than brawns" and that he relates more to the Old Samurai because his actions were "the best way to stop the fight." Ethan affirms that Aikido is about learning to "stop a fight" and that a fighter who uses his "brawns" will always win the first fight, but lose the second. I asks if he could depict the Samurais through art making, he said no and that he wasn't "very good at drawing people". He says he can draw cars better. He stops pacing to check if his drawing is dry. He smears the black pastel pigment to create a "mist" around the boat. I form a "samurai" out of plasticine, inviting Ethan to direct me as to what his helmet would look like, and what colours to use for the armour and sword; he instructs to use black plasticine for the helmet and armor, and grey for the swords. Ethan says it looks like the "Black Samurai from Scooby-Doo". As we work to create the Samurai, Simone enters the studio with the AT. She looks at Ethan's drawing and says "Wow! Did you make that?" Ethan explains his image "there's a boat passing an island". Simone says "there are a lot of coconuts on that tree!" They collect their things while Simone states she would be in touch with the institution about what will happen for next week's session.

Visiting the Hospital

I visit Paul twice in the hospital after the last session; once for a few minutes as a friend of his arrived to visit him as well and I thought it appropriate to take my leave in order for them to have

privacy. The second visit I brought art materials to make wreaths. I found him confused and not in any condition to be making art. Photographs of the family are tacked to the wall in front of Paul's bed. With his permission I pull the photographs closer and invite Paul to share his memories associated with them. He speaks of how little Ethan looks in one and reminisces about a picnic in another. He speaks of a family quilt that is in the background of photograph. He appears very sleepy. He informs me that Ethan and Simone will return soon. I say good bye and leave the art supplies behind. Later that week I call Simone to check-in about the next session and she informs me that had Paul died. Simone extends to me an invitation to Paul's memorial. I give her my condolences and regret to inform her that I will miss the memorial as I would be returning to my home town for the holidays and I assured her that the art therapist would be in attendance. I arranged to connect with her upon my return after the Holidays and offer an opportunity to continue art therapy as a parent-child dyad.

CHAPTER FIVE: Distillations from the A/r/tography Case Study Exhibition

This chapter will look at the data collected from the a/r/tography case study exhibition in order to explore the value and meaning of art therapy with a family living with terminal illness. A/r/tography and poetic inquiry methods were adopted to elicit the data presented in this chapter. With a/r/tography the data is the analysis and cannot be separated. Through presenting the a/r/tography data the analysis emerges. Images of artwork and poetry created by myself and colleagues are included in the chapter as well.

Artist Statement

As a practicing conceptual artist I have often been drawn to installation art and creative interventions with found objects. Installation art provides the viewer with an immersive experience of art, and asks the viewer to be active in his or her engagement with the art piece by journeying through the environment. Installation art harnesses all the senses and allows for multiple perspectives as the viewer circumambulates the environment. With multiple perspectives comes the potential for multiple avenues for enhanced meaning and interpretations. Found objects have an accessible quality; they represent objects that may be encountered every day and when placed in a creative context they become elevated to the status of art. Interventions such as painting over the found object disrupts the manufacturer's original intention in order to represent a new layer of meaning and perception of the object.

This installation became a portrait of a family in art therapy facing terminal illness using creative intervention with found objects and amassed together. The installation emphasizes the in-between of knowing and not knowing, light and shadow, dialogues and the intangible, material conversation and silence between the viewer, the artist, the art therapist and the family. The projection and text lends the viewer insight and as well as obscures pure understanding. The intention of the installation was not to be

certain of anything but more as a way to enhance the meaning of my lived experience as an art therapist intern and to honour the time spent with this family. The installation is made up of three parts; “Ethan’s Plane”, “Simone’s Journal” and “Paul’s Clothes” which act as elements to represent each individual (parts) in the family (whole).

Ethan’s Plane (Figure 14)

When Ethan states “I don’t build a model plane to put on the mantle, I build a model plane so I can fly”. I noticed within myself an intense emotional reaction to his statement. I purchased a 3D puzzle of model plane which I set out to assemble with the intention of exploring my relationship and perceptions of Ethan. Through putting together the plane I was aware of passing thoughts and feelings that arose during the assembling of the plane from which I documented by use of the phenomenological method of writing (Carpendale, 2003; 2009; 2011). I then used poetic inquiry to distill the phenomenological writing into a poem which allowed for an essence of “Ethan’s Plane” to emerge;

Exploration of Ethan through a 3D puzzle

“This puzzle will be simple”

Gently follow the scored lines. Bend the first puzzle piece.

“Let it go naturally, you are made for this.”

It is well designed.

Do not force the pieces together.

The material has strength, yet if I am clumsy or forceful the joints bend.

It weakens it overall.

Do not be careless with the excess, remove intentionally or else it tears.

\Save the excess packaging.

I feel it is important but I cannot explain; what is the purpose of the excess? Why do I keep it? What is its role? Trace out the individual pieces to make more puzzles.

The puzzle goes together like a to b, b to c, c to d, d to e, etc.

It’s a plane!

Imagine this plane in a little boy’s room, somewhere on a shelf collecting dust.

To do the puzzle again, would I have to follow the instructions? I know the parts now, I’ve assembled it once! With some puzzles maybe, with others, I would forget.

Feel the print of the puzzle. It does not suit my situation; “Gesso over it.”

I resist seeing this boy as a fighter plane; a Curtis p-40 Warhawk, used in the Allied forces during WWII.

Shark mouthed; does not suit him.

Is this my bias reflecting back to me? Can I really see him?

I chose the puzzle of this plane because the Stealth fighter didn’t feel right;

Too manly, too serious, too dangerous.

*The propeller rotates with a squeak; foamcore on foamcore
 The plane is light and comes with a sturdy stand.
 Would like this plane? His words echo in my ear;
 "I don't build a model plane to sit on the mantel, I build a model plane so I can fly."
 His plane would not collect dust. I am sure of it.*

This poem reflected to me how I should approach my therapeutic relationship and presence with Ethan.

It reflects my naïveté and assumptions I held about art therapy with children at the beginning of our relationship; "this puzzle will be simple". As I engaged more with the plane I realized how delicate some of the puzzle pieces were as well as how well designed and naturally the pieces fit together if I did not use force. This triggered a reflection about Ethan's resistance to therapy; do not force therapy on him, he will find his own "fit". He protects himself, for he knows there are delicate parts to him. I must respect his process. My own insecurities unravel; so many questions, fears of losing pieces, hoarding excess, and my confusion and discomfort surrounding illness, dying, and abandonment. Eventually I begin to see how this plane differs from other planes; how Ethan is an individual; I see his independent spirit, wit, creativity and energy. It made sense to me that his plane would fly and not stay dormant on a mantle. I painted over the plane with white and printed out the poem on a long narrow strip of paper resembling a ribbon and attached it to the back of the plane like a banner. The plane is meant to be suspended in the air as if in flight.

A Journal for Simone (Figure 12)

I was struck by Simone's passion and self-awareness that she displayed when speaking about her desire to write. I felt an ache in my heart for her; I wanted her to experience a creative outlet for her expression. I desired to be able to support her feelings, and I wished to connect with her on a deeper level. Yet, the role of caregiver to both Ethan and Paul is a priority and we had only known each other for a few months. Her writing would have to wait.

I set an intention to explore my relationship and perceptions of Simone, documented the material engagement with phenomenological writing, distilled through poetic inquiry and followed any further

intervention the process inspired. I bought an iconic composition journal (often used by writers) and engaged in a similar performative process that I had with “Ethan’s Plane”. I decided that a closed journal was an apt visual metaphor for Simone’s inability to write. I took on the daunting task of gluing all the pages together in the composition journal, starting from the back of the journal. It felt laborious, tedious and I noticed that I had a reaction of fear and disgust to how the glue was warping the pages, adding wrinkles. My hands were messy, covered in sticky half dried glue. I noticed that I was getting into a rhythm of applying the glue and slapping the pages together, carelessly and habitually. I desired for the whole process to be over and stayed dedicated to seeing the process through. Self-judgement came in; “what is the point of this? This is ridiculous! This isn’t art!” The whole process took a long time. I wondered if the desire for it to be over and the responsibility to see the process through was something Simone experiences in facing the terminal illness of Paul.

As I glued the last page at the front of the notebook, I noticed the cover would not shut. The glued pages had shifted and swelled in a way that keeps the journal open permanently. On the inside cover there is a blank calendar with the names of the weekdays in French and English. With white paint I painted over the other writing on the cover to emphasize the calendar. Despite the glue rendering the journal useless for writing, it strengthens the object as a whole. I found the glued journal was to be able to support the weight of “Ethan’s Plane”; before the glue, its structure was flimsy. This process reminded me of Simone describing her inability to write; as the primary support person she must stay strong while holding in her emotions as her family depends on her functioning for their survival. There is no time permitted for her to write for herself. I also realized there is hope and time in the future for Simone to write; the journal is not glued shut, but is open to possibilities when the time is appropriate.

It should be noted that I not have poem distilled from the phenomenological writing as a wholistic theme emerged of Simone’s strength, as well as a glimmer of hope for her creative endeavours in the future.

Paul's Clothes (Figure 13)

For Paul's art piece I white-washed a pair of men's jeans and hung them from a clothes line with a white t-shirt. Both articles of clothing were roughly a size which would fit Paul. I intended for the clothes to imply Paul's body without having to literally represent his figure. I drew upon curator Nancy Spector's "Subtle Bodies" chapter in *Wounds Between Democracy and Redemption in Contemporary Art* (1998) to explore the use of an implied body in art;

While the implied body can and does allude to any number of things connected to the corporeal, it has been most evocatively employed in recent art to represent what is essentially without form, to articulate what is singularly inexpressible – the body in pain, the silence of illness, the isolation of death (1998, p. 89)

I had a limited amount of interface with Paul. Due to his physical condition and deterioration throughout the art therapy, many of my questions were left unasked. I can only speculate as to his inner experience of his illness; I ponder his death as the therapy was meant to focus primarily on the family as a whole in the here and now. I wanted to honour his experience without having concrete confirmation about it. During the painting of the jeans, I took the same approach as I did with "Ethan's Plane" and "Simone's Journal"; staying attentive to any thoughts and feeling which unveiled during the process, phenomenological writing and then poetic inquiry. Two forms of prose emerged;

Stage One

*The jeans/genes resisted it at first
Absorbing each stroke
White wash with denim still radiating through
I wondered if it was the right paint
Or if these genes were durable
I mixed the paint better, laid it on thick
Over the seams I heard a voice say "nothing is private anymore"
Letting go of the body means letting go of the boundaries that go with it.
I didn't want any of it to get on me.
The paint started to absorb and requires a few more coats.
How stiff will they be?
Either way this renders the jeans/gene useless.*

Engaging with the paint and jeans revealed the enduring quality of the jeans; metaphorically the jeans triggered thoughts of survival, the resistance of death and striving for life. The paint became death slowly dulling the bright blue of the denim and stiffening the soft fabric. These jeans could not be worn anymore.

I remembered being concerned for the privacy of the family when Paul collapsed in the bathroom. Ethically, I had to protect the family in this vulnerable state and I did my best to provide as much privacy as possible. After hearing Simone say “nothing is private anymore” I began to reflect on the idea of privacy when dying. I interpreted this to mean when facing mortality we shed our modesty and focus on survival. Privacy is a privilege of the healthy.

When we hang our “dirty laundry” out to dry, it is an act of making public our private items. This metaphor is very much a part of the clothing representing Paul’s body. Clothing hanging on a clothes line metaphorically denotes a liminal space; an in-between, transitioning from one state to the next (wet to dry, dirty to clean, unwearable to wearable etc.). It poses a question of will these clothes be worn again? At the time I created this piece Paul’s brain had hemorrhaged and put him back into the hospital. His physical state was oscillating between rallying and deteriorating. Our next scheduled session had changed, and I was unsure if I was going to see the family as a whole again. It was unknown the outcome of his stay in the hospital; he had hemorrhaged before and pulled through. Visiting him in the hospital he would be lucid for parts of our conversation and then he would grow weary and confused. The family was in a place of unknowing.

Jeans and a t-shirt also connote casual everyday attire in western culture and are also complex political and social signifiers with a history of being both conformist and rebellious (Manning & Collum-Swan, n.d.). Jeans and a t-shirt make up a classic uniform of western culture’s working class. I intended to draw upon the “everyday” for Paul’s artwork in order to explore the reality of being ill and

facing death in our western culture. After reflecting about the idea of the “everyday-ness” of dying I wrote this prose;

Stage Two
Profoundly mundane
Mundanely profound
When the everyday object elevates to special
Precious tokens
Cuff links, work shirts, holy socks, and toe impressions on insoles,
A half bottle of perfume and a worn down lipstick.
Links that prove existence.
Out on the street corner
Another everyday reminder of you.
Before you were gone, I would have never noticed;
The things I took for granted I am so very aware of now.
How I feel such a deep sorrow
My heart falls into pieces, spewing despair and yearning all over the pavement.
It is rich and deep as a moonless starless night sky.
Both suffocating and liberating.
And simultaneously as I fall apart from missing you
Someone has the audacity
to repeatedly honk their horn and curse at the driver in front.
It is an ethereal normal
normally ethereal.

Facing terminal illness is a monumental event for an individual and family. It is also a time of living out life in the everyday with terminal illness that often gets forgotten about. Creating Paul’s artwork drew awareness to tending to the family’s everyday life in the here and now had significant therapeutic value.

With “Paul’s clothes” I strung two sheer white curtains, intersecting and dividing the room. Shadows cast and light were accentuated from the digital presentation projected on the clothing and curtains. This effect both caught and blurred elements of the projections. Paul’s clothes were hung alongside “Ethan’s Plane” and “Simone’s Journal” adjacent to an opening in the curtains; the side of the living. The curtains were intended to represent a thin veil and a division between life and death with Paul’s clothes hanging in the balance.

The Installation as a Whole

The first part of the installation to be installed were two clothes lines; they were strung up and intersecting with sheer white curtains which obstructed the flow of the room. A small space in-between the curtains was left vacant which created shadows and light play from the projections. Paul's jeans and white t-shirt were hung from the foreground casting shadows on the curtains and reflecting elements of the projections. To the left front of the jeans and t-shirt I propped up "Simone's Journal" on a plinth to reflect the projections and cast shadows upon the curtain behind. Front and centre of Paul and Simone's pieces I suspended "Ethan's Plane" flying in the trajectory of the viewer, trailing and weaving the banner poem in-between the other objects. "Ethan's Plane" cast a shadow over Paul's t-shirt approximately where his heart would be. A digital slide show was created consisting of a continuous loop of the family's artwork projected upon the installation as a whole. As the projections transitioned the installation shifted in colour and light, re-creating different elements upon the objects. Throughout the slide transition shadows stayed dormant.

It was a conscious decision to have all the individual pieces be white in order to create unity between the individual objects and for the pieces to best reflect the projections. The installation was meant to be viewed from either side of the curtains; the front side emphasizing the light and colour play with the objects and the space for the living; the rear accentuating awareness of the shadows upon the curtains and the space between the objects. This represents the unknown space on the other side of life (Figure 14). This installation was site specific to the studio space and cannot be reproduced once it is taken down. It was temporary and on exhibit for only the course of the case study presentation.

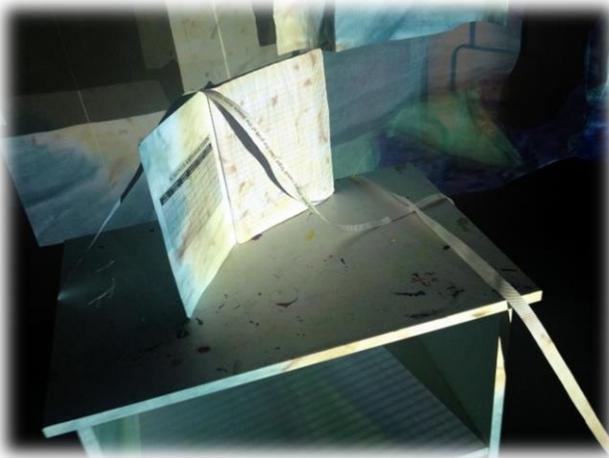


Figure 12- Simone's Journal



Figure 13- Paul's T-shirt with Ethan's Plane shadow



Figure 14- Ethan's Plane



Figure 15- Rear side of the installation



Figure 16- Front side of installation

The Exhibition

As the viewer entered the gallery space they encountered the family's 2D and 3D artwork exhibited in chronological order on the periphery of the studio. Viewing the family's artwork provided a clockwise movement around the room. The viewer found the installation placed at eleven o'clock in the room which disrupted a full rotation of movement round the room. The viewer had to reverse counter clockwise back to the entrance in order to view the back side of the installation. A hula hoop was suspended from the ceiling in the centre of the studio and a long table with chairs and art supplies were placed at six o'clock in the room.

I asked the viewer to quietly enter the space to view the exhibition as a whole. Once they had viewed all the work, the viewer sat at the table where art supplies and lined duo tang paper was placed. I consciously wanted the lined duo tang paper to reference the lined paper in "Simone's Journal". Upon the paper I invited the viewers to document their immediate creative response to the exhibition; either through writing, poetry, drawing or a combination of the three. I presented the oral part of case study presentation in which I discussed the occurrences in the art therapy and my intentions with the a/r/tography approach. My discussion concluded with having the viewer's fold their duo tang responses into paper airplanes and throw them through the hula hoop. I had not predicted the overall positive response of my colleague's garnered by the a/r/tography and many shared their creative responses aloud with the group before throwing the paper airplane through the hula hoop. I consciously wanted to mimic Ethan's desire to fly with the paper airplanes. By bring in the lined paper to construct the responses and planes from I feel I could represent Simone with this gesture as well. It is intangible exactly what this gesture means; are these notes meant for me as data for research? Are they supportive notes for the family? Are they ways of mourning for the viewer? Maybe, it's all three meanings condensed into one. Maybe it's something completely different.

Validation

The a/r/tography was validated by the profound responses of my colleagues and supervisors. Having the viewer's respond immediately to the exhibition before giving the oral part of the case study was an experiment in the efficacy of visual information communicated through art. Each viewer reacted and responded to different aspects of the art on display; some wrote prose and poetry, others drew abstract colour fields, some brought in his or her own connection with nature and pondered existential issues. Some focused on one particular artwork while others gave an essence of their overall experience to whole exhibition. A few visually articulated their interpretation of the therapeutic relationship between myself and the family. A few reflected upon their own losses and experience of terminal illness and the universal experience of living in the face of death. By having the viewer fold his and her response into a paper airplane and throw it through a hoop provided anonymity and a space of free expression. I wish I could include all of the creative responses so generously given by my colleagues, but for the sake of the thesis I am including a few samples.

Response Art of Colleagues

Colleague response #1

*Vessel on the sea, three, we
Who are three on the sea,
Are we?*

Colleague response #2

The white hanging curtains give a feel like the separation of beds in a hospital...thin white cloth that divides one illness and the next. A lack of privacy, only semi-transparent. Thin and fragile like the depths of an illness an interconnected sense of flight, lightweightedness, fragility, freedom, white washed.

Colleague response #3

My eyes were drawn to this piece over and over and a sadness came over me. Empty, lost, and angry where my personal felt senses to this. (see Figure 8)

Colleague response #4

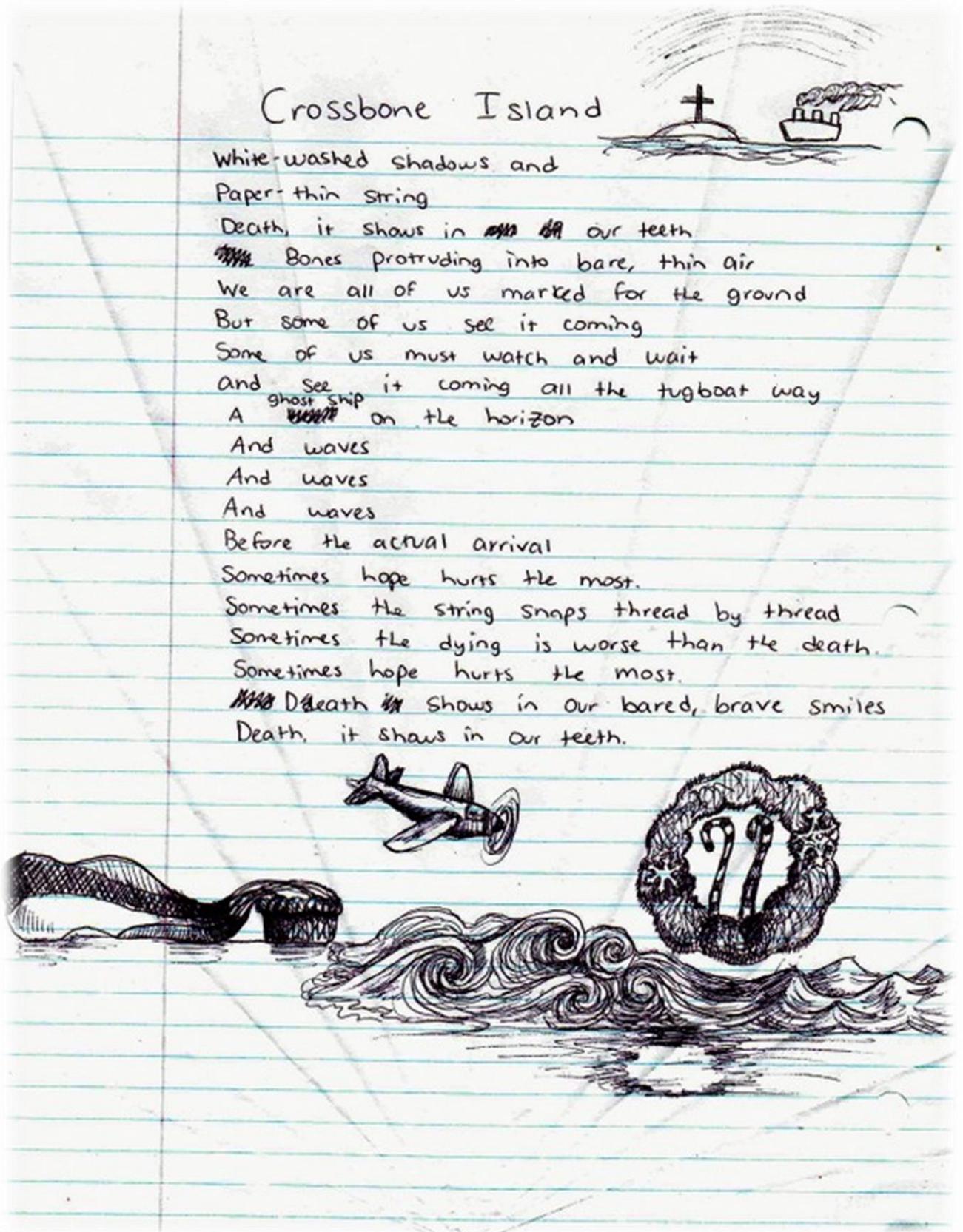


Figure 17 Colleague Response #4

Colleague response #5

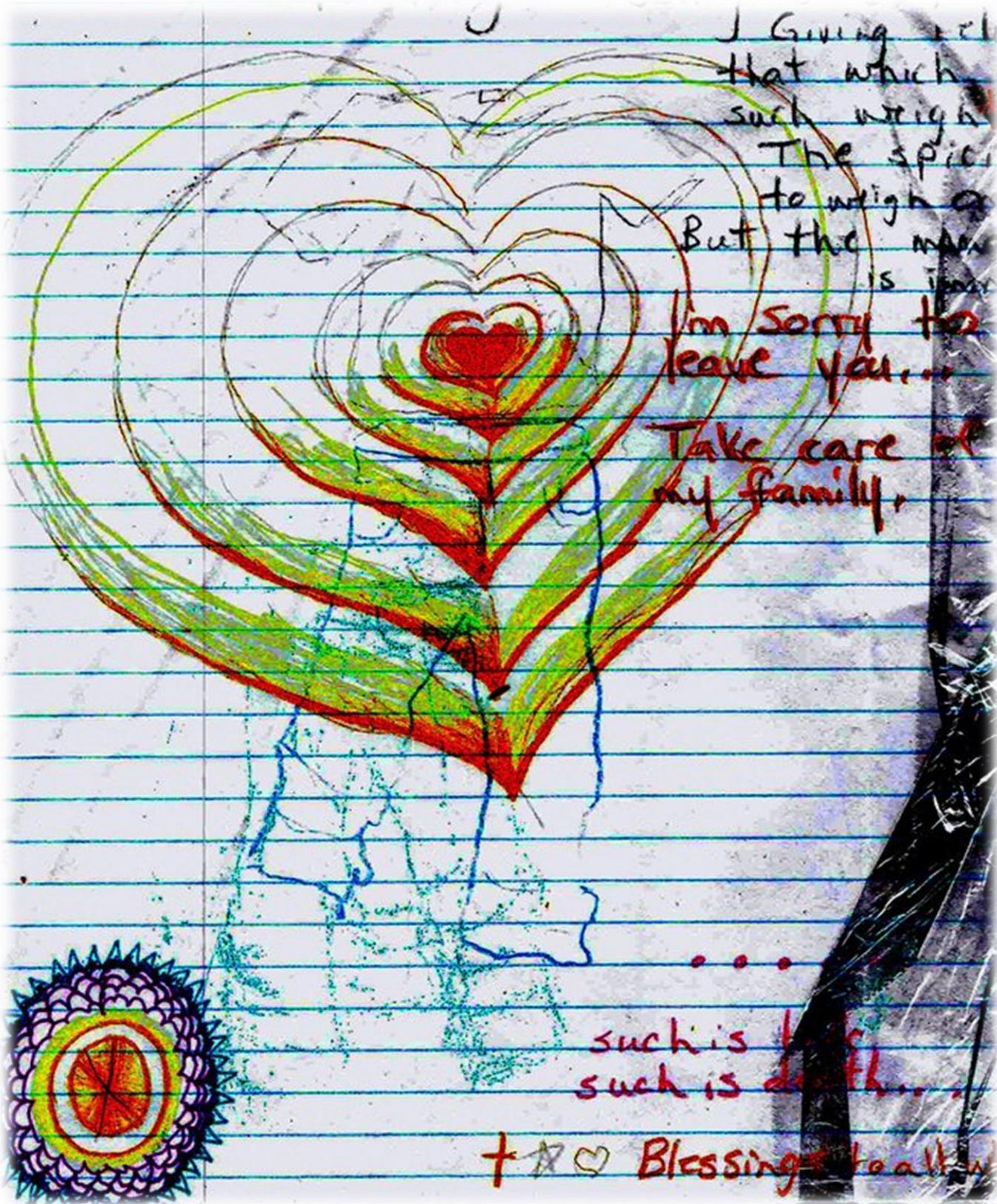


Figure 18 Colleague Response #5

Supervisor response

Monica Carpendale, executive director of the Kutenai Art Therapy Institute and the art therapist who worked with the family in the session descriptions, generously wrote two poems in response to the exhibition. With her permission I have included below *A Raw Voice* by Carpendale which was written in response to viewing the family's artwork.

A RAW VOICE

*Crack open inspiration
A belief in spirit
Permeates the natural world.
The dark underbelly of the ocean
Is an unknown territory
Waves crest under a setting sun
Gold edged clouds
Reflected in the deep water
White edge of breaking wave.*

*A target
A red sun edged
Contained
Stark
White
A red balloon drifts in memory*

*Bullets and targets
Imprints
Can I get my teeth into this?
To chew
To leave a mark
A cookie cutter
Not a cookie cutter soul*

*The spirals move in and out
Shift perspective
Look down or up
A flower bursts with life
The desire
The desire to be alive
To look up
To look down
A lotus
A lily pad floats
On a purple background*

*To build a house
The hearth in process
Not completed
Not glued – attached
Construction zone
Beautiful pieces
Brought together*

*The mountains in the distance
Reveal a shifting horizon
And the stark edge of a cliff
Is smudged with hand prints
Black and white
Ink and charcoal
The mountain is cut off by the edge of the paper
The horizon undulates like the ocean in a storm
Tiny trees detailed and scarred
Against the hill*

*A snake wraps around the world
An ocean liner moves above the water past a desert island
Black smoke in the wind
Blown in a fast moving landscape
The horizon doesn't touch the boat
Or the boat is beyond being in time and space
The deep ocean appears again*

*Not finished
Not finished
Not finished
With having a family
With having a father
Not finished with love
Not finished with desire*

*To clean the face
To play again
To get dirty
A revenge on the illness
A revenge on the diagnosis
A revenge on the threat
To try to attach
To make a hearth
To warm the house
To make a home*

LJ's Hotel, was written by Carpendale in response to viewing the exhibition as a whole. Below is a vignette, and the poem in its entirety is found in Appendix One of the thesis.

*A response: a site specific family portrait
 It will never look like this again.
 A temporality
 An essence
 To hang the curtains
 And the stopping of the clock
 To not be able to complete
 The hourly cycle
 The life cycle
 A work in progress
 A life in progress
 To not know if it is complete
 A completion
 The space between
 The space between each of us
 The space between the moments
 The space between the meetings
 The space between*

*To draw out all the aspects
 To be
 To write
 To always be an artist
 To always be a therapist
 To explore the in between
 To clothe the man
 To plane the boy
 To read the mother
 To write the book
 To attach the tape
 The curtain and the frame in between
 "Living in the borderlands"
 Living in the space
 Therapy occurs between the sessions
 Life between birth and death
 Layers upon layers
 To be human
 To explore
 To magnify the shadows and the light
 The projection catches
 The conversations
 Bleed through
 The elements*

Chapter Summary

This chapter presented the data which emerged from the a/r/tography case study exhibition and response art of my colleagues and supervisor to the art therapy with a family facing terminal illness. As I review and reflect upon all the data contained in the chapter, more meaning and themes emerge. I cannot possibly touch upon all that may be revealed. As time passes, even more will fold and unfold. I will attempt to theoretically contextualize the data I deem as pertinent in the next chapter through a wholistically approach to thematic analysis.

CHAPTER SIX: The View from a Hot Air Balloon

*What do you know, in your inchoate noise
About death's meaning to the girls and boys
It touches?*

Merrill Moore, 1957

What is the value and meaning of participating in art therapy with a family living with terminal illness? This is the question I set out to research. I wanted to understand how the art was being used by the family and what meaning could be found in it. I collected data through the lived experience of art therapy with the family, wrote phenomenological prose and poetry, created an a/r/tography case study exhibition, and asked for response art from my colleagues and supervisors. I then endeavoured to research through writing the thesis. I engaged the hermeneutic spiral by going in and out of this data. The movement in-between the data revealed three wholistic themes; 1) there is a universal experience of death that touches each person; 2) we seek to be in relationship to each other; and 3) art is an indestructible container that can hold all the suffering and pain of the human experience. I will attempt to roll in the relevant theoretical frameworks covered in the thesis to elevate these themes and to validate the potential meaning and value of the art therapy. These are not the only themes that emerge in the data and any other researcher may find other important aspects to explore. The themes are also intertwined and have a symbiotic relationship with each other. To distinctly address each theme is not possible without addressing the whole therefore I will allude the meanings which strike me as most important.

Relating Through Art Therapy; Within the Family

Paul's terminal illness threatened the family's familiar way of being and drastically impacted he family structure (Linesch, 1992). The art therapy offered a 'holding environment' (Kissane & Bloch, 2002) for the family to explore and creatively express their own individual thoughts and feelings regarding Paul's terminal illness while still being together as a family. The art therapy provided a space for the family to be and feel exactly as they do in the present, without riding or hiding the intensity of

the emotions (Moon, 2009). I hoped that the freedom of the space provided an opportunity for each family member to be empowered by the art therapy and to “embrace life as it is” in the everyday moment. There is something in witnessing each other and being witnessed by another that validates the meaning and value of the art therapy. Bearing witness to each other’s art also seemed important; Paul’s impressions, Simone’s painting and drawing and all of Ethan’s artwork appear to reflect their multi-dimensional experiences in coping with a terminal illness. Although verbal processing as to the meaning of the artwork was often disrupted during sessions, it appears there was still value for the family to create beside each other and to be witnessed by each other. This was apparent to me through the family’s motivation to attend art therapy despite the physical obstacles and the stigma of therapy.

The existential approach to the art therapy allowed me to honour the pain of each individual of the family by respecting the art expression and refraining from interpreting the artwork. Role empowerment was supported by their art expression; Paul’s illness impacted each member of this family differently and therefore each person in the family required an individualized support to hold their unique perspective and feelings. I understood that the art therapy was not going to cure Paul of his illness, nor could it make his illness better for his family. I was not going to attempt the impossible act of alleviating the suffering. I honoured the pain and the everyday struggles of each individual by welcoming the family as they were in the present.

A person-centred art therapy approach permitted for the therapeutic structure to remain open to the unique creative and therapeutic needs of Ethan, Simone and Paul while allowing them all to participate together. The person-centred approach also allowed me to set up the studio to cater to Paul’s light sensitivity and support the therapeutic relationship when the session occurred in the family home. The person-centred approach also permitted me to be open the family’s intentions for participating in art therapy; Ethan comes to understand art therapy on his own terms this way. Ethan spoke of art therapy being a place to have fun and forget his pain. By following his direction the art therapy was a space for the family to find psychic equilibrium. The art therapy was a conscious a place for Ethan to have fun and

forget about his father's illness momentarily. A place for rest from the issues related to his father's illness was a benefit for the family's well-being, as most of their time outside of art therapy is spent engulfed in coping with Paul's terminal illness.

Relating Through Art Therapy; With the Art Therapist

Companioning emphasizes the role of observing and bearing witness to another's suffering much like the existential approach (Wolfelt, 2006). A person-centred approach in art therapy provided the family with the opportunity to be accepted unconditionally by me (Silverstone, 1997; Rogers, 2001). Observing, witnessing and accepting helped me attune to the many of the strengths of the family; I observed Paul as loving, grateful, reflective and intelligent. His willingness to attend art therapy despite the discomfort and physical deterioration reflected his motivation, stamina and resiliency in the face of his illness and displayed his dedication to his family. I also observed Simone's dedication to her family. I was aware of her strong ethical nature, her responsibility, and creativity. She was the motivating factor in providing art therapy to her family. She created full evocative images with vibrant colour. She knows writing is a resource for her to call upon when the time is right. From what I observe she succeeds in "keeping her family together." I witnessed Ethan's hope, and his precocious ability to articulate himself poetically. He appears wise beyond his years, much like the Old Samurai. I have seen how inventive and masterful Ethan is with 3D materials. He grew more comfortable with me throughout the sessions and stayed open to overcoming his stigma around "therapy". He deeply engaged with the care of his father and displayed impulse control in the context of the sessions. This reminds me of Moon's existential "openness"; I was flexible and adaptive to the family's needs in art therapy. I could not be rigid with the therapeutic norms; expecting an opening and a closing or having the time to process the meaning behind the art would not be open to what the family actually needed. Nor could I expect prompt attendance or being on time. What mattered is that the family attended and that I held that therapeutic space for them.

Focusing on strengths as a form of grief art therapy is incredibly valuable. I believe it was important for the family to be witnessed in their everyday struggles and honoured for their strengths in the present.

By witnessing and adapting the art therapy to the specific needs of the family a space opened up for each individual to feel accepted and in control of the therapy which in turn may have given a sense of empowerment. Respecting and staying open to Simone's concerns of Ethan in "therapy" allowed for Ethan to come to his own terms with the art therapy. I believe he found a space in art therapy where he could be comfortable to do exactly what he needed to do, as Moon describes as part of an existential approach. This also reflects a person centred approach and the theory of change; by having the experience of being accepted and respected unconditionally, allowed each person to accept and respect themselves in order to foster growth.

The family insisted on being together in art therapy despite the invitation for individual support. I respect that the family felt it was important to participate in art therapy altogether. We all seek to be in relationship with each other (Moon 2009). Companioning this family meant offering them an opportunity to teach me about their experience living with Paul's terminal illness. I believed that they are the experts of their family and their grief (Linesch, 1992; Wolfelt, 2006). By companioning and respecting the implicit family structure I could offer a sense of empowerment and control through the art therapy experience. The value of the art therapy was provided by a 'holding space' for them to be accepted as themselves, to bear witness to each other and to be witnessed by another 'just as it is'. Being in relationship to each other, to me, to artworks, provides the family with an opportunity realize the purpose and meaning of their experience (Moon 1990; 1995; 2009) and to re-inforce/revise the patterns of attachment. The art studio was a supportive environment to persevere through the challenge of terminal illness (Kissane & Bloch 2002).

Doing With

I expanded upon Moon's idea of doing with the client through the a/r/tography. Through making art via a/r/tography to the lived experience of art therapy I found strengths in each individual that I may have overlooked without engaging in art. The experience of a/r/tography re-affirmed art making and processing as a worthwhile endeavour not only for clients in art therapy but as a valid practice for art therapists as well. Through art making I found ways of being in relationship with each individual. I also found value and meaning as a professional art therapist and researcher through art as research and grounding. This supported my need to be congruent and upholds my integrity as a professional art therapist intern.

Countertransference

Art psychotherapist and author of *The Dying Patient in Psychotherapy* Joy Schaverien (2002) speaks of the experience of working with a client with terminal illness and how it can bring the wounded healer sharply into focus. I was motivated to engage in a therapeutic relationship with the bereaved and dying in order to heal a "wounded aspect of my psyche" (Schaverien 2002). I can relate this to the many losses and complicated grief that I have experienced in my life as well as my own acknowledged death anxiety. The therapeutic process I engaged in with Paul, Simone and Ethan triggered a confrontation of the inevitability of my own death and of those I love. Schaverien (2002) warns that with this may come a heightened identification with the terminally ill, and it may cause anxiety to be a "good enough" therapist. I am aware that I went beyond my role as an art therapy intern, diffusing the edges of my boundaries; I provided organic healthy snacks bought with my own money, and I offered a plethora of art materials, some purchased again with my money despite the vast amount of materials provided by the institution. I was purposefully accommodating to lateness, and to sessions exceeding the prescribed time. I advocated to move the therapy into the home and I visited Paul twice in the hospital. Admittedly, I wanted to visit more, but refrained.

Often in sessions, I felt as if I was “in over my head”. I felt “victimized” by the institution; “why is it me who has such challenging clients? I am not ready for this! I am just a fledgling art therapist intern!” My perceived inadequacies experienced in session reared my habitual self-hatred and fear of failing. In order to face my personal struggles I participated in weekly art therapy supervision in order to feel supported and to ensure my issues did not interfere with the art therapy with the family. During the course of writing and creating the art accompanying this thesis, I experienced many moments of feeling like the art work did not properly represent my clients and I was not authentic enough to represent what occurred. I often caught myself feeling I am not good enough to be working with Paul, Simone and Ethan. On the dialectic of my low self-esteem as an art therapy intern was my obvious idealization of Paul, Simone and Ethan’s situation. Idealizing this family may have ingrained a power structure that may have limited my therapeutic response in session.

I resonate with what Schaverien says; the experience of working with the dying “takes the analyst to the limits of their experience” and “may justifiably complain that this was not addressed in their training” (2002). This has been a very challenging experience for me.

I intended to explore the values and meaning of making art in the face of death with the assumptions that the focus would be on the family’s experience. A surprising aspect that sprung from this research was the use of a/r/tography that informed the strengths of the family members and revealed my biases of their experience. McCune (2013) advocated a/r/tography can reveal an “enriched understanding of the [client’s] therapeutic issues” and in the process also uncover the therapist’s countertransference. Engaging in the research through a/r/tography in respect to the family revealed individual therapeutic issues; Ethan’s desire for freedom, Simone’s responsibilities as a caregiver, and Paul’s striving for life in the face of his death. A/r/tography helped me see the strengths in Paul, Simone and Ethan. Whereas I may have fallen prey to the despair and sorrow of the situation which would have impacted my therapeutic response, a/r/tography provided me with the re-affirmation of life in the face of death and to see the resilience and health in each of the members of this family. A/r/tography is a

valuable tool for art therapists for this reason; it helped me find the hope and the strength in order to provide the support this family required. This research has confirmed what I intuitively knew before venturing into being an art therapist in that art has a pivotal and integral role in the human experience especially when facing death.

In-between Companioning and A/r/tography

Reflecting upon my a/r/tography process, I realize the role companioning played; my therapeutic approach as a companion provided an openness to whatever the family wished to discuss or needed in a session and also offer an opportunity for authentic dialogue and affective expression. The authentic dialogue evoked a strong response intuitively which directed me to the appropriate materials to create art with and in turn revealed another layer of great insight as to the strengths of each family member. As a companion in art therapy I upheld that the family would ‘teach’ me about their experience of terminal illness. As an a/r/tographer I allowed for the art process to ‘teach me’ what I needed to know regarding research. As an existential art therapist I upheld the idea of that the artwork will teach me what I need to know in the present. . By staying attuned to the art process of a/r/tography I provided myself with a ritual re-enactment of staying attuned to the family. I could not have provided the same support without creating art as research.

Ripples of Relationship- Arts-based Research Value

The a/r/tography case study exhibition visually represents the ripple effect of canonical generalizations inherent in an arts-based method of inquiry (Kapitan 2010). The a/r/tography illuminated the unique perspectives of the individuals within the family through presenting their art work and through describing the lived experience of the art therapy sessions. This rippled out and impacted my approach as an artist, researcher and therapist. In-between the family’s art work, the art installation and the case study presentation, another ripple radiated outward to my colleagues and supervisors. This ripple continued forward through the documented response art and poetry of my colleagues and

supervisors. A ripple now reaches the reader in the form of the thesis containing all the data presented. It is my hope that the study of the family living with terminal illness and all of the data contained in the thesis can now resonate further. The a/r/tography case study exhibition validated how a study of a family living with terminal illness can resonate with the lives of many. The a/r/tography makes tangible the canonical generalization which puts into context the value and meaning of researching a family living with terminal illness. The study performs beyond the family, myself and the graduate institution. It now reaches you.

Art as Indestructible Container

Art has the important role of providing the opportunity to display the truth as far as possible for each individual of the family. Paul's artwork revealed a truth about his physical health, his impulse to persevere despite physical and material obstacles, and his desire to self-soothe. Witnessing Paul in art therapy provided me with an idea of his resiliency to all that he had endured over the course of his illness. Art revealed his desire to live and the everyday challenges that must be addressed when providing art therapy to the dying.

I also observed Paul use the art materials as a way to connect and bond with his family; he gave praise to Simone for her skill displayed in her artwork and he collaborated with Ethan to build the hearth. While making the hearth I observed Paul and Ethan strengthening their attachment while creating a memory. The hearth and the memory are now contain in an enduring object that represents that event through the art making.

Simone's art provided a truth of her experience; a visual externalization of her inner experience in the "storm" and visual articulation of a significant poem in her "flower". Both images are fully embodied and vibrant which leads me to believe she used the art affectively. Her priorities of helping her family survive was an important observation I made during art therapy. I realized her strength as a care giver and her abilities to "keep her family together".

Ethan desired to create “realistic” and functional art work. The realism Ethan renders is not meant to be photographic rather than an experience with a particular object. Mountains, boats, planes, hot air balloons, the hearth; are all objects he has had experience with. Perspective is another distinction in Ethan’s work; he attempts to render the disappearing trees up the mountain, and the mist in front of the boat. I have a notion that Ethan’s desire for the real can be supported by the art as it provides a concrete, tangible entity that is important in the face of grief and loss at his stage of development. Ethan used the many opportunities to put his emotions into his art. He threw, blew, assembled, painted and drew his inner experience. Children at his age may have difficulties cognitively and verbally articulating their inner experiences and in order to express they well act out with behaviours or play. He wanted the art therapy to be a “free space” in order to for him to establish psychic equilibrium. The art provided Ethan with an accessible, adaptable and enjoyable format to focus his energy. If his need was for cathartic discharge then the art displayed the truth of it by throwing and his use the materials and space (plasticine and target). If he wanted to articulate his hope, he told a story of the Old Samurai and illustrated a drawing. The art could hold all that Ethan put into it.

Levine (1992) states that underneath the pain, suffering, confusion and distress is a will to live and a will to be with others (Levine 1992). It is this will that creates meaning and the meaning re-affirms life in the present. Art therapy with the family indeed provided an opportunity to be witnessed in their struggle, to create meaning while being together and re-affirmed the everyday life with each other.

From my perspective as art therapist intern, my art could hold my frustrations, pain and biases to reflect back to me how I could best companion the family. This provided a reflection to my colleagues in which they could respond. The art of my colleagues validated and empathized with both the family’s pain and my own struggles as well as being an avenue for them to connect to their own painful experiences. Through my own learning, the challenges and the distress, the art has re-enforced my will to be with others in pain and has revealed the meaning of the career I have chosen. Reflecting back upon the experience I had with art therapy with this family has re-affirmed what I have learned and what I can

take into my practice as an artist and art therapist. The existential art therapy approach provided me with an opportunity to regard the artwork and process with wonder, and to engage in creative dialogue and narrative and to “figuratively invite artworks to teach what they know” (Moon, 2009, p. xx).

“Ethan’s Plane”, “Simone’s Journal”, and “Paul’s Clothes” were art explorations of my relationship to each family member. I needed to have the insight from working with the art materials in order to better understand how to provide affective therapeutic support for the family. The art helped me be in better relationship to each member. The artwork revealed strengths of each family member and guided me to the appropriate therapeutic approaches. The a/r/tography allowed for me to present a rich context of the art therapy as well as my own biases to my colleagues. It brought in the intangible aspect of in-between into a form to which my colleagues could observe and respond. Art making in response to the art therapy for me was an important avenue. I experienced a great amount of self-doubt working with the family. The a/r/tography provided me an opportunity to research in mediums in which I am familiar and confident with. Art making provided grounding when I felt adrift. In order to companion and stay present to what the family required of me, a sense of being grounded was important. The art provided a means for me to be with this family.

Universal Experience of Death

The wholistic approach (van Manen, 1990) revealed the universal experience of death as a major theme and undercurrent early in the research. I was drawn to working with a population living with grief and loss due to my own experience. By companioning the family, and bringing the lived experience through a/r/tography to my colleagues and supervisors, it is apparent in the research that death and dying are universal life experiences. This was validated by the evocative responses made by my colleagues. It is something we all have in common and it acts as the great neutralizer in-between different peoples and hierarchies. I am drawn to working with those living with loss as I see it as something every client will have been touched by in some form. With my own history of loss, I am aware of how I am touched by

death, as my clients and colleagues are touched by death. This is not to say that the reactions, thoughts and feelings about death are universal; they are as unique as each individual is on the planet. The family coped with their reactions to Paul's terminal illness in their unique and individual ways; Simone focused on keeping her family together, Ethan desired a space away from the illness and Paul reflected and used the time to bond with his family. Another family would have coped differently. It is somewhere in-between an individual's personal experience of death and the universal inevitability of its presence on humanity. This is validated in the overwhelming rich responses of my colleagues. Each person gave personal, thoughtful and empathetic responses. This process seems to reflect the a/r/tography's ability to make meaning of the art therapy experience. The evocative nature of the a/r/tography facilitated everyone involved in this research to be touched by the universal understanding of life and death.

Chapter Summary

This chapter attempted to synthesize the presenting data in the thesis in order to reveal themes and the inherent meaning of the themes. The inherent meaning and value of art therapy with a family facing terminal illness is related to the wholistic themes that emerged throughout the presenting data of the research. Accepting that everyone has their own individual experience of death and dying puts us all on common ground. Knowing that everyone seeks to be in relationship in order to cope with their experiences of death allows for meaning to be created from the suffering. Art is an indestructible tool which can hold the suffering. Being in relationship and facing our suffering through the reflective nature of art creates meaning. When we have the ability to create meaning from our suffering and losses, we can re-affirm life in the present.

CONCLUSION

The psychotherapist is changed a little by each therapeutic encounter, but none more so than when the patient is confronting death.

Joy Shaverien, 2002

This thesis explored the nature of practicing art therapy with a family facing the terminal illness of one of the members. It ventured to discover where in lies the meaning and value of making and sharing art during intense moments of losing a loved one. The thesis offered a literature review of terminal illness, the impact on child development, specific approaches to families in crisis and relative bereavement theory for the clinical and research approaches employed. The family was introduced followed by five phenomenological art therapy session descriptions accompanied by client artwork. As a form of data collection, analysis, and as a method to enhance meaning a/r/tography was utilized in the form of a retrospective case study art exhibition. Art works and poetry written in response to the practicum experience have been included as part of the data. Validity of the a/r/tography came in through response art of colleagues and are a part of the data collection. Through applying a wholistic approach to thematic analysis of all the data collected, three themes emerged; the universal and existential experience of death and dying; the impulse to be in relationship with another; and art as an indestructible container for suffering.

What I have found is that we all struggle with the inevitability of death and dying. We have our unique feelings, thoughts and beliefs which must be honoured. We need to be in relationship with each other in order to feel honoured and supported in our suffering. When the suffering is intangible or verbally inexpressible, art has the capabilities of holding and expressing the pain. The art becomes a mirror which reflects back to us our experience which then can be integrated in order for meaning to be made. When meaning is made in the face of our pain we re-affirm our life in the present despite the inevitability of our death. There are three valuable aspects that appear as themes in art therapy with a family facing terminal illness. The first is the universal awareness of each of us being touched by death;

witnessing the death of loved ones and eventually experiencing our own. The second theme is our impulse to be in relationship with each other; to witness and to be witnessed by another in the everyday struggles and triumphs of life. The family was motivated to come, despite lateness, and physical challenges which demonstrates the importance of participating in the support. The family was offered opportunities for individual support, and decided to do it together for as long as they could. But why art therapy? Any other kind of therapy could have provided a similar opportunity. The third theme that has emerged in the research is art as an indestructible container for suffering and pain. Art therapy with the family indeed provided an opportunity to be witnessed in their struggle, to create meaning while being together and re-affirmed the remaining everyday life with each other. A/r/tography provided a similar aspect; it provided an opportunity for me to see my therapeutic challenges and biases, it helped me exhibit these struggles to my colleagues. Through their response art I felt the research was validated and re-affirmed my choice to be an art therapist who practices arts-based research.

I would recommend a/r/tography as a means of art therapy research be encouraged in art therapy graduate training institutes. The methodology lends itself to the clinical practice of art therapy profoundly and it may invigorate and inspire other art therapists to engage in research. If more art therapists engaged in research, more resources would be available. I found a vast amount of valid resources in regards to art therapy in palliative care with individuals as well as a great amount on grief and loss in art therapy. It was a challenge to find resources and academic material that referred to family art therapy and terminal illness, especially in regards to anticipatory grief and therapeutic approaches. I found one source of a/r/tography and art therapy. The creative voices, perspectives, and interpretations of my colleagues proved to me there is potential for innovation in the area of a/r/tography and art therapy joining forces.

This has been one of the most challenging and rewarding experiences in my life up to this point. The clinical practice and research has amalgamated my knowledge and skills as a conceptual artist, an

academic, a therapist, a poet and a grieving human being. I feel re-affirmed that my past experiences can be utilized in the present not only professionally but as a way of being in the world. I have found a vocation through what claims me.

EPILOGUE

After Paul's death, art therapy sessions re-configured as a dyad with Simone and Ethan and resumed weekly for an hour and a half over the course of four months with fifteen sessions all together. With the loss of Paul, the dynamics of Simone and Ethan changed and shifted, as did the therapeutic approach. Ethan continued to be attracted to a variety of 2D and 3D materials. He also utilized the sand tray in many of the sessions. Simone spent most of the sessions re-constructing the "Hearth" Ethan and Paul had initially created as well as returned to painting in the later sessions. The hearth was re-constructed into a fully functioning miniature fireplace; both Simone and Ethan expressed pride in creating the hearth and smudge was burned inside upon its completion.



Figure 5- Paul and Ethan's "Hearth"



Figure 19- Reconstructed "Hearth"

Unfortunately, the therapy concluded because I graduated from the institution, and I wonder if we may have continued had I not been an intern. They seemed to have found grounding and had plans for the future when the therapy ended; Ethan was planning on returning to public school and was

showing great academic growth. Simone had decided to take on a landscaping project and was considering returning to work.

In the final session I had Ethan complete an evaluation form about his experience of art therapy in which he shared his feedback with Simone and I. Ethan stated that “other than my dad dying, I wouldn’t change a thing”. He also appeared to have come to a comfortable place in regards to “therapy”. Simone had asked him to share his thoughts about what he used to think therapy entailed and now that he experienced art therapy, had his thoughts changed. His response was “I didn’t want to go to therapy because I don’t want to be crazy.” I disclosed to Ethan my own personal experience with therapy to which he responded “So you are crazy too?” We all laughed and I assured him that my therapeutic journey was not because I was “crazy” but because I needed support through my own grief. Ethan paused for a moment and concluded “I guess therapy isn’t just for crazy people.” When asked if he would like to participate in art therapy again Ethan enthusiastically agreed that he would like to in the future.

REFERENCES

- Canadian Hospice Palliative Care Association (2015) “Advanced Care Planning Terms” *Speak Up: Start a conversation about end of life care* [website] Retrieved from <http://www.advancecareplanning.ca/making-your-plan/advance-care-planning-terms.aspx> on May 26th, 2015.
- Canadian Hospice Palliative Care Association (2013) “A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (Revised and Condensed Edition)” [PDF] *Canadian Hospice Palliative Care Association*. Retrieved from <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf> on May 26, 2015.
- Christ, G. H. (2000) *Healing Children's Grief: Surviving a Parent's Death from Cancer* Oxford University Press, 2000.
- Carpendale, M. (2009) *Essence and Praxis in the Art Therapy Studio*. Trafford Publishing. Victoria, BC.
- Carpendale, M. (2011) *A Traveler's Guide to Art Therapy Supervision*. Trafford Publishing. Victoria BC.
- Da Vinci, L. (2004) “Prolegomena and General Introduction to the Book of Painting” *Notebooks of Leonardo da Vinci* (Vol. 1). Translated by Jean Paul Richter (1888) [ebook] Retrieved from <http://history-world.org/Davinci.pdf> on July 14 2015. *The Gutenberg eBook*.
- Freud, S. (1962, 2002) *Three Essays on The Theory of Sexuality* (3rd ed.). Basic Books Publishing. New York.
- Guest, G., Namey, E. & Mitchell, M. (2013) “Qualitative Research: Defining and Designing” *Collecting Qualitative Data: A Field Manual For Applied Research*. Sage Publications Inc. Retrieved from http://www.sagepub.com/upm-data/48453_ch_1.pdf on February 9, 2015.
- Guggenheim Foundation (2014) “Conceptual Art” *Guggenheim: Collection Online: Movements*. Retrieved from <http://www.guggenheim.org/newyork/collections/collectiononline/movements/195208/description> on Nov. 16th, 2014.
- Hooyman, N. & Kramer, B. (2006) *Living Through Loss: Interventions Across the Life Span*. Columbia University Press. New York.
- Hoshino, J. (2008) “Structural Family Art Therapy” *Family Art Therapy: Foundations of Theory and Practice*. Routledge: Taylor & Francis Group. New York, London.
- Hyland Moon, C. (2002) *Studio Art Therapy: Cultivating the Artist Identity in the Art Therapist*. Jessica Kingsley Publishers. London and Philadelphia.
- Irwin, R. (2013) “Becoming A/r/tography” *Studies in Art Education*, Vol. 54, No. 3, Spring 2013.
- Irwin, R. & Sinner, A. (2013) “A/r/tography and the Arts” *UNESCO Observatory Multi-Disciplinary Journal in the Art: Special Issue*. The Graduate School of Education at the University of Melbourne. Vol. 3, Issue 1, 2013.

- Irwin, R & Springgay, S. (2008) "A/r/tography as Practice-based Research" *Being With A/r/tography*. Sense Publishers, Rotterdam/Taipei.
- Irwin, R (2008) "Introduction: A/r/tography: A Metonymic Métissage" *Being With A/r/tography*. Sense Publishers, Rotterdam/Taipei.
- Kapitan, L. (2010) *Introduction to Art Therapy Research*. Routledge: Taylor & Francis Group. London and New York.
- Kerr, M. (2000) "One Family's Story: A Primer on Bowen Theory." *The Bowen Center for the Study of the Family*. Retrieved from <http://www.thebowncenter.org> on June 2, 2015.
- Kissane, D. and Bloch, S. (2002) *Family Focused Grief Therapy: A Model of Family-Centered Care during Palliative Care and Bereavement*. Open University Press. Buckingham and Philadelphia.
- Kornreich, D., Mannheim, H. & Axelrod, D. (2008) "How Children Live with Parental Cancer" *Primary Psychiatry*. Retrieved from <http://primarypsychiatry.com/how-children-live-with-parental-cancer/> on December 3, 2014.
- Levine, S. (1992) *Poiesis: The Language of Psychology and the Speech of the Soul*. Jessica Kingsley Publishers. London and Philadelphia.
- Lindemann, E. (1944) "The symptomatology and management of acute grief". *Grief and Mourning: The Reaction to Death*. [pdf] Retrieved from <http://www.nyu.edu/classes/gmoran/LINDEMANN.pdf> on June 16, 2015.
- Linesch, D (1993) *Art Therapy with Families in Crisis: Overcoming Resistance Through Nonverbal Expression*. Brunner/Mazel Publishers. New York.
- Manning, P. & Cullum-Swan, B. (n.d.) "The Semiotics of T-shirts" Departments of Sociology, Department of Sociology and Psychiatry, School of Criminal Justice, Michigan State University, East Lansing, Michigan. Retrieved from <http://jthomasniu.org/class//377a/Readings/675.pkm.tshirt> on June 25 2015.
- McCrune, S. (2013) "Engaging A/r/tography to Reveal Countertransference: Enhancing Self-Awareness in Caregiving Professionals" *UNESCO Observatory Multi-Disciplinary Journal in the Art: Special Issue*. The Graduate School of Education at the University of Melbourne. Vol. 3, Issue 1, 2013.
- McIntyre, B. & Raymer, M (1989) "Expressive Therapies, Children and Death" *Canadian Art Therapy Association Journal*, 4:2, 9-21
- Merleau-Ponty, M. (1945, 2014) *Phenomenology of Perception*. Routledge: Taylor & Francis Group. London and New York.
- Moon, B. (1990, 1995, 2009) *Existential Art Therapy: The Canvas Mirror* (3rd ed.). Charles C Thomas, Publisher, Ltd. Springfield, Illinois.
- Moore, M. & Holbein, H. (1957) *The Dance of Death in the Twentieth Century*. I.E. Rubin Publisher. New York.
- Naumburg, M. (1966, 1987) *Dynamically Oriented Art Therapy: Its Principle and Practice*. Grune & Stratton, Inc. Magnolia Street Publisher. Chicago, Illinois.
- Pereira-Stubbs, F. & Rawlance C. (2008) "Arts, Electronic Media, Movement: Rosetta Life" *Dying, Bereavement and the Healing Arts*. Jessica Kingsley Publishers. London and Philadelphia.

- Pinar, W. (2004) "Foreword" *a/r/tography: Rendering Self Through Arts-Based Living Inquiry*. Pacific Educational Press. Vancouver, Canada.
- Pratt, M. (1998) "The Invisible Injury; Adolescent grief work". *Art Therapy in Palliative Care: The Creative Response*. Routledge. London and New York
- Prendergast, M. (2009) "Introduction: The Phenomena of Poetry in Research". *Poetic Inquiry: Vibrant Voices in the Social Sciences*. SensePublishers. Rotterdam/ Boston/ Taipei.
- Rappaport, L. (2009) *Focusing Oriented Art Therapy: Accessing the Body's Wisdom and Creative Intelligence*. Jessica Kingsley Publishers. London and Philadelphia.
- Reynolds, L. & Botha, D. (2006) "Anticipatory grief: Its nature, impact, and reasons for contradictory findings". *Counselling, Psychotherapy, and Health*, 2(2), 15-26, July 2006 [pdf] Retrieved from http://www.mentalhealthacademy.net/journal_archive/cph0613.pdf on June 16, 2015.
- Rogers, N. (2001) "Person-Centred Expressive Arts Therapy: A Path to Wholeness" *Approaches to Art Therapy: Theory & Technique* (2nd ed.). Brunner-Routledge, Taylor & Francis Group. New York.
- Rolling Jr. J. (2013) *Arts-Based Research: Primer*. Peter Lang Publishing Inc. New York.
- Romanyshyn, R. (2013) *The Wounded Researcher: Research with Soul in Mind*. Spring Journal Books. New Orleans, Louisiana.
- Saunders, W. Rev. (2000) "The History of the Advent Wreath." *Catholic Education Resource Centre*. Retrieved from http://www.catholiceducation.org/en/culture/catholic_contributions/the-history-of-the-advent-wreath.html on December 3, 2014.
- Schaverien, J (2002) *The Dying Patient in Psychotherapy; Desires, Dreams and Individuation*. Palgrave MacMillan. New York.
- Schaverien, J (1992) *The Revealing Image: Analytical Art Psychotherapy in Theory and Practice*. Routledge: Tavistock and Routledge. London and New York.
- Schubart, J., Kinzie, M. and Farace, E. (2007) "Caring for the brain tumor patient: Family caregiver burden and unmet needs" *Oxford Journals: Neuro-oncology*. Retrieved from <http://neuro-oncology.oxfordjournals.org/content/10/1/61.full> on November 29, 2014.
- Silverstone, L. (1997) *Art Therapy the Person-Centred Way: Art and the Development of the Person* (2nd ed.) Jessica Kingsley Publishers. London and Philadelphia.
- Sobol, B. & Williams, K. (2001) "Family and Group Art Therapy" *Approaches to Art Therapy: Theory & Technique* (2nd ed.). Brunner-Routledge, Taylor & Francis Group. New York.
- Spector, N. (1998) "Subtle Buddies" *Wounds Between Democracy and Redemption in Contemporary Art*. Stockholm: Moderna Museet.
- Van Manen, M. (1990) *Researching Lived Experience: Human Science for Action Sensitive Pedagogy*. State University of New York Press. University of Western Ontario. London, Ontario, Canada.
- Wadson, H. (2010) "Family Art Therapy" *Art Psychotherapy* (2nd ed.) John Wiley & Sons, Inc. Hoboken, New Jersey.
- Wilber, K (1991, 2000) *Grace and Grit: Spirituality and Healing in the Life and Death of Treya Killam Wilber* (2nd ed.) Shambhala Publications, Inc. Boston.

- Wilber, K. (1988) "On Being a Support Person" *The Journal of Transpersonal Psychology*. Vol. 20, No. 2. P. 141-159.
- Williams, L. (2013) "Grieving Before A Death: Understanding Anticipatory Grief" *What Your Grief?* [website] Retrieved from <http://www.whatsyourgrief.com/anticipatory-grief/> on June 11, 2015.
- Wolfelt, A. (2006) *Companioning the Bereaved: A Soulful Guide for Caregivers*. Companion Press. United States of America.
- Yoder, G. (2005) *Companioning the Dying: A Soulful Guide to Caregivers*. Companion Press. United States of America.

BIBLIOGRAPHY

- Aries, P. (2008) *The Hour of Our Death: The Classical History of Western Attitudes Toward Death Over the Last One Hundred Years* (2nd ed.). Vintage Book: A Division of Random House, Inc. New York.
- Brown, J. & Menninger, K. (1940) "Chapter X; Psychoanalysis: Theory of Psychosexual Genesis". *The Psychodynamics of Abnormal Behavior*. McGraw-Hill Publishers, New York.
- Dissanayake, E. (1988) *What Is Art For?* University of Washington Press. Seattle and London.
- Dissanayake, E. (1992) *Homo Aestheticus: Where Art Come From and Why*. University of Washington Press, Seattle and London.
- Fleming, J (2004) "Erikson's Psychosocial Developmental Stages." [PDF] Retrieved from <http://swppr.org/textbook/ch%209%20erikson.pdf> on Oct.26th, 2014
- Glaser, B. & Anselm L. Strauss (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Alkaline Transaction, a division of Alkaline Transaction Publishers, New Brunswick.
- Goleman, D. (1995) *Emotional Intelligence*. Bantam Books, New York.
- Hartley, N. and Payne, M. (Ed.)(2008) *The Creative Arts in Palliative Care*. Jessica Kingsley Publishers. London and Philadelphia.
- Harvey, L. (1990) *Critical Social Research*, London, Unwin Hyman, retrieved from [http://www.qualityresearchinternational.com/csr/CSR%20Basics%20\(1990%20publishe%20original%20version\).pdf](http://www.qualityresearchinternational.com/csr/CSR%20Basics%20(1990%20publishe%20original%20version).pdf) on Sept. 23rd, 2014.
- Katie, B. (2002) *Loving What Is: Four questions that can change your life*. Harmony Books. New York.
- Kerr, C. (2008) *Family Art Therapy: Foundations of Theory and Practice*. Routledge: Taylor & Francis Group. New York.
- Levine, S (1984) *Meetings at the Edge: Dialogues with the Grieving and the Dying, the Healing and the Healed*. Anchor Press. Doubleday and Company Inc. Garden City New York.
- London, Peter (2014) [video lecture] *Friedl Dicker-Brandeis: The Redemptive Power of Art*. Retrieved from <http://vimeo.com/19848450> on Oct. 6, 2014.
- Lowenfeld, V. (1947) *Creative and Mental Growth*. Macmillan Co., New York.
- Manovski, M.P. (2014) *Arts-based Research, Autoethnography, and Music Education: Singing through a Culture of Marginalization*. Sense Publishers. Rotterdam, Boston and Taipei.
- Moon, B. (2006) *Ethical Issues in Art Therapy*. Charles C. Thomas Publishers LTD. Springfield, Illinois.
- Moon, C. (2010) *Materials and Media in Art Therapy: Critical Understandings of Diverse Vocabularies*. Routledge Taylor and Francis Group New York.
- Muri, S. (1996) "Dali to Beuys: Incorporating Art History in Art Therapy Treatment Plans" *Art Therapy: Journal of the American Art Therapy Association*. Vol. 13. Number 2.

- Neimeyer, R. (2006) "Bereavement and the Quest for Meaning: Rewriting Stories of Loss and Grief" *Hellenic Journal of Psychology*, Vol. 3, 2006, pp.181-188. Retrieved from <http://www.pseve.org/journal/upload/neimeyer3c.pdf> on October 20, 2014.
- Neimeyer, R., Burke, L. , Mackay, M., vanDyke Stringer, J. (2009)"Grief Therapy and Reconstruction of Meaning: From Principles to Practice" *Journal of Contemporary Psychotherapy*. Retrieved from http://www.traumaptsd.com/uploads/library/gt_practice_j_contemp_psyc.pdf Oct. 20th, 2014.
- Pratt, M. and Wood, J.(Ed.) (1998) *Art Therapy in Palliative Care: The Creative Response*.Routledge. London and New York.
- Rinpoche, S. (1993) *The Tibetan Book of Living and Dying*. Harper San Francisco: A Division of Harper Collins Publishers. New York.
- Romanyshyn, R. (1999) *The Soul in Grief: Love, Death and Transformation*. North Atlantic Books. Berkeley, California.
- Schaverien J. (2008) "Mirror of Art: Reflections on Transference and Gaze of the Picture" from the Psyche and Art Conference. San Francisco. Retrieved from <https://aras.org/sites/default/files/docs/00037Schaverien.pdf> on Oct. 28th, 2014.
- Schaverien, J. (2000) " The Triangular Relationship and the Aesthetic Countertransference in Analytical Art Psychotherapy" *The Changing Shape of Art Therapy: New Developments in Theory and Practice*. Andrea Gilroy and Gerry McNeilly. Jessica Kingsley Publishers. London.
- Stroebe, M. & Schut, H. (2010) "The Dual Process Model of Coping with Bereavement: A Decade On" *Omega: Journal of Death and Dying*. Vol. 61(4), p. 273-289. Baywood Publishing Co., Inc. Utrecht University, the Netherlands.
- Volavkovd, H. (Ed.) (1993) *...I never saw another butterfly...:Children's Drawings and Poems from Terezin Concentration Camp, 1942-1944*. (2nd ed.) United States Holocaust Memorial Museum. Schocken Books. New York.
- Weininger, O. (1996) *Being and Not Being*. International Universities Press, Inc. Madison.
- Weller, F. (2012) *Entering the Healing Ground; Grief, Ritual and the Soul of the World*. WisdomBridge Press, Santa Rosa, CA.
- Wennstrom, J. (2011) "Art and the Creative Life: Jerry Wennstrom".[Lecture] Pacifica Graduate Institute. Uploaded to YouTube on Nov. 16, 2011. Retrieved from <https://www.youtube.com/watch?v=LVVnxThwKLU> on Oct. 6th, 2014.
- Wilber, K (1979, 2001) *No Boundary: Eastern and Western Approaches to Personal Growth*. Shambala Publications. Boston.
- Williams, T. (2008) *Finding Beauty in a Broken World*. Vintage Books: A Division of Random House Inc. New York.
- Williams, T. (2012) *When Women Were Birds: Fifty-four Variations on Voice*. Picador: A Sarah Crichton Book. Farrar, Straus & Giroux. New York.
- Wilson, L. (1985) "Symbolism and Art Therapy" *Approaches to Art Therapy: Theory and Technique* (2nd ed.) Edited by Judith Aron Rubin, Brunner Routledge, Taylor & Francis Group. New York.

Yalom, I. (2002) *The Gift of Therapy: An Open Letter to a New Generation of Therapists and Their Patients*. Harper Perennial. New York,

APPENDIX ONE

LJ's HOTEL by Monica Carpendale

*A screen hung on a clothesline
The washing
The line tied to a plane
Leaving but still visible*

*A bull's eye imprinted on
Fine gauze screen
Moving in and out of love
Letting go
To care and to care for
The catastrophic
The end
So final in the world
Yet left in this world of memory*

*I am deeply touched
To live in the face of loss
To desire life in the face of loss
To make an impression
To make a hot air balloon
To travel
To be brave
To stay in the light
To know
But not to hear anything bad
To express
Or not to express
To cry or not to cry
To let go
To hold on*

*A frightening reality
Trying to stay present
To live in grief
To live in hope
To stay in process
To value
To resist
To reject
To not die
To not love
To not die*

*To not lose
To not die*

*To not grieve
To not let go*

*To want it to stop
To not want it to stop
As that would mean death*

*To lose control
To be out of control
To have life out of control
A flower and a moon
A reflection
A growth
An unwanted growth
Cancer as a growth
Love grows in new awareness*

*“This must be weird for you” the boy says
This must be weird for the boy.*

*To go to the home
The black and white image smudged
The landscape has been printed with hands
A stark reality cut off by the page*

*The horizon moves like an ocean
Trees disappear in the distance
Edged by the mountain*

AS a Son and AS a Father

*To check on your parents
To keep an eye on your father
To explain your father
To be proud of your father*

*To lose a father
To lose a son
To be a son
To be a father
To grieve a father
To grieve the loss of being a father
Becoming an ancestor
Asking the ancestors for support*

*An emergency
To emerge*

*Identity shifts
Identity peeled back
Caught in the wave
The ground dissolves
And is awash with desire for life
For more
To love and to be loved
To survive
To be cared for
To meet the other*

*A response: a site specific family portrait
It will never look like this again.*

*A temporality
An essence
To hang the curtains
And the stopping of the clock
To not be able to complete
The hourly cycle
The life cycle
A work in progress
A life in progress
To not know if it is complete
A completion
The space between
The space between each of us
The space between the moments
The space between the meetings
The space between*

*To draw out all the aspects
To be
To write
To always be an artist
To always be a therapist
To explore the in between
To clothe the man
To plane the boy
To read the mother
To write the book
To attach the tape*

*The curtain and the frame in between
"Living in the borderlands"
Living in the space
Therapy occurs between the sessions*

*Life between birth and death
Layers upon layers
To be human
To explore
To magnify the shadows and the light
The projection catches
The conversations
Bleed through
The elements*

*To put the puzzle together
To fly a plane
To be attached
To a poem
To weave all the aspects
To fall between the cracks
To what is revealed
To what is not revealed
To not have to understand
How can we understand?
The mystery
To obscure
And to reveal
The desire to write
a 'book'
To glue all the pages together
A tedious process
To care take
A tedious process
To not be able to shut the book
Hope is emergent
The glue in the book is strong
The resolve
There is a right time and a right place*

*The plane is to fly not to be a fixture - I don't make a model plane to put on the mantle place
To have a real father not a symbolic father
To let the father fly
To connect to ...*

*A new process
Of being revealed
Clothing represents a body without the physical body
Holds the presence
Painted white
Absorbed
Jeans absorb the paint and resist the white
Resilience to stay in the colour
To stay in life*

*Projections unify
The disappearance of colour
Reflections
A disappearance
A mystery
To be digested
The remnants
The essence of a body remembered
Worn with the daily felt sense
A clothes line and the pane drifts off but is tied to the world
A ribbon of connection
Water and stone
A target and an end point.*

*Making meaning in the process
To be changed by death
The movement towards the end
The changes and the complications
Of being alive
One's own inevitable death
To lose the other
To lose the self
To go beyond
The boundary of the self
To be authentic
To be limited
Not needing to "do" therapy
To toss the analysis
Part of the process
The question of finding meaning in the face of death*

*To share
To story
To cherish
To companion
To be present to pain
To go into the loneliness
To not know the way
To walk with
To hold space
To be still
To respect disorder and confusion
Humility, caring and curiosity*

*Art therapy as being too much fun
To not want to sit on the mantle
To do
To make noise*

"He is in the hospital so my mother can recuperate."

A/R/T ography
Artist advocate
Researcher revolutionary
Teacher therapist